NAMI Ask the Expert
What to Know Before Using a Mental Health App - May 21, 2020
Presented by
John Torous, MD, Director of Digital Psychiatry, BIDMC, Harvard Medical School

Teri Brister (00:00:00):

And I've got one minute after the hour, so I think we want to go ahead and get started. We've got a great presentation lined up for you today. So, let's go ahead and get going. We want to welcome all of you to the call this afternoon, and we're so glad that you're here. This is Teri Brister. I'm the National Director of Research and Quality Assurance at NAMI, and I have the privilege of being one of the hosts and one of the producers for this Ask the Expert webinar series.

So, we're just super excited, and what we're most excited about, besides our phenomenal speaker, is that we're able to come to you this afternoon in this new platform. For those of you who've been on our calls before, you know that we've done these in the past using a technology called Adobe Connect, which is phenomenal, and it served us well, but we've had such a tremendous level of interest in the webinars that we've been doing during the COVID-19 pandemic that we got immediate approval from Dan Gillison, our CEO that you'll hear from in just a few minutes, to move to a bigger platform. So, this is our first webinar. You guys are the very first ones in the universe to attend a NAMI Ask the Expert webinar using this technology. So, you can tell your children and grandchildren about that.

It allows us to have 3000 people, so we won't run into the problem we've had in the past, where we couldn't get everyone into the call that wanted to join. We actually have the capacity of increasing to a 10,000-person capability. So again, we have a lot of potential here, and we're just super excited to see how all of this goes today. You'll see that it looks a little different than Adobe Connect. It looks a lot like Zoom, and many of you, if not all of you, have been on more than your fair share of Zoom calls in the last few weeks, I would imagine, for personal and professional reasons. So, the buttons on the bottom will look familiar. If you just move your mouse along the bottom of the slide, right under where it has Dr. Torous's information in there, Elyse has got the instructional slot in front of you again, which is super helpful.

You'll see there's a button that you're all muted, so we can't hear you, but you'll see, there's the button that you click on to open the chat feature, where you type. If you look at the bottom, you'll see a QA pod. If you click on that arrow to the left, it'll expand it so you can type your questions in, and that's how you'll be submitting your questions for Dr. Torous during the presentation. As with our past webinars, we're going to hear from our presenter and then Dr. Duckworth will be looking at the questions you're all submitting and consolidating those, sorting those, and presenting them to Dr. Torous at the of the call. So be sure and type your questions in.

Is it possible to activate the video? We're not using video for this. I just saw someone type that in the chat. We're not using video for the presentation, simply because of the bandwidth, and we want to make sure that this all works, and we don't have any

disruptions. That might be something we do in the future. But for this first one, we're not going to. Again, as a reminder, all callers are muted. Clicking on the chat button and the QA buttons we've talked about already. The call is being recorded. So, after the presentation, you will receive a link to the recorded webinar and you'll also receive a file of the slides that Dr. Torous will be sharing. We'll send out a PDF copy of those, and you'll get a certificate for participation in this.

Reminder, we are closed Monday for Memorial Day. So, it may be Tuesday morning before you get that link and the slide deck to download, but you'll either have them tomorrow afternoon or first thing Tuesday. And with that, again, just a huge welcome to this first of WebEx NAMI Ask the Expert. I'm delighted for you to hear from Dr. Torous. He's actually a colleague of mine on a project that we work together on with the APA. And with that, I want to hand it over to Dan Gillison, NAMI's CEO, to get us started.

Dan Gillison (00:04:33):

Really, I'm very appreciative that all of you all are here, and we have representation from across the United States and from many different disciplines. We have representation from Harris County Protective Services for children and adults. We have a nursing student from California online. We have representation from Hawaii, Indiana, Montana, South Carolina, Texas, Florida, and so many other places that I don't have the time, or don't want to take your time away from this presentation, to mention.

So, the biggest thing here is that we are doing this for you, and we're always looking for suggestions on our topics. We think that this one today is outstanding. And we also recognize this from the number of you that have signed up for it. On behalf of NAMI, our alliance, which includes over 650 state chapters and affiliates, our leaders of those, and our board, we'd like to welcome you today. And with that, I'd like to hand it over to Dr. Ken Duckworth. Ken.

Ken Duckworth (00:05:42):

Good afternoon, everybody. My name is Ken Duckworth, and it's my great good fortune to be the Chief Medical Officer for this amazing organization. Ask the Expert lives on the website, if you ever want to hear a prior recording, and we try to cover every topic under the sun, from talking to your children about COVID-19 to the latest treatments, including ketamine and esketamine. And today we're taking on one of the more common questions that I am asked. Ken, what mental health apps do you recommend? And what is humbling about this is not only my answer is I'm not sure what the right app is. I don't have unlimited 24/7 access to our speaker today, who is actually the right person to ask. Dr. John Torous is the Director of the Digital Psychiatry Division in the Department of Psychiatry at Beth Israel Deaconess, a Harvard Medical School affiliated teaching hospital, where he's also a staff psychiatrist.

John's a bit of a renaissance man. He has a background in electrical engineering and computer science from Berkeley, before going to med school at UC San Diego. He has written over a hundred peer reviewed articles, including one with us at NAMI, and five book chapters on this precise topic. John serves as the SMI technology expert on the core clinical team for the SAMHSA funded SMI Advisor Project, which is what we are

also involved in. John is a friend of the family. And John, we're very grateful to you for your expertise in this area and for donating your time so that our NAMI membership can learn more about this wild west space.

John Torous (00:07:32):

So, thank you, Dr. Duckworth and to NAMI and to Teri Brister for inviting me. It's a pleasure to be here. And as I said, I want to really explain today, we're going to talk about this world of digital health apps and technologies, but first I want to go for conflict of interest for this topic. There's none. I do receive unrelated research support from Otsuka that has nothing to do with this talk. I also want to acknowledge that the Argosy Foundation gave us a very kind philanthropic donation to do work on the app database that we'll talk about later. So, the Argosy Foundation really has made so much of this work possible.

As Dr. Duckworth said, I work with SMI Advisor, which is a good resource that you can use to look up questions about apps. We have a lot of videos and resources there. You can also reach out any time and ask consults and personal questions about mental health and technology. I wanted to put that website there, and for the outline of today, we're going to talk about why apps, what is their goal in care today? How can we use them? And then what is out there? What does the marketplace look like? What are we being offered? What do we have to make decisions about? We'll talk about a framework that we can use to make a little bit of order of what's out there. We'll talk about efforts from an app evaluation with the American Psychiatric Association, and then look at an actionable database and a project to kind of help make more sense of it. And then next steps in the future of it, I'm hoping we can recruit some of you who are listening to join us as volunteers. We can tap into your expertise.

