

Patrick McGovern  
All of Us  
Oral History

The All of Us Research Program is an ambitious effort to gather health data from one million or more people living in the United States to accelerate research that may improve health. All of Us is working with participants across the country, collecting many types of information over time, and building a database that many researchers can use. This new model could shape how people do research in the future. All of Us will share lessons about what works well with other research programs around the world. The program is supported and overseen by the National Institutes of Health (NIH) and is the result of NIH's Precision Medicine Initiative Working Group of the Advisory Committee to the Director, which concluded its work in 2015.

Condon: I'm Aaron Condon. It is Monday, November 20, 2023, and I am joined by Patrick McGovern, who is the Chief Business and Strategy Officer for Wondros and an All of Us principal investigator. Today, I'm going to conduct an oral history interview to explore the origins of the All of Us and document it as part of a series for the Office of NIH History and Stetten Museum. How are you today, Patrick?

McGovern: Great. Happy to be here, Aaron.

Condon: I'm glad you're here. Thank you very much for joining me. We appreciate it. Hopefully, this is a good discussion. And if you feel that you need to expand on anything that we haven't discussed, or isn't in the list of questions, I'm going to ask you please feel free to add. To begin, can you tell me a little bit about yourself and your background?

McGovern: I'm Patrick McGovern, as you said, the Chief Strategy and Business Officer at Wondros. We are a creative agency that specializes in designing strategic communications and storytelling strategies that are really meant to be actionable in terms of how we engage and work with a diverse set of stakeholders, and in many different communities. I think the other thing that's unique about the work that we do is it's really in service of building social movements. Instead of more traditional advertising, we're oftentimes focused on advocacy, if you will, how to ensure that we're translating the complexity of many different communications programs and initiatives that have a purpose to engage with the wider public. That's the focus of what we do. My background is actually in advertising as well as entertainment, doing a lot of world class storytelling and working with the entertainment industry to build a coalition, like Stand Up to Cancer. Wondros oftentimes brings in cultural ambassadors into our campaigns to help ensure that we're reaching people in a way that resonates depending on their unique audiences and diverse coalitions.

Condon: From what I know about the All of Us Research Program, your [Wondros'] fingerprints are all over it that way. Hopefully we can talk a little bit more about that, but that's great. How did you learn about the Precision Medicine Initiative, and how did you become involved with it?

McGovern: So, at Wondros we've had a really long-standing commitment to working on health equity initiatives and challenges and, in particular, had been working in a number of different healthcare networks. Going way back to our work around 2006—it started with an initiative called the Collaborative Chronic Care Network. It was a pediatric Crohn's Quality Improvement Network that started with just a handful of clinics, all different IRBs [Institutional Review Boards] sharing best practices and ideas for how to better care for kids with Crohn's disease and ulcerative colitis. That work we were actually brought in through Cincinnati's Children's Hospital Medical Center; they had received a TRL1 grant. The RL ones are the basic science. This was a high stakes, high reward allocation of funding from the NIH. And we were actually written into the grant to really serve as the communications and social networking part of the network that could help patients, clinicians, and researchers more collaboratively share information and outcomes, data.

Through that process, over many years, we got involved in a number of open source science initiatives and projects that were all about how we democratize data and medical knowledge and information in a way that empowers everyone. Obviously, with all the safeguards and critical governance layers that are necessary to enable that and ensure the privacy and protections required, we have been tracking for a very long time [the] efforts to build a broader, more collaborative research ecosystem. Through a lot of different projects and partnerships that we had developed over the years, we became aware of an initiative called the PMI, the Precision Medicine Initiative, that President Obama announced at the White House. Then we attended a Partnering for Cures Conference—so, part of a FasterCures Track that the Milken Institute puts on. [It's] a really a great program to bring all different stakeholders together around medical research initiatives, and several different pillars around how do we actually bring everybody together to create more breakthroughs. Dr. [Francis] Collins [then NIH Director] was a keynote [speaker] there and gave a presentation around the initiative. This was like, right after the Working Group Report was coming together. The White House announced the effort was going to be led by the National Institutes of Health and Dr. Collins, and we had an opportunity to hear the vision.

We immediately knew this was, in so many ways, the culmination of a lot of the work that we have been doing in our design, research, practice, marketing, as well as the communication strategy work that we've done with a range of different partners, all really focused on this particular mission. To us, we knew this was something that we were well equipped to serve. We had a lot of the capabilities in place over years of hunting how to really ensure that there's actually evidence-based communications and storytelling strategies that can truly reach all the critical internal stakeholders, but then also build that bridge to the public and to oftentimes underrepresented communities. That was something that we had our eye on. Then as it came out as in terms of a public opportunity for organizations to respond to the solicitation, we pulled together a team and responded and went through the process and ultimately were successful in receiving the initial award for the communications team.

