Michelle:
Hi, I'm Michelle Jobin, and this is My Time, My Voice.

Michelle:
The healthcare field has used quite a number of weapons in the fight against disease. And increasingly, data is becoming one of those weapons. Data fuels innovation. Imagine you're a cancer patient, or maybe you don't need to imagine. Everything you do, everything your body does can potentially generate data. The regression or growth of a tumor, that's information. Your white blood cell count, that's information. Even your mental state along your journey is information, and all of it could be useful to a medical researcher.

There's plenty of these kinds of data out there. But as our guest will explain, researchers can't always get access to pieces of information that could help them in their work. It's even been said that Canada has a data deficit.

Michelle:
Dr. Helen Chen is a professor in the School of Public Health and Health Systems at the University of Waterloo in Ontario, where she studies health data.

Michelle:
Hello Doctor Chen, and thank you so much for being here to talk with me today.

Michelle:
let's talk about a central challenge for people that are in your field. What are we talking about when we say Canada has a data deficit?

Dr. Helen Chen:
Yes. So we don't really lack of data. We have lots of data, right?

Dr. Helen Chen:
But in a typical hospital, you're going to have 30, 40 different systems and working together. And the patient information is stored through those systems. So it is very hard to hop over the different technology, different systems to get a high quality data about certain patient and for the disease.

Michelle:
So in other words, the data is siloed. So, specifically, why is access to data such an important issue for researchers?

Dr. Helen Chen:
basically for the health researchers, that data itself is our bread and butter, right? So it's the most essential part of our research. If you want to understand what's happening, if you want to build a predictive model of what treatment, what is outcome a patient likely to have, and if you want to evaluate the effectiveness of the treatment and the economic benefit of a new drug, all those things need the data, need the high quality of data to bring us that insight.

Dr. Helen Chen:
We still have lots of barriers in accessing data, even sometimes in our own organization, right? We still need really some innovation there. I think there is, currently, there is the national provincial and the institutional effort to get better access to the data.

Michelle:
It's a little bit of a catch-22 because we need this information quite badly. But it's also incredibly important to protect the privacy of the people that the information belongs to, I assume.

Dr. Helen Chen:
That's indeed the case.

Michelle:
Can we talk perhaps a little bit more about the role that privacy concerns play in all of this?

Dr. Helen Chen:
Privacy, it's at the center of what we actually need to mostly ensure. That the health data is sensitive, and the hospitals, as the custodian of those data, they're highly sensitive information. They have the obligation to ensure that the privacy is protected. But there is actually the way that while protecting the privacy of individual patients, the data itself can be a part of the datasets that contribute to bring us insight.

Dr. Helen Chen:
Traditionally, the best way to provide your data, your privacy, is actually lock it in a basement, right? And have the door locked with double locks. But now, in everything digitized, and there is also many ways to protect your protection, such as we can de-identify the information and we can actually now even building some insights with your data not leaving your premises. So there is actually the number of ways we can protect the privacy. But it's technology is one thing. And patient consent is another.

Dr. Helen Chen:
So right now I think that we always start from the proper consent. So that the patient is fully aware how the data is collected, where it is stored, and who can access their data. So there's a trust between the patient and custodians [that] should be there.

Michelle:
So I would assume, putting myself in the shoes of someone that would be a cancer patient might be happy for a tissue sample that they're taking away to be used for research that might help others or information and data from their charts that have been generated by their care. You know, presumably a lot of patients would gladly give consent for that kind of thing. So, do you think that they want to share that data?

Dr. Helen Chen:
Some study indeed show that the very high percentage of the cancer patient is willing to let the researchers access their data, as long as they actually have the trust of the custodian and the researcher is respect their privacy. They do very much want to be part of the advancement of the treatment and development to have a so-called better weapon to fight the cancer, to fight that disease.

Dr. Helen Chen:

So I think trust, it's at the center. You do have to actually facilitate that to ensure the trust between the patient and that data custodian. I think how to facilitate the trust, how to enhance the trust, and that one of the pillar in this case is the transparency. If I know, who has access to it, and what studies my data is part of.

Michelle:
And beyond yourself and researchers in the field, do you feel that there's a consensus with all levels of organizations and individuals that are involved in cancer care, including patients, of course, that we really should collectively figure out a way around these challenges?

Dr. Helen Chen:
I think it's particularly in the cancer treatment. And I think that the consensus is really very strong. And there's a research networks, and the cancer registries, and they collect lots of data. And also I think that because the cancer patient often was managed around the larger centers, the cancer centers, I think their data is in a better position to contribute for these kind of better integration and better transparency in accessing the data for research purposes.

Michelle:
I understand that more researchers are becoming interested in using what is called real world data in their research. What does that mean?

Dr. Helen Chen:
Right now we are moving towards… we call it real world data. So the real world data is data not collected just through the clinical trial. The real world data is the data routinely generated through the care in the healthcare systems. And also the real world data may contain the different types of data, such as the payers data, and the treatment choices, and the patient self-reported data and the data collected from the census for actually indicating the patient's certain behavior, or certain monitoring outside the clinical setting. So that is a much richer set up data in a real environment that you can actually understand, What works for this patient, but does not work for that patient. So that is the whole push for accessing for the electronic patient record data, and actually connecting with richer set of patient data and it's the right way that we are trying to push for, to leverage the potentials of having the massive data in our electronic patient record systems.