So, to start around the question of why apps and what can they do, I'll take an example from our Division of Digital Psychiatry at Beth Israel Deaconess Medical Center. We've developed an app. It's non-commercial, it's free. It can be downloaded by anyone. But it's a good example, because what you can do is two things. You see in the green box, we can use apps to collect real time surveys and sensors, like step count, to really understand people's unique, lived experience of mental illnesses. So, when I'm working with a person in the visit, it's a lot more impactful if we're not kind of saying, well, how do I think I was sleeping? I'm not sure how many steps. I'm not sure. And to say, well, let's actually look at how is your mood changing with your exercise? How is your anxiety changing with your sleep? Are there more hallucinations on days that you are more active? So, by capturing real time data from technology, we can really make clinical visits a lot more impactful. We can practice evidence based, clinical psychiatry and really have a better sense of what's happening.

Of course, I think we all know the other use case of apps is that they can kind of augment care on demand. We can ask for tips on demand. We can receive information to kind of be there when we want them the most. So, you can kind of think that one-way apps can collect information and they can respond and give us useful information back, and of course it's possible to combine both of these. There's a lot of different use cases for apps, and what we'll talk about with a lot of self-help apps that are on the marketplace, I think the true potential of apps is to drive personalized, responsive, and

evidence-based care. And to really do that, you want to be using apps in the context of a relationship.

So, we run a clinic at our hospital, and one thing that we do is we're not telling people, talk to the app and never talk to a person. What we're saying instead is, for each person we meet, what are some questions that we want to learn about people's mental health for each person? You can see on this graph, there's a lot of different information a smartphone may know about us, from those sneakers, how active you were, that heart, how much you're exercising, how much you're sleeping. And there's a lot of different questions we can ask about people's symptoms and their experience. And you can imagine that for each of us, there's different things we want to learn, and we can collect that data and personalize treatment.

So, I think no matter what app we kind of pick on, thinking of how can we use it in a way that's personalized response and evidence based, and in the context of a care relationship. And I think we're going to likely see a lot more clinics moving towards what we're calling this digital clinic model. But I think it's been very impactful for the people that we work with that we can customize care using technology, but then look at the data and information together.

One use case of technology, again, with the clinician, that we do in our group is we can look at can how we use the smartphone help us understand when someone may be at risk of having a relapse? So, for each person, this is a single person's data, we can say, you know, what is the baseline of how John uses his phone? How many steps does John take, and how many surveys does John take, and how social is John? And each day we can say, is the way that John's using his phone a little bit different? And you can see when things cross that dotted line, that threshold, where this one person in a research study, we kind of got an early warning sign a couple of weeks before relapse. So, we could really use that sensor data to begin to say, can the phone help us understand new information?

So, you can see, there's a lot of potential in using this technology that really is evolving, we're learning more about. It's very exciting. And before we go farther, I want to say, we recognize that not every person is comfortable using a smartphone, and to make sure that as digital technologies evolve, they have to be accessible by everyone. It's not acceptable if we make technologies that only work for a select few people. So, one program, you can see the link here, we've made is called DOORS, Digital Opportunities for Outcomes and Recovery Services.

And the idea of DOORS is simple. It's a [inaudible 00:13:43] curriculum, and again, all the content is for free. It's online. You can look at our manual, our slides, but the idea is, we can teach people how to use their smartphone as a tool, as part of your recovery. You can learn simple things that you may not know your phone can do. So, without even downloading any app, what are some things that your phone can do, from setting reminders about appointments, to kind of learning about how to access accurate and good health news. These are things that you may have access to already. So again, that link is there, and you can learn about what does the DOORS program look like.

And once we're kind of saying, well, let's say we're wanting to use a smartphone app. We feel that we know how to use smartphones. How do we pick them? We've estimated that there may be over 10,000 mental health related apps. I like to think the analogy of

kind of cargo containers in a port you could seem to [inaudible 00:14:39] right. It's hard to look at all 10,000 of them. They keep switching cargo containers. They come and go, they update. So, it's really hard to get a sense of what is out there on the marketplace. What can you download? What will be useful? What do you maybe want to avoid? I think we all have experience of just going probably to these different app stores, or looking at different software, and going, this is really hard to make a decision. And I think no matter who you are, it's a hard decision to make. I think if you're a clinician, a family member, a policy maker, someone with lived experience, really none of us have expert training or knowledge on what makes a really good app, and which one is going to be a good fit.

And I think the challenge is actually even greater, because there's a lack of regulation from the federal government, especially around mental health apps and software. So, this is a screenshot from April 2020, and it was basically the FDA was saying, how are they going to look at digital health devices again for treating psychiatric disorders during COVID-19? And this is a public document. You can download and look at it. But what the FDA in essence said was it's very hard to make sense of claims in the mental health space. And the FDA said, if things look very dangerous, we're going to step in. But in general, if things don't look overly dangerous, the FDA is going to take a very hands-off approach to the mental health psychiatry space or technology.

And that's pretty unusual, because usually regulators are kind of making things stricter. They're setting more guidelines. But this is a case where, again, we're saying, well, if it's making mental health psychiatric claims, the FDA is saying, unless in some circumstances they will step in, but a lot of times they're going to right now not step in, because it's not quite feasible.

So, and that said, I think all of us may have experiences. I'm excited for the question and answer. We can talk about it. But there are some really good apps that can exist to augment care, I just will talk about. There are also some really dangerous apps, and sometimes those dangers are subtle, and they expose or sell personal health data. And I think one of the things that took me a while to wrap my head around in this space is that a lot of these apps may market themselves as medical devices. It may look like it's kind of making medical, psychiatric, mental health claims, but really in the fine print they say, no, no, no, no, no, just kidding. We're actually a wellness device.

And you say, well, what's the difference between a wellness device and a medical device? They're both kind of helping me with my mental health. And the difference is, if these things are claiming to be a wellness device, they don't have to follow some of the regulations around privacy, like HIPAA, that are so important, that we've come to expect when we talk to a therapist, we talk to a peer specialist, we talk to a psychiatrist. We expect there are some things that are going to be kept confidential and private. When we're in the wellness space, it's a little bit different. The regulations aren't as strict. And we'll talk about who governs and what happens to your personal health data in that setting.

So with the American Psychiatric Association, we've built this framework, and it's actually a very universal framework, I think all of us can relate to it, where we really start by looking at what is the context, where does the app come from? But looking at that blue bar, what are the risks? If we're going to use an app, what are the risks we should

think about? And then if the risks seem too high, we should walk away. If the risks seem acceptable, we should look at the evidence. How is it going to help us? And then we say, well, if the evidence makes sense, we agree on risk benefit, is it going to be easy to use? Is it something we can stick with? And if we think yes, then the last layer will be, how are we going to meaningfully use this in our health? How are we going to share the data with the people we want? What impact is it going to have? We don't want to be tracking something for the sake of tracking it.

So, looking at risk benefit, ease of use, and kind of interoperability or meaningful use of the data, is a framework I think that we can all agree on. There's actually nothing mental health specific about this. It could be for anything; from any kind of thing we would want to use in healthcare. We want to look at the risk benefit. Can we actually use it, and will it benefit our health?

