

Pulse on the Principles EP 1 Final Transcript

Allana: We live in a time when the world is more interconnected than ever before but this has never been more apparent than it was in early 2020 when the novel coronavirus, COVID-19, swept across the globe shutting down cities and overwhelming health-care systems. While governments scrambled to respond to the crisis, the development and humanitarian communities stepped up to offer their knowledge, tools, and decades of experience to help fight the virus. At the forefront of the response, digital technologies are being deployed to curb the spread. But how can we ensure that these tools are being used responsibly and designed in a way that includes, rather than harms, individuals. This is "Pulse on the Principles."

Welcome to "Pulse on the Principles," a podcast series that gives you a live look at putting the principles for digital development into practice. We are your hosts from the Digital Impact Alliance at the United Nations Foundation. I'm Allana Nelson.

Claudine: I'm Claudine Lim.

Laura: And I'm Laura Walker McDonald.

Allana: The principles for digital development are a set of nine living guidelines intended to help practitioners succeed in applying digital technologies to development programs. With featured experts and practitioners from different organizations, sectors, and backgrounds, we discuss what good implementation of the digital principles looks like, explore challenges in development, and share tips and guidance for improved digital-development programming.

Before we get started, if you're new to the digital principles, you can check out Episode 0 for a primer on the principles and further context.

This season will be split into four mini seasons over the coming months where we'll deep dive into how the digital principles intersects with other topics like responsible data use, gender and inclusion, and digital literacy. The first mini-season will explore a topic that's heavily impacted the world and saturated headlines in recent months, COVID-19. While future episodes will feature guest experts, this premiere episode is intended to really ground the digital principles for our listeners. So, we're keeping it simple with just our regular hosts.

Today, we'll be honing in on just two digital principles and how they can inform the COVID-19 response, be data-driven and address privacy and security.

Laura: For the latest news and resources be sure to visit digitalprinciples.org and follow us on Twitter @digiprinciples, that is @ D-I-G-I principles. You can also use #digitalprinciples. Don't forget to leave a 5-star rating and subscribe wherever you get your podcasts for more episodes.

Claudine: The use of digital technologies has never been more prevalent and relevant. The COVID-19 pandemic has changed the way we work, learn, and interact with each other. Due to stay-at-home orders, lockdowns, and closed borders across the globe, our lives have moved nearly entirely online and we are more reliant on digital tools in our day-to-day lives than ever before.

Furthermore, the direct response and recovery efforts to COVID-19 rely heavily on digital tools, from diagnostics to data mapping to contact tracing. With the influx of new digital tools in emergency response and health-care systems, we are reminded that more solutions don't always equal better solutions. Allana, you've been working with the digital principles for some years now. Usually, when we think about using the digital principles, we think about them as a tool for everyday development projects to help ensure that technology solutions don't exacerbate problems and inequalities. How do you see them being applicable in the context of a pandemic?

Allana: One of the most pervasive challenges of the COVID-19 pandemic is the way governments and companies are proposing to use personal data, how it is collected, used, and evaluated, and for what purpose. Data can be a central component of the COVID-19 response. It allows us to trace the rates of infection across communities, it helps us better understand trends, and it enables governments and healthcare workers to better respond and outbreak hot zones. The analysis of collected data has allowed us to observe the disease's impact on minority communities as well, exposing systemic problems in the U.S. healthcare system based on where you live and the color of your skin. Be data driven is one of the more hotly debated principles. The response to COVID-19 is a great case study on why that is. Laura, let's just jump right into it. How do you think that we can balance this need-to-collect data? Because we're talking about an individual's rights versus the need of the collective.

Laura: This is a great place to start and a tricky one. It's always been a problem. I think public-health decision making often requires you to do things like institute a quarantine, or require testing, or mandatory vaccinations, that kind of thing, that it does impinge on people's individual power to make decisions. Sometimes governments make the decision. Say for example, I live in D.C. and,

when you send your child to a D.C. public school, they have to be vaccinated and have a certificate to say so. And the government's made that decision because they feel it's in the best interest of the community. So this has been always the case in health work and also in humanitarian work where organizations might be providing aid to people. And in order to do that for as many people as possible, they maybe have to require that they're in a certain place or something like that or that they register for it.

