**Guiding Cancer Treatment with Evidence, Not Opinion**

**Speaker 1** 00:02

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**Dr. Bill Evans** 00:20

Welcome to the cancer assist podcast. I'm your host, Dr Bill Evans, professor emeritus of McMaster University here in Hamilton, Ontario, Canada. I'm starting to mention that where Hamilton is, because we now have viewers in Germany and Hong Kong and across the United States, as well as many sites in Canada, of course. So those of you don't know where Hamilton is, you should get out a map. Find the Great Lakes. Look for Lake Ontario, and Hamilton's on the western end of Lake Ontario. So wherever you're listening, welcome to the show. The focus of today's podcast is on development of evidence in cancer, and specifically through what we call the program in evidence based care that's based here in Hamilton and at McMaster. Before I introduce my guests, I want to just remind folks that the cancer assists podcast is brought to you by the cancer Assistance Program here in Hamilton. Cap is a charity that provides a variety of free services, including free drives to and from medical appointments and visits to the cancer center, provision of nutritional supports, incontinence supplies, head coverings, like wigs and other head coverings, mastectomy bras, and importantly, access to medical equipment that can keep a patient safe in their homes or allow them to get outdoors. So we have access to wheelchairs and ambulators, rotators, rollators, I should say, and commode chairs, other pieces of equipment. It's really a wonderful charity, and it's all supported by donations. So we're very appreciative of those supports from the public and from special events. And I particularly want to do a shout out to the Hutton family for their continued support of the cancer assist podcast. Well, today's guests are Dr Jonathan Sussman, who's a professor of oncology here at McMaster. He's a radiation oncologist, and he's the scientific director of the program in evidence based care. Welcome Jonathan, thanks for inviting us. Good morning, morning, and Carolyn swall, who's the managing director of the pebc and an experienced health research methodologist. So I'm going to assume that many of the listeners or viewers of this podcast have no idea what the program in evidence based care does. I think it's a fair assumption, and probably they wouldn't have much idea of why it needed to exist, and they may not even know what we mean by evidence as it relates to cancer treatments or cancer care in general. So I think a good place to start is to try and define evidence as it relates to medicine in general, and where does evidence come from? So maybe I'll start with you, Jonathan, tackle that question.

**Speaker 2** 03:16

Sure. I mean, really at its core, evidence is a collection of facts or truths that can lead to the ability to define a phenomenon, an outcome that is what would be considered valid meaning that if you studied it over and over again, you should get the same result. So that at its core what evidence is. And you know, obviously evidence is important, because when individuals are trying to make a decision about something or assess something, they will collect facts to develop a profile of the problem that they're trying to solve, perhaps generate a bit of a hypothesis, a little bit of a an idea about what needs to be done. And they then, very well, if they feel like they have enough evidence that's good evidence, can hopefully be able to make what's called an informed decision, and a good decision that can lead to the best possible outcome. That's, I think, trying to, trying to sort of break it down to its core elements. I think that's really what we're what we talk about when we talk about evidence. So where does evidence come from then? Well, evidence can come from a lot of different places. In medicine, evidence typically comes from research studies. And I think that probably takes us a little bit back to this whole idea of what is evidence based medicine, and why did we have to define this thing called Evidence based medicine? Because I think generally people would say, well, wouldn't that be obvious that you'd want to have good evidence or good for. Products. But in fact, when you think historically about medicine, a lot of medicine was learned somewhat by rote, and then by experience and accumulation of experience, which, of course, is incredibly important. And each individual provider, for example, can collect up experience through different interactions that they have, and become experts and wise, but may not have a full view of what other possibilities may exist when when presented with a particular problem, and it was recognized, I mean, in the probably the 1940s and the 1950s and so on. When there were collections of, for example, textbooks that experts would contribute to, a lot of that was based on opinion and experience, sometimes a little bit regional. And it was pretty clear that some a lot of that didn't necessarily apply to a general population or to the person sitting in front of you. And as medical research increased in doing large studies that involved many, many individuals who agreed to have information collected about them as they went through a particular treatment process or experience, the picture or the validation, if you will, becomes clearer, and that's really where evidence based medicine came from, is trying to improve the quality of care by collecting these facts and then trying to apply them in a rigorous and consistent manner.

**Dr. Bill Evans** 06:31

So Carolyn, just to draw you into the conversation, Are there levels of evidence? Like talking about evidence is always all one phenomenon, but are there different sources and different strengths to the evidence that you're looking at?