And the reason we start with privacy concerns and safety is, as we've talked about, a lot of apps may not follow HIPAA, because they don't claim to follow HIPAA in the fine print. There's a lot of research. We'll go into some of it. But a lot of these apps are not sharing data as securely as we want or would hope. And again, we'll go into some studies, but in essence, when you're using a smartphone app, that data is going hopefully to an [inaudible 00:19:46] health source, that cloud. But sometimes the data is also going to third parties. And when we're entering our mental health information, sometimes we don't always want our data shared with third parties, and it can sometimes be difficult to figure out who am I actually sharing data with when I'm using this mental health app, and is my...

Who am I actually sharing data with when I'm using this mental health app? And is my data being kept secure? This is a 2018 example from the New York Times. I put the link below. And what I really like about it is it showed an app called WeatherBug. So, weather WeatherBug was an app that you could use to learn the weather. You gave it access to your GPS, your location. And it would tell you what the weather was where you were. That sounds great. But it turned out that weather bug was also selling your geolocation information to advertisement. So, in this case, Weightwatcher’s could push an ad based on different areas where you were. And again, so this is a 2018 picture. So, these privacy concerns of apps are not new, but again, you can see that when you're giving apps a certain information, that information may go to different places in the advertisers.

Last year, we did a study with a group in Australia. And what we did is we actually kind of intercepted traffic in signals from mental health apps, popular ones for smoking cessation and for depression. And what we did is we said, let's try to figure out where this data's going. Maybe I enter a mood survey, maybe I tell the app about who I am to stop smoking. When I kind of push send or enter data, where's that app going? And what we did is by tracing, found that that data goes to a lot of places that aren't always disclosed in the privacy policy.

So, we actually presented these results to the federal trade commission, not the FDA, because the FTC actually worked with things that are post-market. In this case, we presented to the FTC and they were certainly concerned about it. They took this very seriously and have been looking into it. And the project we'll talk about later on actually today was just accepted to be represented to the FTC at the privacy convention. So,

you can see there's privacy concerns and the ones that we're aware of we want to make sure everyone's aware of. And the FTC is also kind of aware there's kind of this gap in privacy.

And what I'm going to do now is, again, throughout this whole talk, there is no companies or services I'm recommending. There's none that I'm not recommending. But these are kind of some news articles. This one is taken from, I think, early March 2020. So, this year. And the headline says "Talkspace threatened to sue a security researcher over a bug" so that the security researcher said he was forced to take down his blog post describing it, apparent bug in Talkspace's website. Within hours of this person publishing his findings, Talkspace sent a cease and desist letter accusing the researcher of defaming Talkspace.

This was a story from February of this year, and it said, "sensitive information does end up being shared all with the sensible goal of better tracking user behavior and perhaps giving social media companies an easy way to see who's depressed." "Better Help brings the question of how a person's intimate, supposedly private session might be exploited by advertisers and industry that isn't exactly known to operate in good faith." So again, you can see that these issues still of privacy are kind of still out there and lurking. And you really do want to understand where your data is going and who's seeing it for mental health.

The other thing we'll talk about is privacy being one risk. But also, what are the claims that these apps are making and what are they doing? This is an app that Sarah Lagen, who worked on these projects as a research assistant with me and has contributed tremendously to all of this work, found this app that purports to provide treatment for depression, bipolar disorder, schizophrenia. And it kind of makes claims around treating tones to kind of ... "Vital Tones has discovered evolutionary brainwave technology that can stimulate specific parts of the brain." So again, we're seeing some perhaps unfounded claims on the marketplaces.

And to really quantify, can you trust kind of what an app says, is this was a different study we published last year. It's open access, you can read it. But we actually looked at some of the top mental health app and we've read kind of what the app store description says. And they would make claims, "we can reduce depression by this percent." "We can reduce anxiety..." "Symptoms of bipolar will be this different." And we saw that in that red box, little heartbeat, 54%. They were kind of making medical claims about the kind of clinical potential of this app. And what we did is we kind of did our homework and track those claims back. And we said, how many of them actually can back up those claims with some citation to the scientific literature? And the answer is only 1.4%.

You go, "Well, John, how do we go from over 50% to 1.4%?" And the reason is that a lot of apps will say, "Well, we're based on evidence-based treatment that worked in person." So of course, it's going to work the same on an app. Sometimes if you had a book you really like and you saw the movie, they're pretty different or vice versa. So just because something works well in one mode, doesn't mean it's going to work well in a different mode.

And going back to the perils of misinformation, I think no one is making a mental health app trying to hurt people. But what we are seeing is sometimes people may be not keeping their mental health apps up to date. This was a published paper published in

late 2019. And it basically said in some apps non-existent or inaccurate suicide crisis helpline phone numbers were provided by mental health apps downloaded more than 2 million times. Only five of 69 apps offered all six evidence-based strategies for suicide prevention. So sometimes these apps, again, people making them have really good intention, but they may not really know all the details of how to provide safety resources for mental health, or they may not be updating the app enough. And again, so you really do want to be able to make sure you're avoiding, apps again, that are giving, inadvertently, but information that really could be dangerous.

So, we've talked a little bit about different risks. And again, they're ones that we may not always think about in privacy around misinformation. We've talked about evidence, that some of these things may have evidence, but in general, the claims may be a little bit exaggerated. Not always. But we want to kind of check with it. I think the next thing we want to talk about this yellow part, this usability and adherence in the app. And just because it's an app, doesn't mean people are always going to use it.

Our group did a research study with this app that is targeting patients and people with schizophrenia. And what we did is we got a research agreement and were able to look at how many people have kind of downloaded and used this app that was for free. And what we see here is from the data that we got, the top about 225 people in America had actually kind of used the medication feature to track a medication that they took, a medication one. But of course, for medication tracking to be useful, we want to track the medicine over a week, a month, a year. So, you can see, we looked at how many people were kind of actually consistently able to stick with the medication tracker was about 50 people. And that's a pretty small amount considering the population and the need. So again, just because an app is out there doesn't mean that people are going to stick with it.

And I'll take your attention to this graph on the right. This was a fantastic paper by Annette Baumel and John Kane, et al. And what they did is they looked at apps that were very popular. Had over a hundred thousand downloads. And they've got market research data on how many times both apps opened after the first time. And you can see that by about two week, only about 4% of apps are ever opened again. There's a 96% chance if someone downloads a mental health app that they may not be using it in two weeks. What's very interesting is that light gray bar above it that has higher engagement, more people are using it, those are pure support apps. The peer support apps are doing better. People are sticking with them. But in general, if you just hand someone an app, there's a good chance that their engagement may kind of decline.

And the graph on the left, that kind of pale salmon and that yellow one, what that can show is, if you kind of say, well, let's just pick apps that kind of have high star ratings. Let's pick all the five-star apps. You can kind of see one scale is clinical utility and one is usability. What the point is, all those things are clustering together because this app star rating, it doesn't really tell you much about how good the app is or how bad it is. Most of these apps kind of have between a four and five per rating, and there's not going to be too much information that you can get from that one.