Condon: That sounds great. And so, you spoke a little bit about the mission of the program and the concept for the PMI. Can you give me what your interpretation of that mission is? And also, while you're at it, if you could add, what does precision medicine mean to you?

McGovern: Yeah, we in design, strategy, and research, talk about it as a BHAG, the big, hairy, audacious goal. We knew, having done a lot of different projects over the years that were trying to chip away at different aspects of this mission, that in order to really do this in a way that was going to build the critical mass necessary to truly breakthrough, that we needed national federal leadership to do it. And we were just incredibly inspired when President Obama took on that challenge and announced the effort to make good on the promise. For us that promise—I'll tell you what it means to me personally—but for us as a company at Wondros, that promise really represented a passion and a mission that we had at the company. We actually thought about it in various different ways building up to this, including working with groups at Harvard Medical School and around an initiative that we branded, called People Powered Medicine, and various other smaller efforts all focused on bringing different siloed data together. But mostly, across more institutional affiliations, even at these institutional groups there are still various different silos of data. This, as you can imagine, was really making good on the promise of everybody coming together across the country to share and making good on the promise, most, I think, importantly, around ensuring the rich diversity of the United States, the true diversity of the United States, is reflected in the actual cohort. That cohort, really became, in so many ways, a community and making good on the idea of, we're no longer just subject matters, subjects in a research study. We're no longer even just participants, but we're true partners. That was important for us in terms of the mission, and obviously for the medical research establishment, and for communities because there has been so much past abuse across the research establishment.

We early on realized in order to be successful but also to be, which is core to the mission, truly engaging people as partners and working to build that rich diversity, that we needed to come together across all kinds of different communities that have often been underrepresented or left out and or that have had the past abuses, and really confront the issues head on and discuss them in ways that are oftentimes difficult, but necessary, and for everybody to learn from each other and to make good on the promise of where we're going. For me, personally, you look at our founding documents and the ideals of this country, and to me this program truly is historical in nature. To get into the brand and different aspects of it, we purposefully designed it and worked to create something that was almost like a national anthem, and almost like a declaration of health and purpose because this program, in so many ways, represents the best ideals of what this country is all about. For me, personally, this has been such an incredible program and I think of it as much more than a program, but I think of it truly as the best representation of our ideals of our democracy, of the incredible, unique diversity that is only, frankly, represented in the United States of America. To really plant that flag in a way that builds that unity, and that declaration of purpose, but in a way that truly represents the rich diversity, which means confronting past challenges [and] abuses, [and] coming in and working to build and repair those-bridges-and making good again on the on the idea of being true partners with participants. To get there, it really is about going from a cohort into a true community of people coming together to participate and partner and to drive the breakthroughs.

Condon: Excellent, excellent. So you did mention branding there, and it was called at the beginning the Precision Medicine Initiative. Somewhere, I think at the end of 2016, the name changed to the All of Us Research Program at the NIH. Can you talk a little bit about how that change affected both, I would say the community, the healthcare community, and the research community, and also why that change was impactful?

McGovern: I think one of the unique things that we do at work with partners [and] Wondros is we question all our assumptions and ideas. I think for this program, when the initiative first started, it represented the promise of scientific ingenuity and opportunity. Precision medicine really does mean something very specific to the people that are part of the, not even just the healthcare system, but I think a lot of the true innovators and leaders in the field, and it isn't necessarily something that the broader even healthcare ecosystem is aware of. We really questioned our own assumptions and ideas about our own idea of what precision medicine is, as well as did a lot of interviews with the internal stakeholders to understand what those ideals truly represented for them in terms of this initiative. Then ultimately [we] did a lot of sit down qualitative research with broad-based communities, many traditionally underrepresented communities, to understand what are the feelings and attitudes towards precision medicine and towards an initiative called the Precision Medicine Initiative.

What we've learned is that ultimately this wasn't obviously meant to be a clinical delivery program, and that a lot of the communities that we spoke with felt like it sounded very clinical. It sounded oftentimes even a little bit off-putting, and several [comments] came back from folks and communities that we spoke with [that PMI] almost sounded a little scary. Then ultimately, the internal stakeholders and consortium members and original Working Group Report authors were very forthcoming about the idea that while this is what it's about in terms of working toward eventually—have precision medicine come into fruition for all communities—that ultimately, the first step was truly about building the research cohort. That ultimately, that was the core. We really needed to ensure that as we were working to create not just a brand, but an overarching communications platform around that brand that we were really, really clear on the purpose and the direction and how to communicate the value proposition for participants. The last thing we wanted to do, right, was provide any confusion and/or mismanaged expectations. In particular, when you're dealing with a lot of communities, as we've learned in advocacy, as we've learned in a lot of different initiatives that we've worked on, you have to really make sure that everything is communicated in a way that resonates culturally, that truly meets people where they are and also speaks to the core value proposition and doesn't over-promise and under-deliver. We worked to really understand what are the assumptions, attitudes, ideas behind the Precision Medicine Initiative, and it was just all over the map in terms of people being confused, and those words not even resonating but also not being understood. There were just a lot of challenges with that framing initially, which is what led us to that whole process of designing the All of Us Research Program brand and identity.

