

Minding the Gap: Equity and Justice in AI and Neurotech

Thursday, November 4, 2021

Speakers

- Alena Buyx, Technical University of Munich (Germany)
- Ricardo Chavarriga, Confederation of Laboratories for Artificial Intelligence Research in Europe (Switzerland)
- Oiwi Parker Jones, University of Oxford (United Kingdom)
- Gregor Wolbring, University of Calgary (Canada)
- Moderator: Nicole Martinez-Martin, Stanford University (United States)

Recording and Resources:

<https://www.neuroethicssociety.org/2021-annual-meeting-ethicalneurotech>

Speaker 1: Nicole Martinez

Welcome to this session. Our session today is Equity and Justice in AI and Neuro Technologies. My name is Nicole Martinez. I am an assistant professor at Stanford Center for Biomedical Ethics and a neuroethicist and background in law and social sciences with an interest in AI and the ethics of neurotechnologies. The format for today is we will start off with some prepared questions for our amazing expert panel, and then we invite you to please put questions in the Q and A down at the bottom of your screen.

Speaker 1 Nicole Martinez [\(01:38\)](#)

You can also upvote each other's questions so that we can bring your questions into the discussion. I'll start off by introducing our panel. I am very excited to have all of them here today, a very international panel with a range of expertise, invaluable expertise. We have Alena Buyx, a professor of ethics in medicine and health Technologies, director of the Institute of History and Ethics in Medicine at Technical University of Munich. She has been a member of the German Ethics Council since 2016 and chair since 2020.

Speaker 1 Nicole Martinez [\(02:20\)](#)

We also have Ricardo Chavarriga, who has more than 15 years of experience in computational neuroscience, AI and brain machine interface. He's at the Confederation of Laboratories for Artificial Intelligence Research in Europe Applied Sciences, and you can see the lovely mountains behind him in his background, and he is the head of the CLAIRE Office, Switzerland, the largest European network on AI. We also are very pleased to welcome Dr. Oiwi. Parker Jones, who is a Hugh Price Fellow in Computer Science at Jesus College Oxford with affiliations to the departments of Engineering and Clinical Neuroscience.

Speaker 1 Nicole Martinez [\(03:03\)](#)

His research has focused on developing practical neural speech prosthetics for paralyzed patients. He also developed speech and language technology for Hawaiian and was a founding member of the Indigenous AI Working Group. And Gregor Wolbring is a tenured full professor at University of Calgary's Cumming School of Medicine program in Community Rehabilitation and Disability Studies. He is a member of the Institute for Technology Assessment and Systems Analysis in Germany and a fellow of the Institute for Science, Policy and Society, University of Ottawa. We are very pleased to welcome you all for this discussion.

Speaker 1 Nicole Martinez [\(03:47\)](#)

I'll start off the discussion, since we are talking about equity and justice in AI and neuro technologies, we'll start off by asking Dr. Chavarriaga and then Dr. Parker Jones to talk about what are some examples of AI and neurotech in order to get examples of what are issues or aspects within these neurotechnologies that have social implications or raise concerns regarding equity and justice? So first to you.

Speaker 2 – Ricardo Chavarriaga [\(04:30\)](#)

Ricardo, please thank you, Nicole. Thanks for to organizers for having me here today, sharing this very important topic and how the development of technology neurotechnologies and the use of artificial intelligence can have impacts on equity and justice. And let me start with a personal note. I have been doing research in brain machine interfaces for more than 15 years, including different.

Speaker 2 Ricardo Chavarriaga [\(05:00\)](#)

types, but mostly EEG based BMIs. And it happens that I was never able to test the systems that we were developing, and the reason for that is that the hair that I have because I have dreadlocks and the technology that we use to measure EEG is not really compatible with my hairstyle. So of course, I can choose not to do it. But this is an example of how the type of technology that we use can prevent certain sectors of the population from using these technologies. And as Neuro technologies start to rely more and more on artificial intelligence, then the kind of data that is used to build these models and the inclusivity of these models and how representative these models are will have a stronger and stronger impact on how the Neurotechnologies will work and for whom they will work.

Speaker 2 Ricardo Chavarriaga [\(06:04\)](#)

That's one very important point that we will have to face, particularly as the trends in artificial intelligence today are going into using very data hungry methods. So if we have underrepresented populations in the data, then the quality of the models that we obtain at the end and how do they perform differentially regarding the different sectors of the population across the globe, then we have probably very, quite strong differences that may yield sectors that are underserved by the technologies that we are developing even when we don't use AI.

Speaker 2 Ricardo Chavarriaga [\(06:52\)](#)

When we look in the current studies in Neurotechnology, we can still see that there is a large number of studies that they don't really represent properly people with disabilities. We tend to have still many studies that are with control subjects or very small populations of people with disabilities not very well characterized. And that's another factor where we can end up with these differential effects according to the population. And this may be exacerbated by the drive of developing direct-to-consumer neurotechnology. But we may have motivation and incentives to develop systems for people that are mostly represented in population but this can as well, leave certain people aside or certain groups aside.