App that probably should be taken off the app store is when I type schizophrenia into my smartphone and look for an app for schizophrenia, this app also shows up in the top five, it's a stigmatizing pong game called "Schizophrenia: don't lose it." So, the fact that

this app is showing up highly in the search, I think immediately tells us that looking just because an app is high in a search really means nothing. And so, I think we have to be a little bit more creative in avoiding really bad stuff like this "Schizophrenia: Don't lose it." And again, why a stigmatizing pong game is even showing up is a whole different question. So usability, if possible, we'll talk about it, there's great ways to keep people using apps, but just handing someone an app and saying, " This is going to be effective," it may not be because it's hard to keep using it.

The fourth layer we talked about is kind of what is going to happen to your data. We don't want to have data silos, right? You don't want one app per medication if you're taking those, one app for therapy, one app for diet, one app for exercise. Really, we want app data to be sparking conversations between people that they're going to write. It's used as a way to kind of bring up things we want to talk about, to explore in trusting relationships, to share information. We don't want to just have data silos, but we live in an era we want integrated mental health care. And I think we can talk ... It's not the topic of this talk, but like the digital clinic models, the way to really use apps in the right way. So anytime you're using the app, thinking, how am I going to kind of use this app? How is it going to help me kind of share with the right people how I'm going and what I'm learning about?

So, we talked about these kinds of broad principles of apps. So, kind of looking for things that are safe, things that are evidence based, things are usable, and things that are kind of meaningful that let you share data and kind of move your health in the right direction. There's a lot of app evaluation schemes out there giving guidance recommendations. And I said, this was one paper that looked at them. There's many, many more. It's not possible to cover all the different kind of different schemes and framework that people have made to recommend apps or say, "This is the best app for you." And each of them has merit.

But I think one thing that can be a little bit deceptive of some of these frameworks is sometimes there'll be a list of these are the top apps for bipolar disorder, or we'll say these are the 4.7 out of five apps for schizophrenia. These are the apps for depression. And they'll try to kind of score these apps or give them a number. But if you think about it, when we're talking about a therapy or medication, we don't ever really say that this is the A-plus therapy. And we know that different people react differently to treatment at different times, just like different people react and use apps differently. And there's different clinical needs. The same person using an app, they have different needs than someone else.

And I think we certainly know that apps are always constantly updating and changing. It's not like ... Usually a therapy doesn't change too much. CBT is often CBT. If someone's taking this in, it's often the same medicine. But think how often apps for updating. So, when someone tries to tell you, these are kind of the top apps or these apps have a static score, that's a little bit misleading, because again, really it's a meaningless number to say these apps are four or five stars.

So, this was a research paper that came out in MPJ digital medicine that looked at, again, some of these websites that try to tell you, well, these are websites. Here's kind of top apps. And what I think is most interesting, I've highlighted, is one is they don't all agree what the top app is, which makes sense just because for all of you listening now,

I don't know what the top app is for you because I haven't met you. We haven't talked together. And the best app for you is going to change as your needs change. So, it makes sense that these things can't agree on a top app. But if you look at day since last updated for mindtools.io, it was 714 days. For Cyber Guide, it was 598 days. Orca, it was 109 days. And I think all of us know that apps change pretty frequently. So even if these sites were right, you're giving us stale, out of date information, which again can be dangerous.

I think a different thing that makes it really hard to give these points-based systems, we'll talk about more, is sometimes they'll give ease of use. Again, they're going to make a scoring system. So, they'll say the app will get points for ease of use, but what does ease of use mean for each person is going to be so different. And so, one approach we've taken at the American Psychiatric Association is we've looked over a lot of frameworks and we gathered 604 unique questions from 45 different frameworks. And Philip Henson, who's going to be actually attending Mount Sinai Medical School, really helped go through all these frameworks.

And we took all these questions and said, what is unique about all these frameworks? What is different? And you can see the bar graph short term was kind of very high. You can see credible app developers. So, a lot of app frameworks are saying, well, does the app have good short-term usability? And is it someone you trust? And those were kind of most common questions. But you can see that things in pink, like privacy security, weren't really well-represented. So, what we did is, this pyramid I kind of showed you before, so we said, "Let's put some order of things that we know are most important." Privacy and security has to come first. Then we want to make sure that it has some clinical foundation. Then you could see engagement style, then therapeutic goal.

So, what we did is we kind of reordered a bunch of questions and said, "Here's a framework to kind of make sense of it." And we actually have a lot of resources that you can learn about this framework. I say Google it, because that website links a little hard to go, but if you type in APA, American Psychiatric Association, app evaluation framework, you'll get a very clear picture of it. There's a lot of videos. There are examples. There's links of what you can learn about it. And on the SMI advisor website, we actually have a lot of webinars kind of how to use this as a tool to guide your decision making, how you can kind of use this as a framework. So, I realized this picture is a little blurry, but all the information is on the internet. It's live right now as you kind of type in app evaluation.

And we've had this framework around, it's been ... You can see in 2018 people have studied it. They've written about it. And it's done well. New York City actually kind of took it. And again, you can see the assessment, they were going to look at security and privacy, effectiveness, usability, data sharing. So, New York City kind of used this framework to make their own app library. And again, it's up to people how to use the framework, right? If we give you a way to just think about it, you decide what's important. So, it was exciting to see kind of New York City took this and made their own app library. And if you Google NYCWell, you can see kind of how they applied it and what apps they picked with it. And again, our goal here is not to say any one app is good or bad, but again, you can apply a process to it.

So, what I want to talk about now is how we can transform this framework into a database and a project. So, this actually is a database of apps based on the framework. It's supported by a gift from the Argosy Foundation, which has really made this work possible. And what we've done, and I'll come back to this slide, is we said, "how can we take that theoretical framework? And how can we turn that into a database that people can search to learn about apps?" Again, we don't know what the right app is, but is there a way you can say, "Well, show me all the apps that have a privacy policy. Tell me all the apps that have research evidence. Show me all the apps that may have different engagement styles."

So, we'll come back to the slide as late, but this apps.digitalpsych.org is live right now at work. And I'll explain how we're hoping to get some of your expertise and help on this project. Because, we talked about kind of in red, having a score that says four over five is the score of the app, or we had a five for ease of use, is pretty meaningless. Because let's look at two hypothetical people. Let's look at the person who wants a very secure app. It's okay if less evidence, but really wants a gamified app. And again, a score of three out of five ease of use means nothing because this person wants an app that's gamified. That's going to make them use it. Now, on the other hand, we may have someone that doesn't care about ease of use. They really just want something that can let them track something. So, ease of use doesn't matter in the score. So how do we kind of help match people to the right app based under own preferences and not pulling out.

And again, so to reiterate it, we want to look at individual preferences and values will guide what app you pick, not someone else doing it for you. And so how do we make these things objective and replicable? Because as we said, what does ease of use mean? When someone saying it's easy to use, whose value judgements are being imposed and what cultural assumptions are they making? Again, ease of use will mean different things for different people. So, what we've done is we've taken some like ease of use and switched it to engagement style. If you're using an app, do you want the app to offer you peer support as a way to engage? You want it to be text messaging based? Do you want it to be screening based? Do you want it to offer real time information? Do you want it to be kind of AI driven? That little robot there. Do you want it to offer music? Do you want to offer videos?