**Speaker 3** 06:46

Yeah, certainly there are different types of evidence. So there are, like, randomized, controlled trials, where people are randomized to an intervention and a comparison and and those are usually the best type of type, best kind of evidence. There's also different prospective studies where they just follow people over time and then try and compare who, who's, for example, who smoked and who didn't smoke, and then who developed lung cancer afterwards. We were talking about different levels of evidence and different qualities of evidence too, right? Just because it's published doesn't mean it's good. You have to when you get a study, you have to look at it, and you have to look at it, you have to think about it, and you have to evaluate it, and then if it's a good study, then you're going to put it into like a guideline, or you want to use that good study to in order to make a decision, to make a clinical decision. And there are also case studies where one person something happened to one person, but just because it happened to one person doesn't mean it's going to happen to a lot of people. So that's why bigger studies are better, because it just gives you so much more data in order to make a decision. With that kind of a study

**Dr. Bill Evans** 07:49

in the program, you're synthesizing evidence from as many sources as you can possibly find, I guess. And so can you give me some idea of how that process works?

**Speaker 3** 08:02

Well, I can sort of give you an overall how we sort of create guidelines. So usually we get a topic from cancer here Ontario, so there's a topic, and then once we have the topic, we decide who's the best expert, who's going to help us with that topic. And then we create a question with the experts, because you need to decide on what it is that you're going to actually what kind of evidence you're going to look for. So you might look for one chemotherapy versus another chemotherapy. So then the health research methodologist, me my old job, we go into medical database databases, and we look at all the evidence, and then we select ones that are answered, that sort of answer that question, evaluate them to make sure that they're good studies. And then basically add them all together. I try and describe a meta analysis to people. I just say we add them all together and divide by the number of studies or number of people. And that's what you do. You put it all together, and then you use that information in order to make a decision. You have to make sure it makes sense. You have to interpret what what the results are, and stuff. But it is. It's rigorous, it's transparent. Everything is written down what you do so that anyone who wants to redo your system, Mac review or understand what it is that you did, they can see it so you make sure everything is also written down.

**Dr. Bill Evans** 09:28

Now, you mentioned databases. I wonder if for studies, maybe just explain that a little bit, because I'm not sure that some listeners would understand how it is you find all these articles about

**Speaker 3** 09:40

every time a study is done, it gets, it gets uploaded into a database. And that is, we can look at that electronically, just like you can Google, right? You can sort of Google the database

**Dr. Bill Evans** 09:50

electronically search for these articles using certain terms relevant to the topic area that you're

**Speaker 3** 09:57

That's right. It's fine. We identify, again, sort of like. Google, you'd say, like breast cancer and the chemotherapy and radiation therapy or whatever it is you're looking at. And those will, those will come out, and the type of study, if you only wanted a clinical trial, then you can just look for clinical trials,

**Dr. Bill Evans** 10:15

right? Okay, so, Jonathan, why is it really necessary to do this? Like, I just need to go to go to the New England Journal and get the latest paper. Isn't that good enough?

**Speaker 2** 10:25

Well, could be, I guess. I mean, one could, one could say that it depends, because it somewhat depends on the problem that you're looking at, and it also depends on the problem that you're trying to solve. Generally speaking, though, because of the fact that there are now more and more and more studies, it's very difficult for an individual provider to be able to accumulate all that information and synthesize it. There can be studies, for example, that are published that conflict with each other in terms of their outcomes, and that has to do somewhat, sometimes, with the fact that we intervention that is or the intervention that's being tested doesn't actually perform in as predictable manner as people thought, perhaps because of how it's applied in different populations of individuals, for example. So I mean, some of the principles of assessing evidence at their root are this, even this concept of triangulation, even if you think about a crime scene and you go and interview people, you don't just interview one person to ask what happened. You usually interview a number of people who may have observed what happened from different perspectives, and you put that together to see if it's consistent or not. And that's really what the synthesis process is, very similar in terms of collating medical data, as Carolyn was talking about, the idea of system doing a systematic review, systematically and review and systematically and rigorously collecting up all these pieces of evidence, these studies that are published in many, many journals. And to give you an example, we would work, for example, on a guideline trying to answer a question in breast cancer, we may have to screen up to 8000 journal articles. That's more than an individual can do. You know after a consultation, seeing somebody in their office to try to decide whether I should use this drug or that drug, or this dosage of the drug, or that dosage of the drug. So part of this systematic review process is allows, oh, you know, allows a way to efficiently, if you will, create this evidence base from all these different perspectives and different publications to help an individual at least be aware of what's out there. And then the guideline part of it is really taking the evidence and then turning it into a recommendation.

**Dr. Bill Evans** 13:00

And you touched on the fact that there's sort of this accelerated amount of information coming at us. There's so many journals that it's totally impossible for any medical person to keep up on all the things that they're need to keep up on without some help by some group like yourselves, synthesizing them together and providing it. So it really is an essential for keeping people up to date, and I guess reducing variability in terms of what people are actually delivering as care in the community.