Speaker 2 Ricardo Chavarriaga [\(07:45\)](#)

Even when we look at applications in the health-related domain, it's well documented how women's health is under-researched, under-diagnosed, and we don't really have as much knowledge as we have, for instance, for males. And there is a risk that these bad habits and practices of not properly addressing these gender differences get perpetuated when we try to apply to the development of AI-powered technologies devices. So these are some examples of how the technology that we use can yield different results and can also provide potential causes for different effects across different groups and therefore bringing strong impact on how these technologies will serve people all around the world.

Speaker 1 – Nicole Martinez [\(08:50\)](#)

Thank you so much. Those are some great examples of representativeness and inclusion in the data, particularly, as you say in this very data-hungry kind of area. And I appreciate you starting off with that personal example as well that I think really highlights what you're saying. What kinds of examples or issues would you also like to speak too?

Speaker 3 – Oiwi Parker Jones [\(09:18\)](#)

Thank you, Nicole. Thank you, Ricardo. When I think about AI driven neurotech, maybe the easiest example that comes to mind is from my perspective, are prosthetic arms, robot, prosthetic arms. So one of the difficulties we have in developing these things is bandwidth. So if you have spent any time around neural recording technology, this is a constant problem. Even if you're recording directly from the brain with implanted electrodes, there's a constant problem of getting enough bandwidth. So one possible way to get around that is to use some kind of AI.

Speaker 3 Oiwi Parker Jones [\(09:54\)](#)

Where rather than using the brain to drive a continuous control signal, maybe you use the brain

Speaker 3 Oiwi Parker Jones [\(10:00\)](#)

to specify something like a goal, like a high level of something, and then let the AI do the planning. As soon as you do that, you run into all kinds of questions. Right. So what if the arm starts doing something you don't really want it to be doing? Do you have the ability to short circuit your command? You can see how these sorts of issues arise when you give some kind of autonomy to the AI. But obviously that's also part of the benefit is that we can get around the bandwidth.

Speaker 3 Oivi Parker Jones [\(10:28\)](#)

It's true for things like speech prosthetics as well, maybe less obvious. But often, if you think about speech recognition as an example, there's a backbone of a language model which is pre-trained on lots and lots and lots of previous text. If that text includes racial bias or terrible things, those statistical patterns are likely to come out and they might come out of your mouth if it's being recompiled from your brain. Wherever the autonomy comes in, you have some question of is that right? And usual issues from AI arise as well.

Speaker 3 Oivi Parker Jones [\(11:06\)](#)

Like, how can we interpret these things? Where are our guarantees? We don't typically have them, at least yet in sort of deep learning paradigm, as you might have in other kinds of machine learning paradigms where they're sort of easier to interpret. So we sort of confront issues like that. These are the first things that come to my mind. I'd like to introduce the conversation.

Speaker 1 Nicole Martinez [\(11:31\)](#)

Thank you. That's very helpful. As examples regarding these issues of autonomy and otherwise, and for a different perspective. From the ethicists of our group, Elena and Gregor, moving on from these examples or adding your own examples as well. What do you see as priorities in terms of addressing equity or social implications and additional ethical challenges in the use and development of AI based neuro technologies. Why don't we start with Elena?

Speaker 4 – Alena Buyx [\(12:25\)](#)

Yes. Thank you. Hello, everybody. First of all, I have to apologize. I'm having my dinner glass of wine. It's late where I'm based. So forgive me. I think it [the wine glass] was very visible. So I'd better say something [about the wine glass- lovely to be here. And Ricardo and Oivi have both already pretty much mentioned some of the main issues there are. So I want to do something a little provocative listening to them, but also having worked in this field, I should say the applications I'm most familiar with are mostly all really algorithm-based diagnostic stuff in the neural psychiatric field.

Speaker 4 Alena Buyx [\(13:12\)](#)

So algorithms for mental health embodied and also embodied or for neuroimaging for diagnostic purposes, speech recognition, fraud, dementia, but also actually prosthetic arms. So there's lovely

overlap here. And what I want to say is that I think regarding these topics of bias. If your database is skewed that Ricardo explained the differential effects of that the issues of representativeness of inclusive design and use again regarded some fantastic examples there. But actually they also said something very similar that fits very well, issues of sort of potential discriminatory use or even stigmatizing use of such technologies, inclusive research ethics, that all the groups that should actually be part of development are included.

Speaker 4 Alena Buyx (14:10)

All these things have actually been already described very well by the field of AI ethics. I'm being a bit broad here, but I think ethics has actually delivered this time. So we come from a field that used to be quite focused on the individual and the ethical principles that we employed sort of directed our attention very much to patient autonomy, non-maleficence, beneficence, those kinds of things. And I think we've become a bit better. I think issues of justice, of inequity, of bias, and social implications have been at the very forefront of the ethical debate, as it has applied itself to AI technologies, not just in the field of neuroscience, but also elsewhere.

Speaker 4 Alena Buyx (15:02)

There's a bunch of literature you all know that. So what I think now has not happened at all is that we've been successful enough in having these analyses and these ideas and these sort of warnings, to be honest, penetrate where they need to penetrate. So we've described them, we've published about them, but they have not really been made into or they haven't at least not enough affected legal provisions and regulation. And I'm really worried about that, because if we keep writing about these ethical things and nothing happens at the sort of harder legal level, and we're doing pretty much not that we are doing it, but we're in the danger of being employed as people who do ethics washing, right.