And different apps are going to offer different engagement styles. And some of them will combine them together. And none of us are here to say, "Look, apps that offer AI driven and gamification are good or bad." That's just a feature of them. We want to know that what are all the apps that have video and peer support? And again, we're not here to say any combination is better than the other combination because people are going to respond and want different things. So what our team has done, and again, I have to thank Sarah Lagen and who's really gone through and broken this down, is we took those principles and the APA framework and we said, "Let's think of a way to kind of take those principles and make them questions that are very actionable, that are things that we can answer with a number, and that we can replicate." So, if someone wants an app that can kind of track steps and plot changes of mood, we can figure out what those are. If someone wants to see an app for mood that's free and has strong evidence, we can-

An app for mood that's free and has strong evidence. We can figure out what those are. We can [create an app inaudible 00:00:07] based on what people want, and then we can have people say, here's the things that meet my needs and evaluate if those are a good fit. So, I won't go into all the questions that we have here, but you can imagine we can ask questions that are, who does the app come from? Is it from the government? Is it from a for-profit company? Is it a nonprofit company? And the goal of all these questions is to make something that is replicable. Something that is closer to a fact, something that doesn't have a value judgment attached to it. And we can ask questions. Does the app work offline? Is it totally free? What are the upfront costs? And again, all these questions are on the website I'll show you. And I won't go through even more of them, but it does involve mood tracking, journaling, psycho-education. Does it offer CBT for insomnia? Does it offer regular CBT acceptance and commitment therapy, DBT, peer support? Can it connect you to a coach or a therapist? It doesn't involve bio-data.

And you can see the reason why we have all these questions is these are things people may be interested in. They're going to want to know, do these features exist? We're not saying it's good or bad to have any of them or a combination, but we're thinking we really want to understand how these apps work at a granular level. And again, we talked about engagement style, which way do you want to use an app? If you have a loved one, do they really respond better to videos? We want to find apps that are really just video based.

Do they love games? And we want to make a game-based app. And so, we have a lot of these questions. And so, the website that we've made, the home page, you can go to it and you can enter your preferences. It will guide you through and say, do you want an app that works on an iPhone or Android? Do you want apps that are totally free or have costs? And what privacy settings do you want? Some people say, look, I understand that to use some apps, the app may want some personal data and that's fine. But the point is, that's an informed decision. That's a value judgment that you get to make as a person using it. You get to pick what is acceptable to you. Many apps don't have the strongest evidence because they are new. And that's fine, but that is something you want to say, hey, I'm willing to accept that type of evidence.

So, we have coded these apps and there's over 105 questions about each app. And that's certainly a lot of questions. And oftentimes you don't need to search all 105 questions. Most apps don't do 105 different things and you will quickly whittle down what you are interested in to pretty quickly. But the database can return apps that may meet your search criteria or may get close to it and again, if it doesn't, that could be one, we haven't looked at that app yet or that what you want doesn't yet exist, that you've had a really good idea and no one has actually made that thing happen. What we can do is to make this work is, it's a crowdsourcing program. We rely on volunteers to help us do it. We have a way that we train volunteers, and anyone is eligible to become a volunteer and help us rate apps and answer them.

By answering these 100 questions, a trained rater can submit app metrics and then we can put it into the database. We have a couple people rate these apps, and once we see there's enough convergence on these questions, I showed you, we enter that into the database. And I think we've been lucky to have some very dedicated volunteers who have really helped us understand it. I want to call out [Abdi and Aparna Ramakrishna

00:03:42] who have really gone above and beyond to help us rate these apps, to think about the right questions. But if any of you are interested in learning more about apps, want to go through our training and help us rate these, we would love to get your experience and expertise because by helping us answer these questions, we can enter them into the database and then... Probably went the wrong way... Make this searchable.

The training works that you can attend our group's webinar, and then we have you try to rate a couple apps. We work with you to make sure that you're getting 90% reliability. And then we ask you sometimes to rate apps that we know people want to see or apps that you think are interesting. And we have to update these apps regularly, as we've talked in an earlier slide, these apps change. So, we work to update and see if apps are different after 90 days. But again, I think anyone who has interest is really welcome to join us and help us learn about crowdsourcing and exploring this way. So again, here's what the website looks like right now, supported by the Argosy Foundation. The more apps we get, we can begin really having better searches, returning better results on what it is.

I think now you guys understand that theoretical foundation we based it on, but of course you can search for an app any way you like. In some cases, there may only be a couple apps that actually meet your criteria. You may say, look, I use an Android phone, it has to be completely free, and I want the highest privacy. It's perhaps not surprising, but a lot of apps will fall away pretty quickly from the crowd. We should almost have 200 apps rated, of the most popular ones. Again, the more volunteers and interest we get, the more that we'll keep extending it. If you have immediate interest, you can email Sarah, her email is there and the slides will be available, and we're happy to schedule you, happy to teach you more about it, happy to volunteer. It's an ongoing project that is as strong as the community behind it.

If you have more questions that's my email. Our lab group has a website, digitalpsych.org. where you can find more about this project. With the work that we do have SMIAdviser, it's another really great resource. We have a lot of videos up on technology questions. There's also really good information on non-technology things. On questions about therapy, questions about different medications, the healthcare system. You can ask consults. So, it's a really good library of resources that's evolving and completely free, and a lot of our group's information is also up there. So, three different ways to reach out that I think are all important ways to do it. I think with that I'm going to hand the slides back over.

Ken Duckworth (00:46:45):

Hey John, thank you very much. I want to take some questions. You mentioned that peer support apps seem to be used more than some of the other apps, which people fall off after a few uses. Can you discuss your thinking on that, what you've learned about that so far?

John Torous (00:47:08):

I think it's a really good point and as always Dr. Duckworth, you're an astute listener because that was in there, it was a fast point of the many I talked about. But I think what

we're seeing is that one of the, let's just use the word Achilles heels, of apps is we're excited because many people have smartphones or getting them, they're accessible, but just because we have an app or smartphone doesn't mean we're going to download a mental health app and to just download a mental health app, doesn't mean we're going to use it. I think engagement and lack of engagement has really become the challenge in this space. And in part it's like a gym membership. If your doctor gives me a gym membership, there's a good chance I may go a few times, but I may not keep going all the time, or you give me running shoes, I may go running a couple of times but it doesn't mean I'm going to become a runner and start running every time.

It's the same for apps, how do we keep people engaged? And it can be anything with, how do we make sure that we're taking a medication? If we take it consistently, [mm-hmm (affirmative) crosstalk 00:00:48:15] if we're taking therapy, we go to it. And I think we know even without technology, peer support is one of the most motivating, impactful things that there is. I think we're seeing that peer support digitally is no different. It is still one of the most powerful, motivating, impactful things that we have and that there is out there. There's really good research. Dr. Karen Fortuna at Dartmouth has done a lot of impressive research on peer support and digital mental health platforms, and really shown that having an element of peer support in it, probably, I'm going to make a statement to say I think it's the most effective way to keep your app engaging, to keep people using it, to keep it meaningful and relevant.