**Speaker 2** 13:33

Yeah, I mean, that's in when people ask, I mean, what's the purpose, or what's the ultimate goal of creating a guideline? It's ultimately to improve the quality of care through supporting decision making that should result at sort of a wide level, at a population level of improvement in outcomes. That's sort of at the core of why, why it's done. Part of the idea is, of course, that there can be quite a bit of variability in how care is delivered, and a lot of individuals involved in quality essentially, would say that wide variability in care generally, is an indicator of less good quality of care, especially if there's a good evidence base that can be synthesized that can give a fairly, a fairly clear answer on what the best options are. Of course, there's always going to be variability in care. And I think the other important thing to say about guideline is it, it's a guidance document. It's to guide the ultimate, if you're thinking about it for a healthcare intervention, like which drugs to use, et cetera, that is a decision that's made between the provider and the patient in a shared decision where the information is shared. The guideline, of course, can help the provider and the patient, because guidelines. Often will have summaries that are written in less medical lingo as well, for individuals to be able to have access to this information make a decision

**Speaker 3** 15:11

as well. Actually, we have patients on our working group, so the people that help make the recommendations from the evidence we have. We have patients on their working group to provide their values and their preferences. And we also have a patient consultation group that will also review all the recommendations and give us their feedback on whether they think it's, you know, usable and if it's feasible and acceptable for for everyone.

**Dr. Bill Evans** 15:37

So McMaster is considered, I guess, the home of evidence based medicine, or the birthplace of it, perhaps. And your program started in 1995 and I think part of what you've done in this province, and I think beyond is, is change the culture of how physicians think. And I guess I don't know that was initially what was the plan, but physicians used to just learn in medical school and go out and practice, and they might have continued to practice with what they the knowledge of the 1940s for a long period of time while medicine advanced in its understanding of how to care for people. So creating that culture, getting people to think about, what is the evidence base for what I do, what's the current best evidence for So now, in developing these various documents, and in fact, I was amazed to see that you've developed over 500 guidelines, huge number of journal publications yourselves, they there's different groups that sort of are, are kind of behind them that are doing the guideline work, like you have some that are focused on diseases, like a lung disease site group or a breast disease site group, and you have others that are more programmatic, like nursing group or a pathology group or imaging group. And then you have a few specialty areas, like in scanning with Positron Emission Tomography and the stem cell transplantation, a couple of special areas. So there's a lot of people with ideas, and science is moving very quickly. I think the big challenge for you guys is figuring out which guidelines can you do next. Because my you're only so big as a program, I think you got 11 methodologists have read the website correctly, so priority setting must be very challenging. So you talk about that a little bit.

**Speaker 2** 17:32

I'm happy to I'm happy to take a little bit of a stab at it, because it's actually a very timely question, because it's something that we've been discussing. The Guidelines Group ourselves. Don't identify the priority areas. Those are essentially designed. They're identified by the experts. And the experts are the expert providers or the senior administrative individuals or health policy individuals within the Ontario cancer system. So we work in collaboration with them to try to make sure that we put the resources that you talked about in terms of the people, the methodologists, who can, who can do this work, in front of, sort of the most timely in front of the most timely questions. Not everybody can do everything. So we, for example, our group, and Carolyn maybe can explain this a little bit more, we have relationships with other guidelines groups. For example, big Guidelines Group South of the border. The American Society of Clinical Oncology also has a Guidelines Group. In fact, some of the people in that group were individuals who worked within our group. So we actually have relationships with them, and there are interactions with those individuals, because sometimes we can be and because of the fact that we know and trust each other's methodologies, we can sometimes sort of have a menu where we know they're going to work on certain things, and we'll be able to have them go through their process, and then we can bring it in and review it, and go through a review and an endorsement process, which makes it a little bit more efficient. And similarly, they for us. And as you know, there are a number of guidelines that are published that way. So that's that's another way to try to increase it. I guess the other thing that happens, and that's probably a question that's better answered by the provincial Cancer Agency themselves, is that even in terms of just the way they have to plan, they need to do something called horizon scanning, they have to ask themselves, okay, what's coming up that we're going to have to be aware of in the next two to three years? Most of those things don't come necessarily out of nowhere, meaning that often people are aware of the fact that there are very large trials ongoing that are about to close or about to analyze, and obviously the results are never or should not be shared until the study is completed per. Properly, but we can sometimes anticipate when those things will happen, and that allows us to focus the other thing that happens is that often the sort of a big guideline question about how do you treat X, we'll have a framework from a guideline that we've already developed, and then what we need to do is update because there's a bit of big data that's coming in so that it's not, you know, necessarily a guideline right from zero, but it's an augmentation of what we've already done. And sometimes the recommendations do not change, and sometimes they will, will have to adjust. But it is an ongoing it is an ongoing issue, for sure, a challenge. Want to add

**Speaker 3** 20:38

anything to that. Carolyn, I think some of the things that people at cancer care and Terry are also thinking about is, like you said, practice variation that might make make a certain topic more important or more timely to get done. Patient need is also a big issue. You know what? What is needed out there. I just finished a guideline fear of cancer recurrence, and that was a big issue that people were having. So that was a very important one to get done, as well as as some Jonathan said, if there's a new study coming out, or if there's a guideline that just got released, you know, we could easily endorse a guideline, and that can be a quick guideline that we know that wait, people in Ontario know that we've looked at it, it's and we endorse it, and we've had our experts look at it, and so that can be used pretty quickly, without having to go through all of the data and all the studies, because someone else has already done that. And that's what jonka was saying with ASCO as well. We, we are in communications with them all the time. Know what they're working on. They know what we're working on. We can use their systematic reviews.