Speaker 4 Alena Buyx (15:56)

We talk about this stuff and then nothing happens on the regulatory side. So that is one thing that I think we really need to have in mind and try and get as much of this into actual regulation. I'm not going to go into detail because those differ very much across the world. But that's just one point. And the other thing that also hasn't happened is it hasn't penetrated development very well. It hasn't penetrated development practice. And I just want to mention that this is something that's easier to affect than legal provisions to some degree, because we can collaborate with developers very directly.

Speaker 4 Alena Buyx (16:33)

And I know some of us do that. And so the slightly hopeful note I want to end this short input with is that there are approaches such as embedded ethics, for example, that we do at Technical University, where we work with developers, with also developers who are sort of between academia and companies from the very beginning of research and development. We sit if you want at the development bench, and we

scrutinize the algorithms, and we are part of the development process from the very start. And I'm not saying that's the solution, but it's something to get these considerations into practice.

Speaker 4 Alena Buyx [\(17:16\)](#)

If you have somebody there who will tell you, have you thought about how this might affect this group or that group? Have you considered these kinds of things that might be problematic in terms of inclusive design and so on and so on? So I think that's one of the things that we might be able to do. But again, the legal side is probably the one where it's really at. So I'll stop here. Thank you.

Speaker 1 Nicole Martinez [\(17:39\)](#)

Thank you very much, Alena, for raising these challenging questions. Indeed, that does seem to be one of the big focal points at this point. Now that a number of these principles have been put forth, that a number of these ethical questions have been raised, how do you put that into practice? And certainly the regulatory and legal side is one of the bigger challenges. And definitely, as part of this discussion, be talking more about some of these potential areas for addressing these challenges. But first, I wanted to have Gregor also speak to this question.

Speaker 5 – Gregor Wolbring [\(18:28\)](#)

Thank you, Nicole, for having me on this panel. Very excited. I want to first say that I position myself within the increasing Anglo Saxon discourse around EDI. Literally, every University has an EDI office and so on. And it seems to morph into employment equity, as in having people employed, by different diverse people, but not diversity of research, definitely in relation to disabled people. And I see five issues based on my scoping reviews on BCI social robots, artificial intelligence by itself, and AI neuro-interface. The tone of coverage is mostly techno optimistic.

Speaker 5 Gregor Wolbring [\(19:10\)](#)

The second one is at the imagery of disabled people. One can, of course, have two, and the main one is the medical deficiency narrative. For example, social robots will mostly use the negative imagery of autism ADHD, but very rarely “neuro-diversity” as a term. When we're looking at BCI, the invasive ones, you will see, of course, the medical ones because you have to go to clinical trials. The consumer products normally don't cover disabled people at all. And so we looked - Ai mentioned disabled people in a medical and non medical way, but there are other problems.

Speaker 5 Gregor Wolbring [\(19:53\)](#)

The third issue is impact -- disabled people are impacted as therapeutic users, obviously as non therapeutic users, which is where the AI is where it covers; when they don't use the medical imagery, it's about access to their products. What they do not cover is the impact on disabled people for changing societal parameters caused by the societal use of the product, whether it's AI, AI, neuro and so on. And

they also don't cover how it really impacts disabled people. That AI makes autonomous decisions eventually and is linked to certain products in health care.

Speaker 5 Gregor Wolbring [\(20:36\)](#)

We do the algorithm bias, but as we, for example, know with Amazon and it's AI HR human resource one which was biased against women. If we mostly cover disabled people within the medical framework, what the machine learning gives AI is a very one sided view of disabled people and what their problems are. Issue 4: the role of disabled people. It's mostly therapeutic users in Europe and so on. Social robots and non-therapeutic user and AI purely without any research subjects as in medical aspects, not social aspects or social implications.

Speaker 5 Gregor Wolbring [\(21:16\)](#)

They are not there as educators, not there as designers, as was already mentioned. They're not there as AI researchers on the social aspect. They are not there as victims of, as in negatively impacted by, the products. They're also still not there as influencers, contributors of, and knowledge producers of the AI neuroethics and governance discussion. There are occasionally people involved, but this is when you look at the literature. There is very little if we're talking about the non-medical disability rights approach, not the patient ones, which is a different story.

Speaker 5 Gregor Wolbring [\(21:52\)](#)

And then the fifth one actually is allyship. Disabled people can't change the world for themselves by themselves. And we did some work around whole narrative and health professions. We use nurses and we use speech, language and audiologists. We use social workers and occupational therapists. And when you look at their association, they ask, of course, more than just being service providers, let's talk about change agents, advocate learners, educators, active citizens. But when you look at the whole narrative of these professions in these discourses around AI neuro and so on, it's literally only around service provision, very little around efficacy or change agent.

Speaker 5 Gregor Wolbring [\(22:37\)](#)

And we did interviews with all these groups, and, for example, lifelong learning is not used to enable them to become literate on the social implications, so they actually can get involved in the non clinical aspects of these discourses. And they also are not trained to think about themselves out of the profession as active citizens as every one of us is. Thank you.