And again, I think all of us on this webinar, I think NAMI knows this. I don't have to say it. It's involving the family, it's involving people with lived experience, it's building a community that's supportive. And I think we don't want technology to become isolating. I think we've seen pretty good evidence that these self-help apps that say, look to download the app, you don't have to talk to anyone, you don't have to look at anyone. You can sit and just use the app yourself. That may be helpful for a few people, but overall, it's really going to pale in comparison to using technology to activate and to engage the community. I think we're seeing that the evidence is bearing it out. One reason maybe that we haven't seen apps yet transform mental health care is we haven't seen enough activation of the peer community yet. We're beginning to see it, and I think people are realizing it's important. But until we really bring what we know works into apps and technology, we're probably going to be spinning our wheels for more time than we want instead of making rapid progress.

Ken Duckworth (00:50:21):

Thank you, John. A couple of questions relate to paranoia and technology. One individual says "I have schizophrenia and I have struggled with the belief delusion/delusion. That technology is holding on to my information. And I wanted to ask what your experience had been with the challenge of living with a delusion and using technology, and what you found in that regard."

John Torous (00:50:50):

So, it's a really good question. And it's one that often comes up as saying, is technology going to be something that triggers me that could bring up delusions and make me feel unwell? And I'll give two answers. One, we've done survey research and I'll now give

our experiences in clinic. But with that survey research, where we've asked patients at our clinic...we do a lot of work at something called the Massachusetts Mental Health Center, and we do work in our Beth Israel Deaconess Medical Center clinic...but we've asked many people this question, is using technology going to make you perhaps feel more triggered as it could be a way that it'll increase delusion. And we also asked the same question to people in the general public that were not in our psychiatry clinic. And what we found was there was a subset of people in both populations, people getting mental health care and people not getting any mental health care.

And about 5% of people in each said look, I don't want to use technology as my health care, I don't trust it, but it was actually no higher. It was the same amount of people that weren't working with a mental health condition that [mm-hmm (affirmative) crosstalk 00:52:04] people that weren't involved. So, I think that the concern about technology is universal. As we talked about early on in the talk, there are some serious privacy concerns around this technology that we covered. I think that we have to be upfront that sometimes information is not going where we want with it and the wrong people are seeing it. Which one, I think it means that we have to really do our homework before sometimes committing ourselves to one of these apps. But overall, the evidence, again from research we've done is, there are these apps... For some people, they may not be a good fit, maybe 5%, we don't have the exact number, but like anything there's not going to be one thing that works well for everyone.

In working directly with patients, our group really works a lot with people with early core psychosis, and in first episode programs, what we found is there's no... Some people may feel uncomfortable using apps and they have questions about where their data is` going, but there's no consistent evidence that this is going to trigger hallucinations, this is going to make delusions worse. [mm-hmm (affirmative) crosstalk 00:13:24] It's going back to what we talked about at our hospital, we have what we call a digital clinic. So, I will see a patient or the social worker that I work with, we'll see patients together face to face, and we'll use technology as a way to augment and extend our care relationship. We'll work with someone to say, here's why we want to use technology, here's what we want to collect, here's how we're going to use it to make a decision at your next visit, And we're going to share it with you.

So, I think when we use technology as part of the care relationship and as part of the therapeutic alliance to extend it, then every patient we've worked with has been excited. They understand it. [They can see that it works inaudible 00:54:10] I think though for anyone, if someone told me, John, you have to install this app, you don't know what it is, you don't know where the data's going and don't touch it or else you're going to get in trouble. I wouldn't want that on my phone. No one would want that on their phone. So, I think it's a really good point, but I think it's not specific to any mental illness. It's saying, if we're going to use any technology for anyone, with any condition across all of health, you want to know a lot about it. You deserve to ask, have those hard questions answered.

We saw that right now the FDA isn't really giving a guarantee for a lot of these things. So, it does put more of the burden on us. So asking the hard questions makes sense because if you ask those hard questions, or again I think that's why we've tried to build this database to make it a little bit easier to get some answers, and I'll put that link up

there. Then you can have more trust in this. So, you can say look, I do agree to give my data, I'm interested in it, because I think all of us know the foundation of good mental health is trust and shared decision making. And if you don't feel it's something you can trust and if it's not going to lead to shared decision making, it's not something you want to use.

So, the short answer to your really good question is, there is no evidence that they will trigger delusions or hallucinations, but some people have rightful skepticism. And I think you do want to see these apps used in a way that's compatible with your beliefs, your interest and your care. And if it's not, it's just not going to be helpful. As we've talked 96% of these things, no one is going to be using them.

Ken Duckworth (00:55:52):

I do like the service to science model, where when people try things, they give feedback to you and then you will help to organize this database because this is an unregulated space and people's experience is going to help to drive a lot of the evidence about it. Different question. Let's talk about YouTube videos that relate to insomnia, deep breathing, mindfulness. Are YouTube videos included in this rubric of things you're reviewing or is it simply if it exists on a phone and if it is on the phone, are we talking about the Calm app, all the meditation apps. I wanted to ask is that in the universe, YouTube and meditation?

John Torous (00:56:44):

So really good question. There's a lot of impressive YouTube videos that people have made that I think are amazingly high quality and very educational and informative. Because we also know too, there is some pretty stigmatizing, inaccurate, harmful stuff on YouTube as well. I guess that is how social media seems to work these days. There's good, and there's bad. What I describe in the system is right now we're not including YouTube videos; we're including things that are more things you would download onto a smartphone as an app from an app store. But I would say, when we talk about that American Psychiatric Association framework and that pyramid of looking at trusting, I think those questions apply really to almost any type of media we may be consuming via a smartphone app or a video. So, the principles behind the database apply really well and that we want to say, are there any safety concerns with the information this thing of sharing.

Then we want to say is it evidence-based or again, is it saying something that makes sense, hopefully it's not inaccurate. Is it something engaging? Is it a video I want to watch and can I relate to this person? And can I use this information in my health? So, things still around privacy, safety is bucket one. Evidence for is it grounded in truth or facts based on bucket two. Bucket three, is it engaging so that I can walk and stick with it and bucket four, can I use it? Those four same principles will work the same in YouTube as for an app.

But the database that we have right now, we're only coding things that are, you would go to the iTunes store or the Google Play Store and you could download it onto your phone. So, this would include that universal mindfulness, meditation thing [mm-hmm (affirmative) crosstalk 00:58:40] apps. And that said, if there is one we haven't rated,

you can always recommend it to us, we'll try to get it up there quickly. Or again, you can join us as a rater. We'd love to teach you and then you can help rate it and help rate other ones as well. So, I think that there is only so much that we can cover, but the more people that help us, we can definitely expand it to things that you think are important.

Ken Duckworth (00:59:06):

Excellent. John, a question about non-English language apps. The question refers to refugees, immigrants, people whose English is their second or third language, and how you thought about that in terms of the increasing diversity in our country.