**Dr. Bill Evans** 21:43

Well, it's good to hear this collaboration with the people south of the border, but one of the things I wanted you to talk a little bit about is something that was in the earliest publications from the pebc, when they were describing the whole process, which is the practice guideline development cycle. And you touched on it a bit already, I think. But I think it's would be important for people to kind of understand that that cycle of how you guidelines developed and and sort of reviewed, and various experts are involved. So I'd want to get ahead with you. But why don't you talk about that?

**Speaker 3** 22:18

So there's the guideline cycle is five steps. So the first step is sort of the initiation, getting the project and knowing who the the main clinical expert is that who's going to help with that group, with that project, and identify the other experts that can also help think about the data and then the research and how it's can become a recommendation. Then step two is project planning. So you need to, once you have an objective, like, what is a topic going to be, then you need to figure out what the question is going to be, and you have to think of the population that you're looking at, what is the intervention you're looking at, what chemotherapy or radiation therapy, or or whatever it is you're looking at nursing guide. What outcomes are you looking at? Because sometimes you want to look at survival. How long people will survive? How long progression free survival? So how long will you go without the cancer coming back, as well as quality of life, outcomes are very important, so we need to look at those outcomes and decide which ones are important. And so the clinical experts help make those decisions, as well as the patients that are in our groups make those decisions because, you know, that's who it's about as well as. And we can decide on what database we're going to look at, and anything that's very specific about the topic, if you were going to publish it, and who's going to again, who's going to be involved in in all of that decision making. And then the health research methodologist does their bit. That's part number three is the guideline development. We get all the data. We make tables out of the data. We make it easy for the clinical experts and for the patients to read, and then we can all look at it and discuss it in a way that makes sense. And then we can put all that data together and make recommendations. You make recommendations by looking at whether all the all the studies look in the same direction. Are they very precise? Are they coming up with a very exact answer, are they good quality data? And then once you make recommendations, well, just because you know, there's six or eight of you that think that they're good recommendations, you don't really know for sure. So now we get it by internal we have what we call internal, external reviews. That's number four. Is the review. We have other HRMS read it. We have Jonathan read it. We have this report approval panel that reads it, that our three clinical experts, they read it for methods and make sure it's right and done well. And then we also get clinic other clinical experts to read it, to make sure it makes sense. And then we send it again out to more users. And target users to make sure that it's accessible, feasible, acceptable, and we put all that feedback in, and we talk about it, can we make any changes that we need to? And we have it written clearly, and then we try and get it published. So all our guidelines will go on the Ecco website, and then we try and get some journal publications as well, just the guideline and usually just the systematic review.

**Dr. Bill Evans** 25:24

I wanted you to review the cycle because it just shows how rigorous the process is. There's many steps involved, and many people, many eyes on the document, and critics who are looking at it with a sharp eye to see whether it's all it's weighing all the evidence appropriately.

**Speaker 3** 25:43

So that's important. It's important that critics get that feedback and to be able to answer it and make the recommendations better, right? That's what you're trying to do, is make the best ones that you can that are going to help the most people. So if you get something that's critical, because maybe you read it a certain way and someone else reads it a different way. You realize that that is that's important. You can make those changes. You can talk about it. You can figure it

**Dr. Bill Evans** 26:06

out. Nasty question, how long does all that take?

**Speaker 3** 26:10

Usually six months to two years. It depends. Sometimes we have a lot of a lot of data, and then it can take a lot longer, because it takes a long time to get the data out and to evaluate the data and to summarize it. So it would be nice if everything took less than two years. That would be good from the very start to the very end.

**Speaker 2** 26:32

That's a lot of work. It is especially when you're trying to synthesize something complicated like this. Quality takes a bit of time. This isn't something that you can just, you know, kind of just do, as Carolyn has, you know, talked about the various steps in the process and the amount of engagement. The other thing that happens during all of this is documentation, because the key to having something that's a valid document, as truthful as it possibly can be, is transparency. How was that decision made? What was the discussion that was held? Because at any you know, part of what we're trying to do as much as possible is manage whatever uncertainty there is, and if you can't, and sometimes there isn't enough evidence to move away from uncertainty, so you have to acknowledge it, and you have to say this is where there is uncertainty where it remains.