I think what's different when you get to data and digital is just a couple of things. One is that we can do so much more so much faster, and so, our power is exponentially greater to influence many more people's lives. And then, the outcomes are often very divorced from the thing that caused it. So we might, for example, institute the collection of a particular type of data point in a particular way, or set up a system in a particular way, and then, many months later or years later, it may turn out that that decision has far-reaching consequences for a vulnerable group that weren't necessarily foreseen and that are far removed from the initial creation of that database. So, for example, deciding to make gender determinative of whether a patient in a health system has a gynecological record can then have long far-reaching effects for people who aren't necessarily living with the gender that they were assigned at birth.

Allana: You bring up a good point about unforeseen consequences. And one of the digital principles, the very first one that we talk about, is design with the user. And I think that this is one of those principles that can really inform prevention of unforeseen consequences. And so, you know, you have a background, Laura, in humanitarian work, and I'm reminded, during this pandemic, of how difficult it is to serve refugee communities. Typically they are overcrowded, living closely together, and so, it's been a real struggle for humanitarian agencies to prevent the spread of coronavirus amongst these communities. But on top of that, it's very difficult for them to collect data on the spread within these communities because they have a legitimate fear for their life. So, you know, in your experience and your familiarity with some of the humanitarian principles as well, what do you think we can take away from that? How can we better serve these vulnerable communities at this time in a way that protects them both physically from the virus but also from other threats from government or other groups?

Laura: An example that comes to mind is Rohingya camps from Myanmar. They fled Myanmar into Bangladesh and there was an intention to create ID cards for them. And those people didn't want to have ID cards because they were concerned that that data set would fall into the hands of the Myanmar government and that it would be used to target them. And so, we sort of grapple

with these competing tensions. We want to design with the user, we want to understand where communities are coming from, but we also want to respect that some vulnerable groups would prefer to be left out of data sets. And for a good reason. If you have a history, as a group or as a person, of being persecuted by the state, then not wanting to be part of a state data set is a very effective survival tactic and we should respect that.

Allana: And something we talk quite a bit about too is the power dynamics when it comes to data. You know, in this case, it was a government trying to enforce IDs and it was a people group saying, "No, I don't want that." So, who really has the power there? And, as we're talking about in terms of a pandemic, there's a lot of power dynamics at play as well. Would you like to lift up some of those conversations we've had?

Laura: There's also a converse here where absence from the data can be as damaging as being present in the data, and then, having your outcomes ignored. And I think some of the conversation in the U.S, where I now live, is about the intersection between public health and data justice and health justice. The same is true in the UK where I am from, where, we just mentioned Bangladesh, people of Bangladeshi extraction are the most likely group to have very serious side effects or die from COVID-19 if they contract it.

And there was a discussion about, "Well, is that a genetic issue?" No, it's not. It's a systemic health inequality issue. We're hosted by the UN Foundation and one of the other alliances of the UN Foundation is Data2x and they exist just to try to make sure that we have more data sets that are gender-disaggregated. It's such a simple thing but data sets that indicate whether a person in a record is a female person or a male person. And obviously that can be more complicated than that. But many of the data sets we have miss out women altogether, so we don't understand what the impacts are. The same can be true of people of different backgrounds, people of different socioeconomic groupings, different occupations. It turns out that who you are, where you come from, what you do has huge impacts in terms of your different needs in a health context like COVID-19. We have to make these very difficult decisions about how to have adequate data about a person that is not too much but also to understand that your data set is...it's almost subjective. I think the assumption that data is an objective thing that is right is a very dangerous one and we have to ask questions about the data we're working with all the time.

Allana: That's a really great point. We talk a lot about, with the principles that context matters, and that's true specifically of data. And your example of the Bangladeshi people having one of the highest rates of contraction due to

COVID-19 not being genetic, we have that same issue here in the United States where our African-American population has the greatest number of cases by designated population, as well as the most number of deaths. I live in Maryland, that's particularly true in my state. And I remember early on there were these questions about, "Well, is it genetic? Is it like sickle cell disease?" it's like, no, it's because you look at these systemic issues within our country where more often the African-American population are the ones that are working the service-industry jobs. So the rate of infection has a lot more to do with societal issues than it does necessarily with someone's genetic makeup.

And, you know, all of this is really important for us to talk about but it kinda doesn't mean anything if our leaders, within our governments and our healthcare leaders, never actually read the data or they don't bother to understand what the data means. So, we talked about how it's subjective and you need this context, but that actually requires some level of discernment from our leaders and some understanding.