John Torous (00:59:24):

It's a really important question because most apps may be in English and not applicable to people that don't speak English. And that gets to that usability question. If we have this app that is really private, it is really secure, we're happy about that. It's really evidence-based, we're happy about that. But that third bucket, usability, if it's not in the right language it doesn't matter. So, what we have started coding already is, we know that there are many people that speak Spanish, so we have started coding is the app in English or is it Spanish, those are ones we are coding right away. And as we begin to expand.

Right away. And as we begin to expand, it's a database. We can add a new flag. But the immediate one we added is, can it kind of support Spanish language or other languages? And most apps; again, if you kind of go to our database and kind of put the Spanish filter on, it's going to be a pretty limited landscape of what comes back.

And that does really identify a practice to research gap, right? We don't have apps that can support all of the right people, but we do have a button to filter for it. And it'll show you ones that can support Spanish. And we haven't coded all other languages at this point, but you'll quickly see which ones are kind of ones that could be a good start.

And I think that's another reason, again, that these static app valuation scores, where it says, "Look, these are the five-star apps." You go, "Five stars for who?" Five stars for like this mythical person that doesn't exist. Or, "These are the top apps." You go, "My gosh." Like, "What a..."

I mean, it's almost, it's just almost unfair, right? To say that, to think that a mental health app is so simple, or people's needs are so simple, they can package it into a number and say, "It's going to be a match for you." It really does. And I think this question of how they fit that? You want to understand; mental health is multidimensional, it's multifactorial. And just like of anything that you kind of work, use to improve your mental health, you want to make sure it's a match for you and your preferences. And language is no exception.

Ken Duckworth (01:01:32):

John, question comes up. If I download three apps, am I three times as likely to have my privacy compromised? [crosstalk 00:01:40]. Or are they all essentially... You know, if I'm not paying for something, am I essentially the product? Which is a question I think

very few people asked when the new world of technology broke open, which has become very painfully evident that there are complex business models.

So, let's say I have three different apps that I feel are helpful to me, for whatever reason. Do I have triple the rate of privacy compromise?

John Torous (01:02:08):

I'm going to say yes. And the reason I'm going to say yes is that we don't know exactly what every app is doing. It gets back to our cargo ship container.

But overall, we've seen that the privacy protections are not great. And I do tell people I work with in my clinic, if the app is free, as you said, you're probably paying for it with your data to some extent. The one exception I'll say is the Veterans Administration, the VA.

Ken Duckworth (01:02:37):

Ah, there was a question about the VA! So, I'm so glad you offered that. Thank you, John.

So please go back to developing that.

John Torous (01:02:45):

So the Veterans Administration, the VA, has put out a lot of apps that are, while targeted towards veterans; and they kind of target things like PTSD conditions veterans may be more likely to develop because of their exposure; the Veterans Administration has done a really good job of putting out a whole suite of apps that really have a great privacy policy. It's readable, it's interpretable. The privacy policy says, "Your data, you keep it. We don't want it."

I often kind of recommend people to look at the VA app as a first stop, because they're less likely to compromise your privacy end.

In our app database, we actually made four questions around cost, because sometimes an app is free. But then, it's a free trial and it starts wanting money. Or sometimes it's free and then there's premium parts to add. Or sometimes it's free for so long and then it changes.

So there actually aren't that many apps that are kind of free, free in the sense that we all think when we think of free.

We have to make literally four different codes around free to understand it. Because there are so many little tricks that apps were doing to kind of not be free. But if an app is free, I think it could be great, like the Veterans Administration. But again, you may want to sit down and even say, ask a friend, talk to a couple of people and say, "Hey, does this make sense?"

Or it can be really hard, it's almost impossible, to go through that privacy policy. But if you see the privacy policy looks so complex, that's kind of a good indication that you may want to run away from that app. Well, I would run away with my arms up in the air, screaming, "Oh, my gosh; this looks like a black hole of legal jargon!" Here I am just trying to track my mood. Something doesn't add up.

Ken Duckworth (01:04:34):

Are people eligible for the VA app if they're not a service-connected veteran?

John Torous (01:04:40):

That's a great question. And the answer is, no matter who you are, you are eligible to download and use the VA, the Veterans Administration, the VA app. They're publicly available on the iTunes store. And if you have an Android phone on the Google Play for those stores, so. And if you type in kind of Veterans Administration or VA app, they actually have a website that tells you all the apps.

And they even have an app called COVID Coach they just released. That has some interesting information and resources around COVID. So, I think that the VA apps are a really good, useful first stop. Because, in that case, you could download three apps and you're not going to compromise your privacy three times.

You can kind of shop around and learn more.

Ken Duckworth (01:05:27):

It's very appropriate before Memorial Day that the Veterans Administration is looking good. Is the Veterans Administration apps part of the rating framework that you're encouraging people to do through the process that you've outlined?

John Torous (01:05:43):

So, we have rated all, we've gone through most of the Veterans Administration apps we've put in our database because we thought they were important to include. Because we know from research and doing work in this field, again, they're free and that they have a really good privacy policy that doesn't try to kind of use your data inappropriately. So, we've kind of done a, we've entered, even COVID Coach, the newest one, we've we've entered and looked at. And so, you're free to look at them in our database, but you're free to just type into Google, Veterans Administration, mental health apps, in apps, and you'll find them through many ways.

Ken Duckworth (01:06:24):

Okay. That's excellent.

Let's take the conversation in a slightly different direction. Let's talk about artificial intelligence. Let's just take your Alexa speaker. What do you think the potential is? Because apparently, Alexa gives answers when you say, "I think I'm depressed."

What do you think the future is? No one is asking you to predict said future or how regulations will work. How do you think, as a computer scientist and psychiatrist, artificial intelligence can be a positive force for identification and even potentially treatment and support for people? Because we're early in the early in the business now, right?

John Torous (01:07:09):

It's a really good question. And this is an area that our group at Beth Israel, there's actually a lot of work in is, kind of... Again, do you, in a research context, collecting a lot of data with people's permission to study it, to learn about, what can we learn from these sensors in our home like Alexa, collecting voice? Or what can we learn from kind of step count or what can we learn from how daily information on people?

And I think the way that artificial intelligence is going to be very useful for the mental health field is, I think every one of us knows that the way we experience mental illness is different. The way that we feel better is a little bit different, the way we feel worse is different. I think we know that the way we respond to treatments is different. The way that we rely on our families is, can be different.

And that's a good thing. But I think we all have been sometimes frustrated because sometimes, when we try to follow guidelines or give evidence, they kind of work for, it says, "This is the way that we treat this." And when we can use an artificial intelligence or kind of a machine learning approach, in an ideal setting, we move towards personalized recommendations. We say, "Well for most people, this was the therapy that we think is the way to start. But because they can draw on, this is the way that you sleep and this is the way that you feel and this is your exercise patterns, we think that we really want to start with this different therapy because this is going to be most effective for you."

So, we really can move towards personalized care. And that begins moving us towards prevention. We need to almost try to look ahead. As you said, we can't predict the future. But in those early slides, I showed you how we can try to use smartphone data to maybe predict relapse a couple weeks early. We can say, "If we have all of this data, can it help us learn about people's personal patterns? And do those patterns, are they going in a good direction or a direction that maybe we can try to reverse?"

