Potential for Electronic Health Records and Online Social Networking to Redefine Medical Research

Bob Barrett: This is the podcast from *'Clinical Chemistry'*. I am Bob Barrett. As a result of recently passed legislation in the U.S., all medical records will soon become electronic. With patient data in easily accessible electronic sources, Electronic Health Records or EHRs harness great potential to aid in drug safety through the study of pharmacovigilance methods. Adverse drug effects can be found and drug safety profiles may be expanded.

EHRs can also aid in the study of head-to-head comparative effectiveness trials and could play a critical role in secondary and tertiary diabetes prevention efforts.

A growing subset of EHRs is Personal Health Records, PHRs. They offer the possibility of engaging patients in their care, as well as new opportunities for participatory research and personalized medicine.

Organizations nationwide, from providers to employers, are already investing heavily in PHR systems. This, compelled with the use of online social networking sites and mobile technologies, aid future research efforts by making available a veritable flood of health information, such as real time exercise monitoring, to health researchers.

This future confluence of health information data enables researchers and clinicians to discover novel therapies and insights into treatments and disease management, easily taking into consideration environmental and genomic interactions all at an unprecedented population scale.

In the February issue of '*Clinical Chemistry*', John Pearson, a Researcher at the Children's Hospital Informatics Program at the Harvard-MIT Division of Health Sciences and Technology and a second year medical student at St. George's University, has detailed the many ways in which EHRs and PHRs coupled with the data that could be culled from patients' usage of social networking programs and mobile updating devices can redefine medical research. He is our guest in this podcast.

John, what is the current status of Electronic Health Records in the U.S.?

John Pearson: Currently in the U.S., many Electronic Health Records over the past decade or so…couple of decades, have been limited to large institutions, such as university health care systems and large insurance systems, and the percolation down to smaller practices hasn't taken place.

Now, what's going to change that and what is currently changing that is the recent passage of the HITECH Act by the Obama administration as part of the Stimulus Bill that was passed in 2009. So not part of the actual Healthcare Bill but before that.

And that is saying that we need to have meaningful use of Electronic Health Records; the definition has been worked out on that by 2012-2013.

The reason why this is going to be moving forward is because they are kicking in somewhere around $27 billion worth of incentives as well as tying Medicare reimbursement rates to adoption of Electronic Health Records, so that people will need to start adopting them.

Bob Barrett: How does that compare to the status of Electronic Health Records elsewhere among developed countries?

John Pearson: The status in other countries actually varies quite dramatically. In England, for example, the NHS is implementing Electronic Health Records for the entire system. But that’s been running into some delays and concerns, so it’s not quite fully implemented at this time.

While some countries like New Zealand have had a fully functioning Electronic Health Record system for quite some time now. So it really does vary from country to country.

One thing is that when the U.S. went forward with Medicare billing, changing that to electronic billing of prescriptions, that actually pulled forward Canada and some other countries into going into electronic billing prescription. So we definitely have some weight, when we decide to move, others follow.

Bob Barrett: How will recent innovations in health records, specifically Personal Health Records, enable novel research approaches?

John Pearson: Health records, currently as they exist, the Electronic Health Records depend a lot on linking up information that is not designed for health research, with the needed information to control for epidemiological design of studies.

So for instance, you are looking at records that are designed primarily for billing of prescriptions or for reimbursing of insurance, and that information is aggregated, and then you are putting information from population health characteristics with that. So there is a little bit of a weakness in the studies in that regard.

Now, with the recent innovations in health records, they are becoming much more holistic in the information that is being gathered by the records themselves, with the Electronic Health Records themselves. So this has been the case in some of the larger institutions, some of the university systems, and some of that larger health insurance systems, but not as widespread. Where you are having all the information, all the characteristics, about your patient and as well as a more comprehensive health history of the patient is in the Electronic Health Record.

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Now, with Personal Health Records, how that's going to change things in a way, and we will get into this a little bit more, is that you are having the patients more engaged in the control of the information in the health records. So they are going and having access to the health record and that's enabling them to correct the mistakes, to reduce duplicate of test, and to also enter in information such as over-the-counter medications and other things such as alternative medicines that they are using into the Electronic Health Records, that is not currently captured at all in the current health records, where they are just getting whatever is reimbursement of the physician.

So with the Personal Health Records that will enable novel research approaches because you are basically filling out much more information to the health records than has been there in the past.

In the past, you had to do very statistical methods for your surveillance epidemiology studies to infer characteristics of the population, whereas now you will be able to take the individual level information. And that’s been the case in some of these studies but not in all, and that brings you to a whole new level where you can start to look at genomics. You can start to look at their exercise regimens and about what they are eating.

So all this information is starting to be enabled, to be tracked, and queried in these new research approaches that will be enabled by Electronic Health Records.

Bob Barrett: You mention that Personal Health Records will enable patients to enter their exercise data and track their environmental exposures, but how will this play a role in genomics and therapeutics research?

John Pearson: Right, so with Electronic Health Records and with the movement towards personal genomics, again, the holistic basis of the health record systems that will be implemented in the next few years and going forward in the next decade will have the personal genomics data of individual patients as part of managing their care.

So when you take the individual environmental exposures and individual -- how often someone is exercising, what they are eating, where they are working, and where are the places that they are playing, you enter that information and then putting that together with their genomic profile, with their phenotypes, and then you can start to look at how the environmental information modifies their risk factors for the disease.

Because what you are doing is you are tracking over time in a similar manner to say the Framingham Heart Study, how that tracked population over time and looked at all the different risk factors, that's where the term risk factor came from, for developing heart disease, for instance, or atherosclerosis.