Laura: It is a challenge. It's not just getting data and then analyzing it and producing actionable insights based on them, it's also getting those insights into the decision-making process. And I remember encountering this in the context of the Nepal earthquake some years back where we had new data for the first time on feedback on how the humanitarian system was performing. And we were excited about this analytics, it was pretty basic but it was the first time we had this aggregated information across the whole international humanitarian response. But it's just not clear how many people really used it because it was new, and so it didn't fit into established standard operating procedures. And that can be a big challenge.

It is also important to make sure that, in making it actionable, that we're not oversimplifying or we're not giving it more weight than is scientifically justified. And of course, frankly, there are lots of reasons why leaders may not choose to avail themselves of scientific opinion or advice all over the world. But definitely I think usability and adoption is one of the things we don't talk about enough around digital development. We can definitely run these experiments but how do we get them to really be used and part of the toolbox every day?

Allana: You also touched on something earlier about how we can do more faster but how sometimes the data we collect might become divorced from the initial need. And because we can do more things faster, I just think there's been like a huge influx of data that might not actually be relevant to addressing a lot of issues. So, how do we actually discern what data points are actually relevant to problems we're trying to solve?

Laura: So, in social change work, particularly when you're evaluating the impact or the success of your work, or, sometimes when you're writing a proposal, you have to develop, what we call, a theory of change. It's a fancy way of saying, "Let's figure out how this would work in the real world and whether people are really gonna do this stuff that we think they're gonna do." And I've been working on the technology space sort of trying to help people think through what they could do for an embarrassingly long time now, and I found this is really helpful just to get flip book and a marker pen and draw out cause and effect in the real world. Like, "Okay, so these guys get a text message," or, "these guys read this actionable information," and then they're gonna do what? They're gonna all run out and get tested or they're gonna stop going to work? "So then what?" And really asking that question, "What is the benefit we're gonna derive from this thing that we're putting together? What's the real-world positive impact?" and, "is it enough to outweigh, one, the cost of doing the thing and the opportunity cost of not doing something else but also like the potential harms and risks that you could be producing for vulnerable populations?" "is the public health benefits so great for most people that it is worth disadvantaging..." and I mentioned vaccines earlier, that's a good example, there are gonna be people who are gonna have side effects from vaccines. Not some of the more well-publicized full stories around that but there are people who have, say, a bad reaction to a BCG. I had one, it was awful. But the public-health benefit of all of us not getting tuberculosis is there, and so, we take those risks. But we do weigh that benefit and risk, and I think that step sometimes is missing in some of our experiments.

Claudine: So, as we're talking about data and its implementation, we also have an obligation to use that data responsibly. We've heard a lot in the news recently about contact tracing, which in practice has become using digital tools to track the spread of the coronavirus by identifying friends, family members, and neighbors who have come into contact with an infected person. It's used to identify who else might be infected and try to mitigate further spread. Is this the most impactful use of data? And what concerns does it raise?

Allana: Well, so, I think it's really important, first and foremost, to understand the nature of viruses. And a bit of background on myself, I did work on the response to the Ebola outbreak in West Africa for 2 and a half years. And I came to learn quite a bit about viruses and their spread. And the fact is not all viruses are equal. With Ebola, there was about a 3-week incubation period, and that was before you started showing symptoms. But you were not able to spread the disease until you showed symptoms. So it was immediately apparent, like you were sick, you were going to get someone else sick. So contact tracing then

was very easy because like, "Are you a sick person? We now can contact everybody you have been in contact with within the last 2 days," and that's easy. The nature of this disease is you might be infectious while you are not showing symptoms.

And that makes it nearly impossible to do contact tracing. And I think that a lot of companies and governments believe that contact tracing is the magic bullet that is going to ensure our safety. And it's just not the case for this disease. And I think South Korea was a really great example of that. They have a lot of experience with infectious diseases and they have actually set up this amazing national system for communicating with the public when an infectious disease has emerged within their communities, and contact tracing was a big part of that. And when COVID-19 came, they realized, "Contact tracing won't work. We can't just identify our sick patient and go out to all of their contacts. We need to reverse engineer it."

And so, instead what they did was that, if somebody was sick, they worked with that person to go back through where all have they been within the last X many days, and then they would blast out mass text messages to anyone who was within that area. And, say, this person was in this grocery store at this time of day on this date and, if you were in that grocery store at the same time, you then had the choice, "Do I wanna go and get tested or do i not?" And then they made sure they had a lot of testing sites. And that's why they dealt with it so quickly. They knew that contact tracing wouldn't work, and so, instead they put more information out into the community and made testing widely available.