And I'm going to precede your next question and say, "Well, what are the downsides of this?" Or again, so we could move towards personalized care and prevention. But to build these models that work well, we have to have a lot of data. And as you said, kind of having a lot of data means we have to agree to share data about ourselves that can be very sensitive.

So, we may be sharing voice data with these kind of things in the home that record voice. We may be sharing information with researchers that, when we're doing our research mission, about how we're using our smartphones. And I think, as we're sharing information, we have to make sure that we're sharing information with the right people, it's being kept secure, it's being kept safe, our privacy is being respected.

And I think that, as we're seeing new players emerge into the mental health space, we're seeing technology companies become very interested in this, offering solution startups, offering solutions. Hopefully, we're going to see kind of more efforts from states kind of offering technology solutions. If everyone kind of wants our data, how do we make sure it's being respected and used well?

And I think one example is, I got contacted by a reporter from the New York Times about a year-and-a-half ago. And she said, "John, have you heard of Facebook's Suicide Prevention Program?" I said, "No." And she said, "Well, anyone who's using

Facebook, if you type words around self-harm or suicide, Facebook is running something called Natural Language Processing, kind of a type of artificial intelligence. If there's enough words that are concerning, it trips an algorithm. And that algorithm sends a message to a person; we don't know who; and that person reviews what you typed. And if that person is concerned, they may call local law enforcement to do a safety check and say, "Are you okay?"

And that was a case, again, where Facebook didn't really announce to people. There's nothing when you sign up for Facebook or use it as, "By the way, we're monitoring every keystroke you do about suicide prevention. And if you type certain things, you may see a police officer or an ambulance at your door." There was no way to opt in, there was no way to opt out.

So, I think the ethics of an approach like that? I think they... Again, the intentions are good. But you say, "Is that the right way to begin kind of using these new digital tools, like artificial intelligence or natural language processing?" And maybe there's a different approach to, again, help people understand what's happening, help people opt in, help people opt out.

So, I guess I'm saying, in part, it's already happening, sometimes without our knowledge and sometimes with our knowledge. But I think, as a community, we want to say the data, our data tells a lot of stories about us. Our data is part of who we are. And it makes sense we want to advance health care, we want to advance mental health. There's tremendous opportunity by donating data, by partaking in research, by sharing it. But I think we want to be informed about it. We don't want these things happening without us happening.

And I think a group that really is going to have the most say in this is NAMI. This is the group that can organize and bring the voice of people and say, "Look, here's what we think makes sense. Hey, this is pushing the boundaries; this doesn't make sense."

So even if you're listening to this and say, "Look, I don't want to use smartphones in my care. I don't want to use technology." I think at least being aware of what's happening in this space and kind of having knowledge will allow you to advocate and make sure that, kind of in the future, your data just doesn't disappear. And you say, "Whoa, how did my digital profile end up here? And I didn't agree to this."

So I think it's something that the most impactful advocacy is going to come from families, it's going to come from people with lived experience, saying, "Hey, we think this makes sense" or, "Hey, this is pushing it too far. Let's take a step back and make sure that our voice is heard first."

Ken Duckworth (01:13:29):

John, last question. And before we close, I just want to thank you for enlightening us about this fast-moving pace. And I want to remind people that, when we close the webinar, you'll get an email, which is a survey. "Did you like it? Did you find the technology reasonably friendly?" And, "What topics would you like us to discuss going forward?" We make a genuine effort at NAMI to make sure we're listening and bringing this on. Because technology's been so hot, we wanted to make sure.

So, I'm going to close with a last question. What age do you think is appropriate to use these kinds of apps? Are you concerned about younger people using apps? Obviously, this is a concern for all technology, right? If a child, a young teen or tween, has a cell phone? But how do you think about that?

John Torous (01:14:32):

It's a really good question in this screen time issue. Is screen time correlated to worse mental health, better mental health, or do nothing? Very kind of hot topic. Everyone seems to have a hot take on it as well.

And from the most current evidence on it, I think what we've seen actually is, it's not screen time, per se. It's the quality of what you do with that screen time that matters a lot more. And I think it's a lot easier to measure how long the phone was turned off and on than what was the quality of your use of the phone? Was it something that was beneficial, meaningful, engaging? Or was it something where you were kind of were distracted from life, kind of ignoring obligations and responsibilities?

So, what we're finding is, certainly if you're having, there's some research, over eight hours of screen time per day, that may be associated with worse mental health outcomes.

And so, kind of at the extreme, or if you kind of are, if you have access, if you've never engaged in technology, you may be probably missing out on some interesting opportunities. But for most people, when you kind of look at it from a hard-nosed research point of view, we're not really sure what screen time is doing, because we're only able to measure the fact that you used it. It's like saying you went into a house and you came out of a house. And we know how long you were there, but we don't really know what you did in that house. We don't know what you kind of did in that session, in that job, in that school.

So, in part, we don't really have a good answer. But what we're seeing is, screen time alone, it's hard to know. We do know that the brain is developing certainly through adolescence the most. And we don't know how screen time impacts the developing brain. How does it change how the brain develops? We know that the way that we kind of use attention online is different. We know the way that we use memory online is different. If you think about it, with internet technology, we kind of remember where things are and we kind of search for them that way. It's different in real life, the way that we kind of think about where things are on the internet.

So, and the way that we interact socially can be a little bit different on the internet. So especially for developing brains, we don't have all the answers. One thing I will say for technology, especially with smartphones. Sometimes there's a little bit of ageism, where we say, "Older adults don't want to use smartphones or are not going to be engaged."

And there's a lot of evidence that, from our research, from Dr. Ipsit Vahia at McClain, who does fantastic work in geriatric mental health and in smartphones, is that really, anyone can use a smartphone. People are willing to engage with it. Sometimes the older adults actually have more meaningful engagement and better outcomes, perhaps because they're following the instructions and using the app more. But there really is no

kind of age cutoff where someone is too old. I do agree when, I think we don't know when the developing brain and how young people are.

We don't have a good answer is the real one. And... But we also don't really have a great answer for how much screen time is too much. So, I think we may have to check back on that when there's more research, comes out.

Ken Duckworth (01:17:59):

John, I want to thank you for your approach to this entire endeavor, which is both thoughtful and humble, right? You know that there's a lot you don't know. And I appreciate you involving our community and giving feedback on what they think of these apps. And knowing you as I do, I know you will use the feedback wisely to make things better for people.

So, with that, I'm going to say, thank you, Dr. John Torous. Thank you all for attending. We had over 750 people attend this webinar. This will be available on Ask the Expert on the NAMI webpage.

And if you could take a moment just to fill out that survey, I'd be grateful. We'd be grateful. All our staffers who are behind the scenes, making these webinars happen, would be grateful. Because we want to give you the best content we can.

Thank you again and have a great day. And thank you, John.

John Torous (01:18:53):

Thank you, guys. Bye.

Ken Duckworth (01:18:55):

Bye, now.