Michelle:
Well, I understand how that would give a much fuller picture. And I mean, I'm obviously no expert. But I understand obviously not everybody qualifies for clinical trials. So that would be a much more isolated group. So if you're getting this sort of broader set of people to get the data from that makes more sense to me. Would that be one of the reasons why it's more interesting for researchers?

Dr. Helen Chen:
Mm-hmm (affirmative). For our health data scientists and the data, the more the merrier. The more data you have, potentially you can actually understand the context of a certain treatment, a certain patient's reactions to the certain treatment. And anything potentially can impact the outcomes of treatment.

Michelle:
So you alluded to the fact that in clinical trials data is very controlled. When we're talking about real world data, what are the potential drawbacks in contrast to what happens in clinical trials?

Dr. Helen Chen:
Yeah, so the real world data compared to the clinical trial data, and sometimes we call it the less quality and dirty type of data, because they have so many different people entering those data at any given point through their routine clinical practices. So that inevitably will render the data, the quality wise may not be so consistent. When you build a model, when you are actually looking at your analysis results, you have to actually be able to acknowledge those limitations. And there's a number of ways to get this. You can still generate a very reliable evidence.

Michelle:
Let's talk about patients and what individual patients can do to help with these issues that we're talking about today.

Dr. Helen Chen:
So individual patient, the patient participation into their treatment, into the clinical research, it's essential a part of we want to do this innovation. We want to build the infrastructure together. First the patient needs to be aware to be even advocate for providing the secure privacy protected data access. To make the data, enable the data for actually research purposes. So that is, I think, the patient needs to be at the center, first to give consent, be aware, and to be advocate for us also to actually access the data. So it started from the patient.

Dr. Helen Chen:
the second, I think, when we design the innovation, when we design those innovative platform and tools, and to provide patient to have direct access to their own data, and actually they are in the driver's seat to give consent to participate, [inaudible 00:44:45] data actually being unlocked, to participate into this clinical research, and that is they need to be also as a driver, in this whole initiative, that they can be part of actually... We call it the code designer of the infrastructure.

Michelle:
Okay, so what about people who work in the healthcare system? Is there anything that they can do to give cancer researchers access to useful data?

Dr. Helen Chen:
So the doctors and the clinicians working in this environment, first they are the data contributor and they are the data consumer themselves. So I think that having better data input qualities and having standardized, structured the data capturing, it's actually the first step. The second is actually to...But probably at the institutional level, I think, when we want to share the data, and when the researchers and the clinicians are collecting the data for research purposes, and sharing the data with other researchers is both a way of collaborating, and the sharing collateral collaboration. But also a sense of contributing to the better good, to participate in the data hominization efforts, standardization efforts.

Michelle:
So there's an initiative that you're involved in that I'd like to talk about. Could you tell us what CPHIN is and what it hopes to achieve?

Dr. Helen Chen:
CPHIN ... The full name is Canadian Personalized Healthcare Innovation Network. It is a not for profit organization, and established three years ago. It's born out of the necessity and the passion for

accessing the real world data to accelerate clinical research. Currently we focus on the precision medicine in the cancer domain, but personalize the healthcare using the data. The clinical research and access to the meaningful data, it's a mission that every discipline of health care can actually benefit. So it is actually consist of the healthcare providers, and the manufacturers, academics, health technology innovators. In this neutral platform, we look at develop the technology to facilitate the faster secure access to the real world data. We look at the advocate for the policy change so that the evidence can be accepted, real world evidence can be accepted. The patient can actually receive the right treatment at the right time.

Michelle:
What are CPHIN's kickstart programs?

Dr. Helen Chen:
So the CPHIN kickstart program is the way we organize our effort and to demonstrate, build infrastructure, and to accumulate the experiences of how this new way of accessing the real world data through the technology with the policy and through the data sharing agreement [inaudible 00:49:12] the data reviewing process can actually have an integrated data network

Dr. Helen Chen:
We also would like to know that to accumulate the experiences of the best practices. Of how actually we can share the data among the institutions, among the different academic sectors. What is the best way to do so? And this kickstart program is often focus around the one particular disease domain, such as, for example, we have a lung kickstart program and it's a number of large center across the different provinces it's getting together with CPHIN.

Michelle:
Doctor Chen, in your work do you ever consider yourself to be an advocate for patients?

Dr. Helen Chen:
Yes. Because sooner or later, we're going to be a patient ourselves. And I know how important it is to be proactively and to be part of this innovation ecosystem. And we are there for the innovation and when they will be in the benefit receiving end of that innovation.

Michelle:
Before we go, do you have any final thoughts on how to advance oncology for the good of patients?

Dr. Helen Chen:
I think that navigating the cancer treatment landscape, it's just so complex. And there's a lot of research going in, lots of promising trends. And so, the idea is to saying that if we could accelerate... We always say we need to conquer the cancer in the certain period of time, but we know that people still die of cancer on a daily basis, right? So we want to really accelerate the cancer research. That is one part of it. And then the second is that if we actually can provide the personalized, the treatment precision treatment for the patient themselves, that's very important

Michelle:
Doctor Chen, thank you so much for sharing your thoughts and your expertise with us today. It's been a pleasure to speak with you. Thank you.

Dr. Helen Chen:
Thank you for having me.

Michelle family cancer:
And to our listeners, thank you for joining us this time. Please do come back for our next episode when we'll be speaking with Judy Glennie, a clinical pharmacist who understands the ins and outs of how treatment goes from the lab bench to the bedside in Canada. Best of health, until then.