Speaker 1 – Nicole Martinez [\(23:02\)](#)

Thank you so much. Those are really important points that you raised and definitely overall, among other things, speak to the need to address different communities with sensitivity and real meaningful engagement in terms of their needs and perspectives, and that really aligns with some common things

that have already been coming up across the panels here today in terms of the need to work with different communities, learn their needs, understand the relationships as well as the relationships that these technologies or practices might affect. And I want to bring in a question from the Q and A that's also related.

Speaker 1 Nicole Martinez [\(23:52\)](#)

And this is a question, Alena. I know already started to answer in the chat, but I put this to the panel generally. This is from Tim Brown. What techniques can we use to both make sure marginalized people are not only represented in data sets used to train and validate AI-driven neuro technologies, but also that they aren't misrepresented by trained models.

Speaker 4 Alena Buyx [\(24:21\)](#)

Is it okay if I just sort of say what I've said in the chat? Sure everybody doesn't see it. I think that's a really good question, and I would suggest it's just an off the cuff response but I think this really is a field for cocreation approaches, and there's quite a wealth of ways to do that to include people from such groups in the development process. One option is to have them interrogate the algorithms or have them interrogate the data sources. That's one option. The other option is to include as many groups as possible in checklist approaches that then interrogate the algorithm.

Speaker 4 Alena Buyx [\(25:13\)](#)

But again, there's various ways, and I think that would be a promising area. It's definitely better to have cocreation than sort of just waving at the problem as it so often happens.

Speaker 2 Ricardo Chavarriaga [\(25:30\)](#)

If I may add as well. I think this is a very good point that Alena just made one is that you should not leave that to the engineers. I am an engineer myself, and I can tell firsthand that we cannot do these things alone, and if we just let us doing it alone, we will end up doing something very bad. But I wanted to highlight that sometimes when we discuss about the inclusivity and the issues of AI, we tend to focus on the algorithm as if it were the entire system.

Speaker 2 Ricardo Chavarriaga [\(26:05\)](#)

So it's important to keep in mind all the elements that lead to a certain decision or a certain application, and also that these systems also have a life cycle, and they may be at different stages of the life cycle where we can intervene. So one of the things that is important it was mentioned is the cocreation, the embedded ethics, the importance to already involve the stakeholders early on in the development, to have a proper assessment of the effects, and this will have an impact on what is the data that is being used?

Speaker 2 Ricardo Chavarriaga [\(26:46\)](#)

What are the sources that are considered reliable when the system is considered to be fit for purpose? And what are the mechanisms that are put in place to monitor the effects it has once it has been deployed? If we take, for instance, example of Amazon system that was mentioned before for human resources, someone decided that the system was ready to be used while in reality was not at all, and this could have been prevented by being more careful about that before it being deployed or to react promptly once negative events appear after deployment.

Speaker 2 Ricardo Chavarriaga [\(27:31\)](#)

So it's important that we don't forget that we don't focus only on the algorithm, but how this algorithm is embedded in the entire social technical system that these applications usually are.

Speaker 1 Nicole Martinez [\(27:48\)](#)

And Oivi or Gregory, did you have any further response you wanted to make to that question?

Speaker 5 Gregor Wolbring [\(27:56\)](#)

Well, as to AI, I know that in the US there are lawsuits because health insurance companies don't want to give up their algorithm and they're saying it's proprietary, right. So you don't even get to that one. But I think it's not. The AI will come in a lot of areas from emergency processes everywhere. Where you do that, you will eventually have AI and involving people is fine. But the thing is, certain products also will be used in certain ways and have an impact on, for example, marginalized groups independent of the AI one.

Speaker 5 Gregor Wolbring [\(28:32\)](#)

We know robots, big literature about jobs taken away or artificial intelligence, and not one paper on what jobs of disabled people are taken away, not one. That was my robot paper in 2016 and the AI doesn't do that either. And social robots, of course, is even worse, because if it can do empathetic, it can actually go for certain jobs other people think the normal robot can't go for. So it's not just as clinical application or in elderly homes and so on. But it can go actually for jobs like occupation therapists and so on the narrative traditional to the rescue.

Speaker 5 Gregor Wolbring [\(29:18\)](#)

And so that goes far beyond the bias of an algorithm and co design. I mean, I still lose my job even if I co design the robot. Right. So there has to be some step back from the actual product and saying if that is really used in society, what does that mean for groups which groups are literally out and get the brunt of the problem?

Speaker 3 Oivi Parker Jones (29:47)

I think I might have a somewhat dissenting view, which is why I didn't say it right away, but I like all of these as best practices, but at least in the context of something like a neural speech prosthetic. I think we're very far from the point where we're worried about individual speech patterns from the patient's perspective, for like a profoundly paralyzed individual. I think they just want anything that works, and the technology is not quite to the point where we're worried about those other issues. But I do take the point that embedding ethicists into the process from the beginning and putting patients into the loop as much as possible are critical from every point, but at least not a specific example.

Speaker 3 Oivi Parker Jones (30:35)

I think they would love anything that works even if they got them wrong. Sometimes I think from that perspective anyway, there's a proportionality.