**Dr. Bill Evans** 27:22

So your guideline isn't just a set of recommendations, it's the documentation of the process to get to those recommendations. So these are big documents, actually, mostly, and have a lot of component parts to them.

**Speaker 3** 27:38

There are five sections to a guideline. So the first section is basically just the recommendations, because we know everybody doesn't want to have to read everything and you want it to be usable. And every recommendation has the information on like who and the amount and when and that kind of very specific information. But we also add what key evidence went into making the recommendation and the justification. So you know what thought went into making that recommendation? Section two is the recommendations, plus the quality statements, as well as more key evidence and more justification. So it's a little more full a lot more key evidences in section two, because some people do want to find out where the recommendation came from, but don't want to read the whole systematic review. Section three is the guideline methodology. So exactly what we've done, we've always looked for guidelines first, what goes into our systematic review that kind of information. So it's a little redundant through all, because we do every one the same. Then section four is the systematic review. So the questions we asked, the outcomes we were looking for, all the data that we found, and in a summary, as well as all the data tables. Then section five is the results from the internal and external review. So everything that someone said to us, it gets put into section five, and then what, how we answered those sections, and what changes we made because of those, because of those, that feedback. And then sometimes there's the Section six, and that is, if we do every year, we assess the guidelines that we have posted on CCO to make sure that they are relevant and they're not causing any harm. And so if we do a review and look at all the data that goes into Section six, so not everyone has Section six, but the ones that we do an assessment on.

**Dr. Bill Evans** 29:29

So guidelines are looked at or updated at intervals, when you can

**Speaker 3** 29:33

every year we assess all our guidelines that are posted every year, every

**Dr. Bill Evans** 29:37

year. Fantastic. Okay, look, let's take a break, and we'll be back to talk a bit more about guidelines and how to disseminate them and get that information out so that practice is actually changed. We'll be back.

**Speaker 1** 29:49

We'd like to take a moment to thank our generous supporters, the Hutton Family Fund and Banco creative studio, who make the cancer assist podcast possible, the cancer Assistance Program. Is as busy as ever providing essential support to patients and their families. We remain committed to providing free services for patients in our community, including transportation and equipment, loans, personal care and comfort items, parking and practical education. These services are made possible by the generosity of our donors, through one time gifts, monthly donations, third party fundraising, corporate sponsorships and volunteer opportunities. Visit cancerassist.ca to see how you can make a difference in the lives of cancer patients and their families.

**Dr. Bill Evans** 30:34

We're back talking about guideline development with Jonathan Sussman and Carolyn swall, and we wanted to talk a little bit about how guidelines are disseminated and who can access them. Like are, is it really restricted to physicians, because it's about the care delivery, or is it more broadly accessible and and how are they used?

**Speaker 2** 30:56

Well, in terms of dissemination. I mean the major dissemination pathway, again, because we work with our key partner, which is Cancer Care Ontario. And I think the other thing that I think is important to say at this point is, although we work very closely with the provincial Cancer Agency, it is important that we are arm's length in the Cancer Agency, because what we want to do is our work has to be what's called unbiased. We can't have any preconceived notions that go into this individuals that comes can come to a certain situation with certain beliefs or strong feelings, and those can obviously skew how you interpret the evidence. So probably a little bit of a tangent, but probably an important piece to say. But then in terms of the dissemination that typically is left the responsibility, if you will, is left with a provincial Cancer Agency, or occasionally with the authors of the guidance document that's created so they are posted publicly on Cancer Care Ontario website that can be accessed by anybody. Typically, there can be some targeted dissemination to certain practice groups who would obviously have interest in that this can be disseminated through patient groups as well. Obviously, we can also do more traditional things, like go to major medical meetings and present these findings at major medical meetings and then publish in journals. And we do try as an academic unit, because the work that we do is quite academic, and in particular the individuals who are donating their time to this process, particularly the providers for all of that effort, should have the opportunity to be able to make academic or scholarly contributions, and that that can result in in publications and medical journals as well. But we don't, I don't know that we, I don't know where we're at in terms of other sort of media distribution. I mean, we're not on TV talk shows, and you are now, well, we are now, that's true, that's, but that's, that's up for an individual guideline. But, yes, but yeah, that sort of, you know, that sort

**Dr. Bill Evans** 33:01

of in because start that. Yeah, okay. So they are quite accessible, if people want even looking for them. So it's good information for people to know globally that you could just search and CCOs website, cancer guarantors website, there's one source. But frankly, if you just Google the topic, the guideline would likely come up. And so that's important to know. Now, had a question about the guidelines, as opposed to, this is how it must be done, kind of documents like strict rules, and why call them guidelines? As opposed to, this is how you should always treat people. Well, I