And people responded to that. They had faith that the government was doing it the right way and that, if they got tested, it would be identified, and they would do the right thing for their fellow countrymen to get tested. And so, yeah, contact tracing I think, for communities that don't have a lot of experience with infectious disease, they're going to it too easily.

Laura: It's one of those examples of the technology being implemented without reference to the real world. Like this is not really how this thing works, that's not even gonna help you. What it is gonna do is open an enormous loophole that could then be used against a vulnerable group by somebody in power. And we know that emergency situations mean massive removal of checks and balances that normally would be there. So, you get contact tracing being carried out on protesters, which has enormous implications for freedom of speech and the right to protest, and potentially for people who have every right to not have their presence or absence of that protest be a matter of public record.

And this is not to say that there's no role for data or that we should do nothing, rather that I think we're often very keen to jump to some sort of moonshot solution when we're worried that we're not gonna be able to meet the demands of a humanitarian crisis or a health emergency. It is a very tall order, we definitely don't have enough money, enough resources to tackle this effectively. I think people reach for innovation to show that they're doing something that could perhaps be it. But I think that risk and reward balancing pieces is critical, we haven't necessarily done that.

And I think another example is Apple and Google, they have built something into their operating systems that makes it possible for app developers to build apps on top of it that do that kind of contact tracing using the location of your phone. But most of those apps would have to have such high penetration into the population that it just makes it kinda unfeasible, even for small populations. Like Singapore, for example, have demonstrated that they didn't get enough uptake of their app for it to be meaningful. And so, even these new solutions and ideas that are very creative, they're just, when they intersect with reality, they have all sorts of problems, you know, not least with people who are just offline or who are disproportionately not connected to the internet, don't have smartphones, who also are among the most vulnerable and most marginalized groups in our societies. So really really problematic stuff.

But there is definitely an important role for data to play. And I think, you know, it's useful to remember that principles that we're talking about, the digital principles, come into play there as well. So for organizations and authorities to be able to share data about people who have had COVID-19, who have recovered, who might be in quarantine, who've been tested. All of those data sets also have very personal information in them but they also need to be shared effectively. So, how do we make those trade-offs and how do we make those data sets talk to each other? What are the data standards that we need to make sure that they can be shared without a lot of effort having to go into cleaning them? These are all equally important conversations to be had.

Claudine: This also brings up like the interesting thing that we started off with, how like the principles often conflict with one another. Because we want to be open and collaborative, we see all these different kinds of solutions popping up. But like you said, there's like low-penetration rates with these apps, so how are we being collaborative while also making sure we're addressing people's privacy and security, not just handing over that kind of data automatically?

Allana: Well, that brings up the role of regulation. What do you think is the role of states in this? And particularly in international development where the

principles are designed for use in international development where sometimes international organizations are coming in and playing part of the role of a state or sometimes operating with minimal oversight from a state? I mean what is the role of regulation there and how can we respond quickly but also be compliant and how can we help states to build those checks and balances that we should be following?

Claudine: Growing up in a capitalist society, I think that I have grown up understanding that corporations, they care about their bottom line. I think it was Rockefeller who said that, "Business doesn't have morals." And that's important, I do think it's an important distinction. Right? Most of these companies have shareholders, they have to care about the profit margins. And so, they're not going to be as concerned with the privacy rights of their users if it means that they can make more money off the latest iOS update, or off these app agreements, or somehow monopolize the population to use their mobile phones and that sort of thing. And so, I do think that that is the important role that a government has to play in regulating and limiting the powers of a company from being able to take advantage of their users. And at the same time, I mean I know there's a lot of cynical people out there that say, "Well, you could always just choose not to use that product." Right? Like, "It is still a free society, you could just choose not to have a mobile phone."

But that doesn't match the reality of the world we live in today where technology is so essential to everything we do. You have to have a phone number to get a job. You have to have connection to the internet to get an education, as we've seen with COVID-19, and these school children who are falling behind because they don't have Wi-Fi at home. And so, I do think that there is a role for government to play, to say, "You cannot take advantage of users. You cannot take their data. There should be regulations around how long data can be held, or how it's anonymized, how it's aggregated." And if they're going to use it in a way that is going to identify you, like contact tracing, that needs to be very clear and there needs to be the option to opt out of it.