Speaker 2 Ricardo Chavarriaga (30:55)

Just to mention regarding what Oivi just mentioned. I think it's an aspect of personality, but also an aspect of proportionality of the technologies that it shouldn't be a reason for disregard these issues, but I rather see it as an opportunity to start addressing these potential outcomes from an anticipatory stance. I guess you mentioned these aspects on if we use language models based on AI, there is a risk that speech prosthetics will inherit the problems that these mothers have. So that already puts a flag on what are the type of scenarios or use cases where these prosthetics could be used in a reliable manner, but also in a responsible manner.

Speaker 3 Oivi Parker Jones (32:01)

They are, totally agree. Great point.

Speaker 1 Nicole Martinez (32:07)

Definitely. And let's see Olivia Matshabane asks, are there any suggestions on how to mitigate power dynamics when we, as researchers approach communities, specifically, marginalized community members to invite them to be involved in how we think through ethical use of AI and neurotech. The power dynamics are very real. Many people are not comfortable or able to confidently communicate in the ways that we expect about these complex issues. And that's an aspect that she thinks that she's not sure that we as a society consider seriously.

Speaker 5 Gregor Wolbring (32:55)

If I may, because I did a master thesis on that and because we often talk about and then we invite disabled people. Right. And the problem is the average disabled person in Canada is unemployed. They can't use transportation, has problems with housing and the totally basic issues, even disabled people,

only 30% work. So that doesn't work, right. So these people now you want to involve and they have to be knowledgeable to really talk about AI and robot and brain computer interfaces and synthetic biology and gene editing.

Speaker 5 Gregor Wolbring [\(33:39\)](#)

And it's not working. So we talked with board members of disability rights groups in Canada, and they said anticipatory governance, cool. And that means they have to do anticipatory advocacy to be involved in the governance. And they say, given that no one has solved our problems, we've had for 100 years yet, how would we find the people outside of some privileged disabled people like me, a privileged one, who can do all of this work because I don't have these other problems, to actually really give meaningful input.

Speaker 5 Gregor Wolbring [\(34:17\)](#)

So the danger is there that you use them and objectify them. So you use your patient and you sell your product, because if it makes your life better for them in society, they will go for the product if this is the only way out for them. Right here in Canada, which is a rich country, we don't want to speak about other countries. Right. In Germany, there was just an article in Site magazine saying only 5% of the restaurants in Munich are accessible, right. That was from October 29 5% on the bottom of normal accessibility, a situation which other people take for granted.

Speaker 5 Gregor Wolbring [\(35:02\)](#)

And now we are inundating them with all the technologies that is literally not feasible, there has to be a total system change, right? To really get to that. They really can contribute in the way that they can challenge the system instead of just being used. But isn't that good for you and you nod with your head because otherwise your life is even worse. Sorry. Yes. Please.

Speaker 3 Oivi Parker Jones [\(35:29\)](#)

So to speak to the point about differential power. Maybe I can interject something about the Indigenous AI communities. There's a conversation that we've been having a lot recently which we call data sovereignty, just trying to take the power of data governance back. And that means not giving our data away to companies who want to build us things and keep our data and then sell us things. But to try as much as possible to build within our communities and control the data, because that's what the power is, and also by grouping together various marginalized communities to have a little more power than we would as each of our individual marginalized.

Speaker 3 Oivi Parker Jones [\(36:09\)](#)

We vary in size. Some of our marginalized communities are relatively less and more marginalized, but together we're sort of all better and we can help each other. So that's one thing that we've been talking about a lot.

Speaker 5 Gregor Wolbring [\(36:22\)](#)

One thing because of data. I think with disabled people, it's not about the sovereignty of the data. Maybe the patient. Yes, but we actually have a problem. We don't even have the problem of fake news. We have the problem of invisible news. We are not visible. We don't have the data. Like the same [Site] article said, there is no national data on how many restaurants are accessible or the employment numbers in the US are for disabled people. But that could be pain, back problem, death, blind, diabetes, wheelchair, crutches.

Speaker 5 Gregor Wolbring [\(36:57\)](#)

And it's not listed in the separate categories. It's one number, right. So the 30% could be much worse for someone with a developmental disability, for example, where it is much worse. So it's not even about the sovereignty of the data. We don't even have the data.

Speaker 1 Nicole Martinez [\(37:18\)](#)

Certainly. That brings up an important point about visibility in the data. And I think there's also been communities that talk about the need for disaggregation of data that also speaks to what you're saying. Certainly coming from the Latinx community that comes up in the US in terms of how Asian American or a number of groups, that disaggregation issue in terms of data, as you say, these sort of downstream implications of how that data then gets used. There's visibility, there's disaggregation and actually to follow up really quickly on your point about data sovereignty.

Speaker 1 Nicole Martinez [\(38:01\)](#)

I remember another point, not in this panel, but you had brought up related issues in terms of the structures that may be available in order to make use of that data, which I was hoping you would give a little more detail about that here.

Speaker 3 Oivi Parker Jones [\(38:21\)](#)

Could you remind me what we meant by structures.

Speaker 1 Nicole Martinez [\(38:23\)](#)

For example, sort of larger resources to be able to make more use of the data?