So with the Electronic Health Records what you are doing is you are having patients entering information about what they are doing and you are connecting that with their genomic data and now you are reducing the amount of work that the researchers need to do when they are doing genome-wide association studies and so enabling many more researchers to do a lot more with this information.

Bob Barrett: With all this information out there, what protections are there for patient privacy and will patients ever really buy into this?

John Pearson: Sure! Obviously that's a big concern, and one of the things that when I talk to people about Electronic Health Records, that seems to be the first thing that people bring up, that patients bring up is that, I don't want prospective employers screening me out based on my diabetes, for instance, or what kind of information, what the government do with this, will they cut benefits in the future for me based on my health conditions.

This is where the field is kind of evolving in a different way towards the patient-controlled health records, and those are a subset of the Personal Health Records, in that they enable patients to delineate access to the health records themselves.

So the patient says, okay, I am going to Dr. Smith's office and that's my primary care physician, and his collaborating physicians and staff can have access to my Electronic Health Records and all my information.

Now, when I get referred to a rheumatologist say, I will then delineate the access to that physician practice group. So you are controlling -- the patient controls who has access to the information.

Now, not all Electronic Health Record Systems are like this, this is just one subset of systems out there that people at

Harvard and with the in-vivo system are working on implementing.

So it remains to be seen whether that is actually what happens, but that is one way that could enable patients to really buy into and be much more comfortable with the Electronic Health Record Systems moving forward.

Bob Barrett: Much of Electronic Health Records are focused on researchers querying large scale databases, yet health social networking is essentially patient run and driven. Why would clinical researchers care about what people are posting on the Internet?

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John Pearson: So with health social networking, just to get into that a little bit, a lot of people go online, they Google, they are trying to like self-diagnosis and they bring stuff to their physician and then they are asking about various things. So people are getting very engaged in their health, and one of the trends that's been going on recently in the past few years has been the advent of health social networking.

So kind of in a similar way to Facebook, you have things like TuDiabetes and websites like PatientsLikeMe, where people with chronic health conditions are going online and detailing how they are dealing with their conditions.

So with PatientsLikeMe, that started around Amyotrophic Lateral Sclerosis or Lou Gehrig's disease, and that patient community started very small, and on this website, they designed an interface for them to track their various health indicators, which is the respiratory volume, looking at things like their sensory and motor functions, and looking also and tracking also what drugs they have been prescribed and how they are tolerating those drugs.

So these websites have enabled patients to take that information and share it with one another in a safe community that's also secure.

Now the patients are connecting with one another and saying, I am on drug x, you are also taking this, are you getting these high headaches from this? Are you starting to get strange bruises from taking this? I have been taking it for two weeks and I am starting to get these bruises.

So you are having the patients communicating with one another and also generating tons and tons of information. And that's also starting to look at, not just side effects, but also starting to look at like multiple drug regimens and how patients are handling those. So that information is out there.

Now, with the Electronic Health Records, the trend towards patients entering information in their Electronic Health Records, the kind of future way that this could move forward would be having the information that patients are sharing with one another on the health social networking site, which has a lot of information that's relevant to clinical researchers, as they are already detailing, since they are going into such detail about their conditions over time. Bringing that information into the Electronic Health Records is really going to enable clinical researchers to -- open up a whole new avenue for research because it's just much more information about what their patients are doing, what their patients are feeling on a day-to-day basis, and how their patients are tolerating drugs.

So you are looking at a population scale of information that is really usually limited to doctor-patient interactions that usually take place in the office and adjustments are made on an individual basis. So now, that information is suddenly aggregated and made electronic. Now you are enabling the researchers to be able to do much more sophisticated investigations into how patients are tolerating drugs, what they are doing with multiple drug regimens, how exercise, how environmental exposures are modifying them, as well as how social networking and social interactions are modifying the effect of the drugs that they are having.

Bob Barrett: Well, finally, how do you see EHRs and social networking redefining medical research, and where do you see this field in the next few years or really in 20 years from now?

John Pearson: So as I have been discussing the nexus and the trends between people tracking their information with the quantified self-tracking tools on these various websites, as well as discussing their health information with each other on the social networking websites, when that information starts to get integrated with the Electronic Health Records and with these Electronic Health Record databases, now you are enabling studies on a whole other level.

Throw into that things such as the environmental exposures, where people are tracking what food they are eating, they are tracking where they are going out to eat, where they are working and playing, and where they are going during the day, now you are bringing in a whole another dimension of information that has just not been there before.

So I see that as more of a medium term or it could be near term, or 20 years from now you could be having things such as completely automated feedbacks of say when you are having a chronic health condition such as diabetes, you could be having blood glucose monitors connected to your smartphone that are sending instantaneous information throughout the day into your Electronic Health Record, as well as your blood pressure, as well as your temperature, and where you are.

So having that physiological data married to the Electronic Health Records, as well as connected to the genomic information, as well as connected to environmental exposures and the exercise and diet, you are really enabling research on a level that hasn't been approached in the past and hasn't been even possible in the past.

So that's where I see things going forward in the future and that will really enable us to understand some of the much more detail and much more into the ideology of many chronic pathological diseases.

Bob Barrett: John Pearson is the Lead Author of the review on Social Networking Programs and Electronic Health Records and a Researcher at the Children's Hospital Informatics Program at the Harvard-MIT Division of Health Sciences and Technology. He has been our guest in this podcast from *'Clinical Chemistry'*.

I am Bob Barrett. Thanks for listening.

Total Duration: 15 Minutes