I think that's one thing I really like about GDPR is it built in regulations around the ability to opt out of your information being gathered and not being upfront and evident. And also having the right to be forgotten. So, when you take your cell phone plan and go somewhere else, when you take your bank account and go somewhere else, they have to erase your history of ever being there. And it's not a perfect regulation but I think that, as a consumer, I'd like to see more of those honest and clear options up front.

Allana: Yeah. It is up to the state but it's also hard to regulate. Sometimes even in the U.S. like there's like a lot of mistrust with what the government actually does with that information and who's actually in charge of making sure that there are checks and balances within our own government.

Claudine: I mean the international system is really struggling with this. Right? So, the secretary general has released a digital roadmap that says, "We should be collaborating to help govern digital and the internet." But international organizations, UN bodies have sovereign immunity, they are not subject to the law of the countries in which they operate. This is diplomatic immunity but for international organizations. So, for example, in Haiti, after the earthquake, some Nepali, I believe, peacekeepers accidentally created a cholera outbreak. And this actually went to court and the UN declined to be held responsible for it legally, which they can do because they have this immunity. So you're talking about a situation where digital transcends borders, governments aren't up to date with regulating. There is a lot of complexity to unpick in data justice and health justice and these are systemic issues that are poorly understood, where cause and effect are not necessarily simple or well-seen.

And then, in the meantime, in international development you have a lot of actors running around who maybe aren't subject to national law. Or who, frankly, if they don't like the national regulation, they can just go operate in another country. So it's a really tricky thing and I think with the technology it is exacerbated by the speed of change. And in situations like COVID where everybody is scrambling to respond, there is a real risk that those checks and balances are not in place. And that's where I think principles of practice come to the fore because, at least if organizations have endorsed the principles, people at those organizations know that there are ways that we try to implement technology well, then that is at least some kind of guardrail for how we implement technology and international development.

Allana: So, how can we, as concerned citizens, go about advocating for these things to those that will be running or overseeing these programs?

Claudine: You know, going back to the idea of the principles for digital development being some kind of guardrail for individuals and for organizations, we do look also at how you can use them to evaluate after the fact, so how did this go, did you design with the user, were you collaborative, were you data-driven, did you address privacy and security. But also perhaps, in the international-development space, we're very driven by donor requirements. Donors can also require us to align with the principles and that can make them more powerful.

It's interesting that we do end up leaning on these voluntary standards over the kinds of regulation that we've been discussing just because it's easier. And because it's easier for a global organization to have one set of principles than it is for us to rely on patchy regulation at the national or the international level to help us know what good looks like.

And I think, you know, as we go through this series, hopefully, we'll be able to look at some of the ways that the principles being used in these other ways.

Allana: I like that you brought up the fact that people like to adhere more to voluntary principles. And I think part of that is because they were created by individuals, they weren't passed through as regulations, they weren't done for political purposes. These sorts of principles and standards that have been so broadly adopted were created by practitioners, people that do this every day who have an invested desire to see it done well. And that probably is why there's so much adoption, because they feel ownership over it in ways that we don't always feel ownership over law or policy.

Claudine: And I think that the digital principles also is flexible in that we always say that you adopt them according to your context, they're not all required. Like we understand that each project, each country, each organization is just like different in the way it operates. So I think that that flexibility aspect to the principles was what made it something that people were keen to adopt and endorse.

Allana: We rely on the diverse members of the Digital Principles Community to share their thoughts, insights, and experiences with us. To that point, we hope you join us for our second episode in our COVID-19 series where we will discuss the use of mobile-network operator aggregate data by governments for identifying and responding to COVID-19 cases in their countries.

Claudine: If you would like to give us feedback on this episode or any other topic in our episode lineup, you can reach out to us at principlesadmin@digitalimpactalliance.org. You can also visit us anytime at digitalprinciples.org and follow us on Twitter @digiprinciples, that is @ D-I-G-I principles. You can also use #digitalprinciples. And that's it for this episode. I'm Claudine Lim.

Allana: I'm Allana Nelson.

Laura: I'm Laura Walker McDonald, and we'll see you next time.

Claudine: Thanks for listening. "Pulse on the Principles" is made possible by the Norwegian Agency for Development Cooperation and produced by Claudine Lim, Allana Nelson, and Abigail Shirley of the Digital Impact Alliance. Special thanks to Podcast Village for recording, sound mixing, and graphics. See you next time.