Condon: Thank you very much.

McGovern: That was a sort of a lot of background before I got into the actual design, but I'm happy to expand.

Condon: That's great. That's very helpful and very thorough. Thank you for that. The All of Us Research Program has separate goals. One of them is to recruit one million active participants within 10 years. Another goal that doesn't really get talked about that much is the sharing of data to research institutions. I love this, and I try to highlight it when talking with colleagues across the agency or describing what I do outside of the office to friends. Essentially, the availability of data that the All of Us collects enables researchers to skip participant recruitments for their own studies. This both furthers the Precision Medicine Initiative in and furthers scientific innovation in general. Can you share with us, or with me rather, how that works practically? The sharing of data?

McGovern: I got a little distracted on the first setup of that question. Just so I have the proper context could you repeat the first part?

Condon: The question is: The data that the *All of Us* collects is available for free to most research institutions, and there are several benefits to that. Can you share how that works, practically, the sharing of information with other research institutions?

McGovern: I'm understanding, do you mean, the protocols for how research institutions apply to access the cohort data from All of Us?

Condon: Yes, and we don't need to get too technical there in general. How does it work when folks need to access information, and what kind of studies can individuals do with the information that they find?

McGovern: Yeah, so we've been involved quite a bit in the workbench and working closely with Vanderbilt and the DRC [Data and Research Center] on actually helping to ensure the design in the same way that we worked on the participant portal. On the other end, the researcher side, really building that in such a way [that] designing and ensuring that the brand values are reflected in a way that puts privacy and security at the top, but also ensures that same reflection of diversity is in the research community. That's been a big effort at the same time that we're working to reach out to underrepresented communities to become participants in the program, that we also enlist the rich diversity of the research community. I think there's a lot in terms of the technical piece that we could get into, but that's probably not what you're looking for, from me. I think, more broadly speaking, for us, it was really about creating that bridge, and leveling that playing field between the participant community, the research community, and ensuring that people see themselves right with it, like participants see themselves in the research community, and likewise, that the researchers understand that they have this rich, diverse pool of data to be able to access. There's, for important reasons in terms of privacy and security, a whole protocol that you have to go through to be able to access the data. There's a whole separate effort to be able to

ensure that we're ultimately bringing in citizen scientists, others. A lot of those protocols and procedures I know are continually building and growing and evolving.

Condon: Okay. Why is it important that participants and researchers both be from different ethnicities and socio-economic backgrounds?

McGovern: Ultimately, we need to ensure that the kinds of questions that are being asked of the data, right, are being asked from the people that are also reflecting the participants in the data. We've had a long legacy of that not being the case. It's not enough just to ensure that we have the diverse data set. We need to also ensure that the questions being asked of the data also include researchers that make up that same diversity. There's all kinds of research on biases, and even with the best of intentions, the backgrounds and lifestyles and just life experiences could potentially lead to the next set of breakthroughs or advancements for a specific community that may otherwise not have that opportunity, if somebody hasn't had that background and experience to truly understand a particular community or what's at stake, or what kind of questions need to be asked. I think it's critical that we have that true reflection of diversity within the researcher network.

Condon: Great. Early on in our discussion, you mentioned privacy. Privacy is always concerned with gathering and storing participant data, health data. From your perspective, what are the main ethical challenges that you see with collecting, storing, and reporting to that data to participants?

McGovern: Privacy and security are obviously paramount. When we're reaching out to the communities, we need to ensure that we're building trust and that we have every opportunity to protect and safeguard that critical data. I would just say it's not just a core value; it's been operationalized against in terms of the privacy and securities safeguards and protocols that have been put in place. Early on, we worked closely with Sage Bionetworks, and frankly the entire consortium, to ensure that those protocols and procedures are done in a way that ultimately have that participant-focused decision making at every point. I think that is something in terms of our experience team. Early on we developed an Ecology Model that basically creates robust and actionable research findings, themes but also personas, scenarios, and other design tools that [were] pretty amazing [and] which enabled the decision makers at the Scientific Committee level, at the executive Steering Committee level, to have not just a human-centered but very specifically the participant-focus-centered decision making at every point. As you can imagine that one of the things that would always come up in terms of understanding people's attitudes, needs, goals, within a participant focused cohort, privacy and security always came to the top. It's not just what are you going to do with my data? How are you going to safeguard and protect it? We would work to ensure that participant-focused set of goals and requirements was at the decision-making level, even at the workbench level, even at the researcher portal level. For us, that's something we not only take seriously; we create the tools that we can put into the hands to ensure that the voice of the participant is not just being heard, but that is being designed against to ensure that their needs and goals are represented in the design. Without getting into the specificity of the technical parts in terms of our process, to

really ensure those design tools, those human-centered approaches from a participant-focused standpoint, is at the center of every decision point that gets made.