**Speaker 2** 33:42

think, you know, there's recognition that there, as we talked about earlier on, there's this recognition that there is variability. And, you know, the reality is that it's rare that we come across evidence like, you know, somebody has pneumonia and they get antibiotics and comments you know, not not only common sense, but you know that that antibiotic is required to treat that pneumonia. You know, some of the issues that we're dealing with are a little bit more nuanced as new treatments come online, and there's an incremental benefit of one treatment over another, but there can be downsides to a particular treatment, toxicities, for example, and individual providers are the individuals that have to make that decision with the with the person sitting in front of them. So it was always the notion that you know the providers, or the users of the evidence, if you will, are the experts. They are ultimately the individuals that have to make the decision. And what this is doing is trying to help guide their decision in a way that uses the best

**Dr. Bill Evans** 34:48

evidence. Again, the evidence comes from trials where selected populations are given as you were describing, maybe the standard treatment, plus something in. Innovative versus the current standard, and then you see whether there's a benefit of adding to that standard. Those populations are generally pretty healthy people. Their characteristics are well defined, but the patient sitting in your office may have some other illnesses or comorbidities, as we refer to them, that preclude using that innovative therapy. So that's why it's guidance. But it couldn't always be used, but you'd like to see it used a lot of the time, I guess, is the answer. So Are there studies undertaken to see how well the guidance is taken up in the populations? Or concordance studies?

**Speaker 2** 35:38

Yep, individuals do concordance studies. And the Cancer Agency in particular, can use the guidance documents in one process that they've been involved in, where they will sort of map out what the expected trajectory are is for an individual, in terms of, you know how they're assessed, how you know what treatment they receive, what follow up they receive, those are often outlined in guidelines that are the basis upon which these policies, if you will, are created. And then you can go back and you can measure at a population level how many people follow that, if you will. So yeah, those are done.

**Dr. Bill Evans** 36:20

And do you see the impact of your work then,

**Speaker 2** 36:23

yeah, yeah, we definitely do. Again. There's typically a little bit of a lag, and you can always question whether, was it the guideline itself, was it the fact that the evidence was accumulating anyways, and people were starting to change their practice, because these things, all you know, people will read individual studies as well. So sometimes that's a little bit harder to pin down, to be completely, completely honest. But yet, typically you will see trends. And I mean, there are some sort of, what are called qualitative studies, sort of higher level studies that observe areas that are more consistently using guidelines, tend to have more consistent patterns of the care that they deliver.

**Dr. Bill Evans** 37:03

And do you think it makes any difference to the speed of uptake of new effective treatments? You know, it used to be said that it took 20 years to adopt a new technology, and I know studies in oncology tend to show shorter times for uptake, but does the development of guidelines in some way accelerate the uptake of a new and better intervention?

**Speaker 2** 37:29

Well, I'd say maybe supports the accelerated uptake. Because, as you've said, in the cancer system is a little bit unique, because rarely in the cancer system, do you have an individual provider, like a provider in a solo office or a solo situation seeing somebody cancer is delivered in teams. One of the ways of providing quality through the Cancer Agency is through having multidisciplinary teams, meaning teams of all the providers that are involved in the care of a particular patient population, say surgeons, radiation doctors and medical doctors who will go, you know, over individual cases to put together case plans and guidelines are always referenced at those processes, but they're much more. Those processes are much more towards the decision making points, so having a guideline to help facilitate that discussion, and having those groups sort of say, well, this is kind of the policy we want to use to approach this particular problem. You know, sort of has that embedded in its process, as opposed to this notion that, okay, the guideline on the website, in and of itself, was going to affect individuals behaviors through the patterns of care. I think there are a lot of intermediate steps. But going back to what we were talking about, one of the issue, you know, one of the key parts of this is the systematic review is really collecting that evidence that most busy providers don't have time to collect, and that, at a minimum, should at least raise people awareness, people's awareness of what's out there, that they know, that there's information out there that they need to look at. So I do, I do think that it probably does accelerate the process, but there's lots of other things in place, I think. And again, I'm biased, because I work within the cancer system, so you could have a bit of a different answer if you worked, if you were talking to somebody that was working with guidelines that were used in, you know, wider populations that maybe are not coming into places like cancer centers, where there's very focused care, for example, guidelines to manage diabetes or guidelines to manage blood pressure. I mean, there's literature to suggest or to show. I mean, those guidelines are important, but adherence isn't as, maybe as tight, and uptake may take longer.

**Speaker 3** 39:47

I also think that they've been very good at adding our guidelines to like the cancer pathways that CCO has, and so we can if you're looking at a cancer pathway that you have the. Links to the different guidelines and what information they use for those and I think some place, some people, or some groups, like the nursing group, for instance, they have champions at their hospital. So called, guideline gets published, then at they'll the champion will report the recommendations to their group at each individual hospital, and like support, conferences and stuff. People share a lot of the findings from nations and guidelines there.