Speaker 3 Oivi Parker Jones [\(38:34\)](#)

Yeah. I think maybe we're talking about, well, maybe like the Hawaiian example, I think we've taken a relatively case by case view on pairing with big tech companies. We've had very good experiences in the

past, but we're cautious as well. We sort of love our Maori cousins. Some of them have taken a militaristic view against releasing any of their data, but they have more resources in various ways. For instance, they're the only Indigenous language in their country, whereas Hawaiian in the US there are many to be marginalized.

Speaker 3 Oivi Parker Jones (39:13)

In that case, there are more of them. Their situation is sort of a little bit better than ours. Likewise, in Hawaii, our situation is better than many other Indigenous communities in the sense of we have talent within the pool. Like there are people like me who can write text to speech software if we have time, but we need to build up that personnel and other communities do it as well. So whether or not you're able to be data sovereign sometimes depends on your resources, how many people you have in your community who can do it.

Speaker 3 Oivi Parker Jones (39:43)

The connections you have, what we're trying to build is a network of communities so we can share the information. But also it's harder in some cases than others. And maybe in your particular community, your best chance might be to pair with a big company. We're not saying that that's wrong, but we're having that conversation very seriously and trying to figure out what are the pros and cons and respecting the cases where some of us have decided not to share and try to use that data to create job opportunities within our communities so that we can reap some of the economic benefits.

Speaker 3 Oivi Parker Jones (40:11)

First, we're all for open data. We think, like in research, it should be open, but there's a sort of historic asymmetry and resources that we're trying to redress in that case, which is the reason why. Yeah.

Speaker 1 Nicole Martinez (40:25)

Thank you. And Alena, I thought you had your hand raised.

Speaker 4 Alena Buyx (40:30)

It's just a very short point on these justified issues of not making a marginalized group, sort of do all the work on top of everything, because I really hear that. And also, I think that point in the chat of sort of this kind of contribution of cocreation requiring a certain set of skills that not everybody might have. So I think those are both a very fair point. It's not actually my neck of the woods, but I work a lot with social scientists who keep telling me that it's lazy to say that those problems can't be solved because co creative, patient involvement, citizen science approaches have been around for decades now.

Speaker 4 Alena Buyx (41:19)

So there is pretty much worldwide database of literature and projects, and some have gone well, and some have gone terrible. But we can't stop saying, oh, it's really difficult. And these are the issues because pretty much for every setting you can think of, you have a good experience that somebody has had, somebody has developed a way doing it without imposing so much work and additional burdens on the people involved and who's been able to avoid all the problems Gregor has been talking about regarding invisibility. I mean, I hear what you're saying, but there have been some really experience.

Speaker 4 Alena Buyx [\(42:26\)](#)

My Internet connection is actually breaking down.

Speaker 4 Alena Buyx [\(42:29\)](#)

Can you hear me now? We could. There was a period, though, where it was starting and stopping.

Speaker 4 Alena Buyx [\(42:44\)](#)

Excellent. I'm sorry. It's breaking up in between.

Speaker 3 Oivi Parker Jones [\(42:53\)](#)

I'd love to tap into some of that literature, maybe offline for the perspective for the Indigenous AI community. I think we don't know all about that literature, so knowing how to make these things work better would be useful for that conversation.

Speaker 4 Alena Buyx [\(43:07\)](#)

I'm really sorry, because we focus, obviously, we focus on AI and neurotech and all of that. But there is sort of literally from the 70s and the 80s, there's great stuff from public health, community public health, community-oriented public health in Britain, in particular. There is this huge movement that has many issues, but there's this huge movement of patient and public involvement, and a lot of that doesn't work. But some of it really does. And then the citizen science stuff in the genomics communities sort of with genetic variants, all of that.

Speaker 4 Alena Buyx [\(43:44\)](#)

So all I'm saying is I think that is a wealth of experience that we can learn from in the AI field very much. So if you want to give me a shout, I'm going to connect you with people who know this a lot better than I do.

Speaker 3 Oivi Parker Jones [\(44:00\)](#)

Thank you.

Speaker 1 Nicole Martinez [\(44:01\)](#)

I think those are important points, and I think it also speaks to in the past year and a half, really the sort of noticing the problems of a number of in medical ethics or otherwise, the focus on individual frameworks and really seeing the importance of things like public health frameworks, exactly as you're saying, not just that we can learn from them. But I think as you're very helpfully pointing out, there already is a rich literature in that area, and that needs to be tapped into and looking at some of the questions in our Q and A.

Speaker 1 Nicole Martinez [\(44:42\)](#)

There's questions really sort of wanting more detail about addressing some of these important challenges that you've been raising. And I'm going to somewhat bring together a couple of questions, such as were raised by Natalia Montez, which are speaking to a lot of development now may be in coming from industry rather than academia, and particularly concerns related to direct to consumer neuro technology. And so they're bringing up questions generally of more how you address that, whether it's the question of embedded ethics, and that those areas have not always seemed hospitable to embedded ethics, or at least have gotten very good at the ethics washing that Alena was talking about, but also in terms of the ability to regulate in that area.

Speaker 1 Nicole Martinez [\(45:45\)](#)

And so I open it up to the panel in terms of thinking through what are ways of addressing or thinking through those challenges.

Speaker 3 Oivi Parker Jones [\(45:58\)](#)

This is the question I want answered as well as someone who builds the technology. I worry about the world that we're delivering it into and that there are not guardrails in place yet. So I look forward to the answers.