Condon: Thank you. From your perspective, what is, or will be, the greatest challenge that the All of Us will have in realizing its goals?

McGovern: I think you know, we just got through this pandemic. That's probably the one that keeps rising to the surface. What we saw was something that obviously, early on in the PMI, then All of Us, was we had been uncovering a lot of those concerns, attitudes, past challenges and behaviors, some very difficult things, too, but critical things to listen and learn from. I think the challenge then, and the challenge going forward, continues to be how do you ensure that we're doing this in a way that isn't, like I said earlier about, quote, unquote, marketing, to people, but it's really about level of education, awareness, and engagement. Sometimes that last one, in particular, is a term that can be co-opted to basically mean a technology solution, right? To connect with people. But what I mean is really about cultivating a sense of belonging and doing it by actually investing in the true kind of education that's required to ensure that people have the knowledge and information they need to better care for themselves and one another. We had seen early on that there were just so many gaps in that. Then during and after the pandemic, of course, I think that's come on everyone's radar. I think the challenge is now the opportunity to say we had uncovered this work to design a brand that was inclusive and work to really do everything, which was that we were designing solutions for, both in terms of a brand narrative and story, and actual outreach and connection with people, [so] that we're able to do that at a broader level where we can actually bring these worlds of art and culture and science together in a way that really culturally resonates and educates people. I think we need a national movement for health to do that. I think what we early on designed with All of Us is a really good case study in how to begin and start that conversation. There are always challenges and barriers; you don't succeed all the time. But like we talked about earlier, like the history of this country, right, you'll never get to perfect, but it's about working to create a more perfect, more representative, more rich, diverse series of participants, of researchers who are coming together as a unit, as a united front, to make good on the promise of where the science and the technology have converged and the last missing link is All of Us, right? It's how we as people can come together around that, to organize around that promise, and now actually advance the breakthroughs because we're coming together. That's the only thing that's stopping us. It's All of Us, coming together, collaborating, sharing, and accepting the past historical abuses and challenges. And learning from them from a historical perspective and working to get better. There's so much. I'll just use the terms that are being thrown around in business and disinformation out there, frankly, because of a lot of that historical abuse and challenge, [and] also because of several other forces at play. But in terms of our ideals, in terms of putting our institutional hats at the door, and really coming together as a country, as a community around our own health and healthcare and driving breakthroughs and research, I think that's the opening and opportunity that we have. I think we've made some good progress with All of Us as a broader level [to] get the national headwinds. I think it's not having a level of awareness and education around how the speed of science, you know, how science works, and what's really needed to drive the breakthroughs and how, again, now that we have this convergence, what that missing link is. It's on all of us, and we all have an opportunity. Frankly, I think the average person doesn't know that. There's just a lot out there that's kind of counter-programming and

leaves people out and lets people be dismissive and, frankly, not even understand, probably in the majority of cases, about that opportunity. That was kind of a high-level answer. But that's the broader challenge that we're facing.

Condon: Right. Yeah, that's wonderful. I will tell you I try not to give my opinion during these discussions because that's not really the purpose of these discussions, but I will say, getting through the pandemic, or the worst of it, a lot of groups didn't do so well. I think one of the reasons the All of Us did is because there are people invested that are genuinely in support of it, believe in the mission, which is, I think integral and something that is unique from my perspective, working in the government for more than 20 years now. That was my last question though. Patrick, thank you so much for joining me. Is there anything that you'd like to mention or say before we stop the recording?

McGovern: No, there's obviously so much. I mean, I would love to be able to share more about how we create the brand story and why storytelling as a strategy is something I think that's really required here to kind of speak to that broader set of challenges we were talking about. We'd love to share more about our teams and things over time, but I really appreciate this opportunity because I think you can tell I'm very passionate about this work. I just thank you for taking on an opportunity like this because I think this story and these important lessons hopefully that you're collecting over time can help inform where we could go and how to better help each other get there.

Condon: Yeah, and maybe even more importantly, how somebody can do it again, right?

McGovern: Yeah, exactly.