**Dr. Bill Evans** 40:27

Just occurred me to ask, you know this, this is a program that's in Ontario. It's supported by the provincial agency and so on, but the reach of it must be much greater. And what evidence do you have, or what information do you have of impacts in other countries and other jurisdictions, and get any feedback from around the world about people using CCO, PPE, DC guidelines?

**Speaker 3** 40:56

Well, we go to a guideline International Network conference every year, and we talk about guidelines and how best to develop guidelines. And I think some information comes out there. I've only worked with a psychosocial group and a nursing group, and I know that, for instance, the fear of cancer recurrence guideline is going to be adopted by a group in Australia. We actually had a couple of people from Australia on our on our expert panel, because that was their expertise, yeah. And so now they're gonna adopt our guideline and and I think that happens, that does happen.

**Dr. Bill Evans** 41:30

So there's a global influence from from here in Hamilton, yeah, yeah.

**Speaker 2** 41:35

And, I mean, we're part of, we're part of a global network, as I was talking about, like with the American society. I think the other thing, though, that's important is goes back to what you're talking about in terms of guidance. It also lives within the context of where you're working. So for example, a guideline can situate it differently in Ontario than it can in other places because of the populations that they see, as well as the access to the therapies there are, I mean, having a guideline to say you should use this therapy, or you should use this test when that test is not available in a particular area, you know, pragma, you know that there's, there's a little bit of pragmatism there as well. And this is where, you know, it had been recognized, I think, more globally, around guidance and guidelines, that if you want to try to you know if you want to, if you think you can make your work more efficient by looking at somebody else's guideline, you still have to probably have a process to be able to adopt it to your own context, because it may not, it may not land exactly the right way.

**Dr. Bill Evans** 42:39

I also felt, in full disclosure, I would been involved in guideline development for 20 years, sharing the lung cancer disease anchor that the probably the greatest benefit of the guidelines were the people who actually developed them, that physicians were around the table discussing the literature, and who had attended the meetings and heard the presentations and more and more thoughtful about how to apply the evidence. So there's a real benefit to be engaged in the guideline process. A bit of an advertisement to physicians here in Ontario, but more widely, get involved in guideline development, because there's a great opportunity to learn about the evidence in a much more rigorous way. Of course, if you're a busy clinician, going to the kind of summary of the recommendations is a great help to decision making, but being engaged in actually reviewing the literature is an excellent way to advance your learning. Caroline, I wanted to ask you, because I think the toughest job you have in your managing role is, is the volume, and I was thinking about whether artificial intelligence is of any benefit in terms of synthesizing the information that you're buried under.

**Speaker 3** 43:56

Well, that's interesting. That is something that we're working on right now, because we're rigorous and we want things to be very exact, we don't want to just, you know, go on AI and say, Hey, chat TTP for a systematic review on this topic. But it can be used if we like. We were doing a study right now, where, where we find our we do the search, and we find what studies we will we would screen, and you select, and then ask an AI to check what, what would they choose, and compare it to what we choose. Those are

**Dr. Bill Evans** 44:31

actually studying how AI compares to your, your process, and yeah, and

**Speaker 3** 44:37

we think that we could use it as a second check, like, I don't think we'd ever want to just trust it, but we can use it as a backup, because we always have a second check. That's part of our rigor. We know one, we always have a second person looking at what studies we choose, doing data audits and and that kind of information. And AI can help us with that and make things maybe a little quicker. I think there are a couple ones that we're looking at.

**Speaker 2** 45:00

Specifically, yeah, there are, there are some commercial artificial intelligence that use this thing called large language model training, where, essentially, you try to teach it, you try to teach it what, what it should be looking for with the criteria that you set. Most often it's used in the screening process. So again, when we talked about, we want to do a guideline in there 8000 studies to look through. And for a person to look through 8000 studies and say, Okay, here's the criteria that I'm looking for to decide if the studies in or out. And you may be looking for 30 studies that are appropriate for the question. You have to find those 30 and 8000 and that can take long, long time. And the question is, so the first upfront question is, Can AI help with the screening? So this is one of the things that we're testing now, there are, there are, I mean, there are, there's lots of interest in this. Because, again, it's, it's, it seemed to be a repetitive task. But again, as Carolyn's talking about, even though on surface, it seems repetitive, there's still something cognitive that happens when you have to make a choice about whether this study is in or out. Right? I mean, there's a checklist that people go through, but they often still have to make a choice sometimes, or our process would involve if you're not entirely sure if a study should be in or out, that can be flagged, and then there can be discussion with other individuals to debate whether or not this, for example, this particular study should be included. So how you know how the AI programs help with that is going to be is going to be very interesting. I mean, preliminary, preliminary sort of feedback seems to suggest that it may, you know, cut our time by about 30 to 50% on the screening, which is, which is a big, significant task. I mean, if you think that an individual can maybe screen, I don't know somebody who's, you know, who's young with a fresh brain, can probably do, you know, maybe, maybe even 200 articles a day. I mean, I don't think I could do more than 50, but you know 200 you know 200 articles a day. And you know you're trying to and you're looking at this mountain of 8000 you know, 8000 to 10,000 articles can take a lot of time. So having the human be able to check the machines work, if the machine can be reasonably accurate, I think, is pretty pretty could be pretty interesting. I think, you know, taking it into science fiction, the question then, you know, is it ever going to get good enough that the these machines can think and write the recommendations? And I think, you know, I am by no means an expert in this area, but when you continue to hear news reports about people, even just trying to have them write up little pieces of paper, using them for communications program where the machine seems to kind of make things up. That's a little bit frightening. That's a little bit frightening in terms of how the llms actually interpret certain phrasing. And our methodologists