Speaker 2 Ricardo Chavarriaga [\(46:14\)](#)

Well, I can comment. I certainly cannot answer that completely. I think there are different layers to the question on regulation, but I would like to expand the discussion from regulation to governance as a whole. I think there are several factors that are important to take into account. One is that we are, in most cases dealing with emerging technologies, where there are still many things to understand about how do these systems work and what is the impact that they have. And this can put us in this dilemma either.

Speaker 2 Ricardo Chavarriaga [\(47:01\)](#)

We stop it just flat and we don't go further. We just leave everything open and see what happens, move fast and break things, or what is the right point in between. That should be set in terms of the governance. And the second thing that we need to realize is that we are putting in a single bucket artificial intelligence and neurotechnology as if it were a monolithic set of technologies, and there is a huge diversity. Some of them have existed for 100 years, even if they don't work with deadlocks.

Speaker 2 Ricardo Chavarriaga [\(47:37\)](#)

But we know a little bit more about it. Others are just at the stage of experiments in vitro, so we cannot just throw the same mechanisms to all of it. So it's important to know what are the tools that we may have to govern this? So we have, on one hand, the bounding laws, the hard law. We have regulation. We have legislative framework that says what can be done, what is legal? What are the requirements that need to be fulfilled in certain areas before putting a system into the market?

Speaker 2 Ricardo Chavarriaga [\(48:18\)](#)

But we also have the soft law, and we enter, for instance, the ethical recommendations. We have more than 150 in artificial intelligence alone, and others coming in neuroscience and neurotechnology as well. That can help us. We have technical standards, we have good practices that can help us guide. And rather than saying, okay, everything in the same bucket with the same tool, it's important to start identifying which of these technologies are mature for a regulatory framework, and we start to see some attempts with the EU AI Act, which is a proposed regulation, artificial intelligence, risk-based that is still in discussion with some critics, but at least the first step towards it.

Speaker 2 Ricardo Chavarriaga [\(49:15\)](#)

And we have to also think about that in the neurotechnology area to identify what are the type of technologies, what are the type of applications? And here comes the tricky question, what do we do with the direct to consumer technology? I think there are certain approaches that can be interesting to explore. One is the regulatory sandboxes, where we allow certain flexibility to develop and test some of the systems in real conditions, but still with oversight and control before expanding it to a wider use. There are other cases where we may say it's considered low risk, so it can be deployed, but with requirements, for instance, post market surveillance and the requirements to report and requirements to be transparent and to act whenever a negative incident is reported.

Speaker 2 Ricardo Chavarriaga [\(50:21\)](#)

Through a combination of these tools, we may try to enter and identify what are the critical points where we need to act? What are these ones where we can move on with a little bit more freedom? And what are those where we better wait and just proceed with caution.

Speaker 1 Nicole Martinez [\(50:45\)](#)

Are there any other panelists I know, Alena, you had started addressing a couple of these questions within the Q and A itself. So, Gregor, Alena, Oivi, were there any follow up that you would want to comment on for this question?

Speaker 5 Gregor Wolbring ([51:05](#))

if I look at [...], because that's indeed, when you look at the social robot language, they don't use very neuro diversity. And that goes back to the language. I mean, do you medicalise them or do you look for social justice? How do you perceive the very person? Right. And then maybe a product is not useful if you really come from a new or diverse angle because it's done for certain purposes and governance. I'm not so even so with the science and technology.

Speaker 5 Gregor Wolbring ([51:38](#))

Governance is the right thing, because indeed every product is different. BCI is different than social robots, DBS, and so on. But I think what we need as a society is literally "ability expectation governance", and all the people who know my little thing, they can call the eye. But I think really depending, we noticed with human enhancement, I did like workshops back in 2006. What drives human enhancement? Which is ability expectations, which is about competitiveness and so on and so on. If you set the stage in certain ways, you will get certain products.

Speaker 5 Gregor Wolbring ([52:21](#))

It's just the reality and we know around Covid, it's all about different visions of which abilities we should have. And I think technologies are so bought by now, even sustainability. What will be the solutions? What do we go for? What are the impacts? I could give a lot of the same problems I showed. I said for AI, we also have in the sustainability discourse, who depends on the medical model of disabled people often because to sell their stuff by saying, well, it's environmental toxins, it leads to a disability as an impairment and so on.

Speaker 5 Gregor Wolbring ([53:02](#))

And there are quite a few nice studies showing the disabling culture of environmental activism. And when you look at the academic literature, it doesn't cover disabled people as environmental activists. Right. So this is not just the technology. It's not like neuro as a bad guy and no one else. I think there are systemic problems and there is a difference between patients and disabled people who do not see themselves as patients. Patient Engagement, the discourse is totally different and has much more resources. And in my University I'm in community health Sciences.

Speaker 5 Gregor Wolbring ([53:43](#))

Everything, every second sentence is patient engagement. That's really big, but that has nothing to do with disability rights groups. Right. So I think there has to be a little bit of a step back and look at these groups and look at them holistic and which technology is flowing to the top. And why.

Speaker 1 Nicole Martinez [\(54:04\)](#)

Definitely. And Alena, your comments.

Speaker 4 Alena Buyx [\(54:08\)](#)

Yes. I just wanted to say a few things on this question by Sarah Berger in the Q and A, which I think is really good and really difficult and can't be answered in an easy fashion. But I think what's necessary for that problem on how to encourage people who built this stuff to consider the impact of their work or in their work actually more concretely. It's a multi-pronged approach. We do need again, I will reiterate this. We do need more legislation here. We need sort of some rails that can only be provided by hard law.

Speaker 4 Alena Buyx [\(54:53\)](#)

We need education. So at my University, we're sort of lucky, because in the sort of the ecosystem in Munich, Bavaria, led by a Christian Socialist party, and they are very much pro business and tech and all that stuff. But there's also quite a bit of attention on social impacts and some attention to I mean, a lot of that is strategic. That's a whole different thing. But at least there is this commitment that those who develop this kind of stuff need to consider impacts of their work beyond the very narrow sort of tech or business oriented impact.

Speaker 4 Alena Buyx [\(55:47\)](#)

And that's better than nothing. And it also means that at the University, you get money to establish chairs and groups that work on this, that projects are being funded. There's a certain funding stream that looks at this stuff, and that means that all our I think almost 50,000, IT, engineering and tech discipline students get ethics education of some form and social science teaching of some form, and that's going to expand. And again, that's just one step. We also could think at schools to get people a lot earlier to sort of understand how the interaction between technology and society works.

Speaker 4 Alena Buyx [\(56:35\)](#)

I mean, that's a fundamental challenge for our entire century, I guess. So. I think that's something I would like to see on school curricula. So there's plenty of things that I think we should do all at the same time on top of sort of mandating companies to some degree that they simply they cannot externalize all the social problems and internalize all the sort of economic benefits that's just not on. I mean, we as societies, we have to push back to some degree. I think there's a lot of recognition of that.

Speaker 4 Alena Buyx [\(57:14\)](#)

This is not something new, I'm saying. But I do want to stress these other things. So there's a whole bunch of stuff that needs to happen.

Speaker 1 Nicole Martinez [\(57:21\)](#)

Thank you. And Ricardo, I'll pass it to you in just a moment. But since we're coming up near the end of our time, I wanted to add in an additional part of the question also from Sarah Berger, because I thought it would help as a wrap up, since we have a lot of people here joining us who are early in their careers framing this also in terms of what might be some priorities for neuroscientists or ethicists moving forward. But I passed it to Ricardo to comment either on what you were going to say before or this additional part of the question.

Speaker 2 Ricardo Chavarriaga [\(58:07\)](#)

I just got a bunch to say.. So I think it's important to think about the environment in which these technologies are developed. So it was mentioned the importance of education and how this cannot be an add-on. When we talk about impact, social implications or ethical aspects of technology, it shouldn't be an add on that it should be really core education of what being a tech developer is. But we should as well consider what the incentives are. We can have all the courses that we want, but if at the end, all these it engineers and tech students are somehow valued by their academic publication, their production.

Speaker 2 Ricardo Chavarriaga [\(59:00\)](#)

If the companies will depend on the evaluation, and these don't depend or don't include comprehensively the consideration of this ethical legal social implications, we attack one part of the beast, but we just don't attack the entirety of the problem. So it's a need to revise the incentive mechanisms for developing technology. What is considered to be a successful technology company. Is it just enough to have a big valuation, even if the product is rubbish or even if you don't even make a profit? Is it saying it's acceptable to have a business model that is based on collecting as much data as you want, and therefore you will act accordingly when it comes to address some of the ethical issues that it imply.

Speaker 2 Ricardo Chavarriaga [\(59:56\)](#)

So this is something that we need to consider and that requires a structural change, as Gregor was mentioning, because we can have all this education, all these measures of impact. But if in the case of people with disabilities, if it's only framed from a medical perspective, the outcome is not going to be the one that we intend or the one that we expect from this from this system. So this is very important. Another thing regarding early stage researchers in new technology and new ethics. One thing that persists is that this vision that ethics can slow down development, this is something that still exists in the community, and there is a need to counter that and to have an earlier and earlier implication of the ethics in the development.

Speaker 2 Ricardo Chavarriaga [\(01:00:55\)](#)

And I think this is something where students that are in Neuroethics and technology and programs can try to facilitate these early approaches and see this basically part of the entire system that produces the technology at the end.

Speaker 1 Nicole Martinez [\(01:01:16\)](#)

Thank you very much. We've come to the end of our time. Obviously, there's so much to talk about here and panelists, I really can't thank you enough for some really thought provoking and stimulating conversation in this area, and we definitely hope with the audience and otherwise for people to find ways to continue the conversation. But thank you so much. Alena, Ricardo, Gregor, and Oivi, it's really been an honor to have you here today and thank you very much.

Speaker 2 [\(01:01:50\)](#)

Thank you, Nicole.

Speaker 4 [\(01:01:51\)](#)

Thank you.

Speaker 1 [\(01:01:52\)](#)

Thanks, everyone.

Speaker 3 [\(01:01:53\)](#)

Thank you. Thanks, everyone.

Speaker 5 [\(01:01:55\)](#)

Take care. Bye.