**Dr. Bill Evans** 47:54

aren't feeling threatened yet, not yet. No, we're doing okay. Okay. What are the issues that keep you up at night? With regard to guideline development? Are there any?

**Speaker 3** 48:06

Does that? There are a lot of guidelines to be developed. I think that is one thing that is, is keeping me up at night and updated. You know, we have a lot of guidelines. And so then ones that were developed, you know, like 2015 Well, lots has been happening in the last 10 years, and we don't have the capacity to try and update it all, all the time, so we have a big list of to do's, and then new information, news, new new guidelines could come out right like there's new new questions and new new treatments and new things to look at. So it's, it's a tough combination trying to figure out what to do.

**Speaker 2** 48:42

Yeah, I think, I think similarly, I think the other thing is that we are at a point now where we're asking questions, and the reason the question is being asked is because there's not a clear answer. And the guideline process sometimes can maybe even make it clear that there's not a clear answer, and then that can be difficult, taking it back to clinicians to clinicians to say, not enough. I mean, one of the conclusions of a systematic review and guidance process is, there's not enough information to give guidance. You know, that obviously, as a provider, somebody who is on the receiving end of that sometimes is a little bit, you know, unsatisfying. And then the idea of how you leverage that, or how you use that to say, well, we should probably be doing a research. Can we actually do a research study in this area? Can the guideline process actually in ball? So maybe keep, keep me up at night is more in maybe I'll spin it in the positive and say, you know, that's something can keep you up at night, because you think about, okay, what's the study that we actually need to do to answer this

**Dr. Bill Evans** 49:43

question? That's a cool way of thinking about it. So as we wind up here, I give each a chance to say a key message that you'd want listeners to take away from this discussion about the program and the development. Of evidence based guidelines. What? What? Thinking that most of them are probably non medical people. Maybe I'd never heard that there's such a program that evidence is synthesized to try and get guidance to physicians. What message would you like to leave them with?

**Speaker 3** 50:14

Carolyn, I guess that there's a lot of evidence and a lot of research out there, and it's nice to be able to try and find a way to make it smaller and make it reasonable and make it understandable and try and answer a question, and to be able to use doctors and providers and patients in order to help make a recommendation, to help somebody. I think the one thing I've always liked about this job, and I started, actually, 1997 worked for a year, and then I came back, and I've always liked the fact that these help people, that I feel like what I job does helps people, and I make decisions, help people feel better, help them figure out what's going to go on. That's That's what I've always liked about it, and I like that the guidelines do that.

**Dr. Bill Evans** 51:03

Great answer, yeah. Jonathan,

**Speaker 2** 51:05

yeah. I think we're very lucky. I think we're very lucky that we live in a place where there is a provincial Cancer Agency that puts a very high value on using evidence to inform care and to support best quality of care. And I think that makes us very fortunate to be living in this province, in this place, and that individuals should hopefully take some comfort in knowing that when they walk into a cancer center that there is evidence available, there are summaries, there are supports available to their providers, the providers who both provide direct care, as well as providers who organize the care in terms of how that care is organized in this province, that are trying to use the best available evidence to try to give individuals the best experience. And maybe I'm making that sound a little bit more like a plug for the provincial Cancer Agency, but I think that we in Ontario in particular, I think we're very fortunate and in a unique position that that relationship is there. Well, I

**Dr. Bill Evans** 52:12

think we're very fortunate to have you guys and the program and evidence based care. And I think an important message is that patients should know that doctors aren't just sort of making things up on the fly, but that there's an evidence base behind what they're doing, and that given the large amount of effort going into research that is being synthesized and distilled to what is the best practice for individuals at the present time. So I really admire the work you do. I really appreciate you sharing what you do with a listening audience today and keep on doing it. Thank you.

**Speaker 1** 52:52

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