## JOED HANGE

## The role of innovation and data in Global Health

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<u>View lecture</u>

Mark Dybul: Thank you, doctor van Rooijen. Nice to call you that. It's a great privilege to be here and I really want to thank the guitars for that beautiful piece. It is one of my favourite composers and pieces. Thank you very much for such a beautiful rendition. It's a good reminder that, while it's the Joep Lange Institute that Jacqueline played a key role in, everything about the Institute infuses her spirit into it as well.

It's a fascinating time in the world. The flux that's happening right now, the change in the world is in many ways unprecedented. It's absolutely massive. From a political standpoint - power shifts within countries, you'll be having an election yourselves in the not too distant future. Between countries - power-based geopolitics has changed dramatically in the last twenty years. Socioeconomically – there's growing wealth all over the world, growing powers, economic powers, dramatically different than it was fifteen to twenty years ago. With that is growing inequality and inequity, economic inequity, the greatest inequity we've seen in decades in the world. There's massive demographic shifts, and I'll come back to that. I think you know that the population, for example, of Africa is projected to double by 2050. Massive changes in the demographics of the world.

And with that, migration. And I want to mention specifically migration – normal migratory patterns. Everyone is obsessed with refugees right now. The refugees are a fraction of the actual migration that is happening in the world today. If you put those things together, population growth and economic inequality, we will see refugee and migration shifts in the next twenty years that make what we see today look like child's play.

But also ideas, innovation and technology are migrating. Moving faster than they ever have, because of the technology that's available. And that will change and expand. And when ideas move, and people move, the world becomes a very exciting place. It can be a scary place, but it can also be a remarkably exciting place. And development, global health, HIV/Aids which is an area I worked in for many years, TB, malaria, really have to be seen within that context. It doesn't stand alone. It doesn't sit off by itself. It actually sits in that global context. And those global changes will have an impact on development, global health and HIV, just as HIV, global health and development will have

an impact on those changes. So it's a very dynamic time, it's a hugely exciting time to be engaged. But as I said, it can also be a little frightening. Whenever there's frightening change, whenever there's massive change in the way we are seeing today, there are a lot of challenges. But there are also massive opportunities. If we focus on the opportunities, while we're focused on the challenges, we can see a very optimistic, wonderful future.

The Sustainable Development Goals actually give us a window into seeing the opportunities. The wonders, the possibilities of the future in this changing world. You know, this pin - everyone asks me about this pin by the way, it's a beautiful symbol of the Sustainable Development Goals. Each colour is a goal, but it's a circle. They all come together. Because they tell us the Sustainable Development Goals shifted from the Millennium Development Goals in a couple of fundamental ways. I think the most important way is to say: we have to stop looking at issues. We have to stop looking not only at diseases, not only at development issues, we have to stop looking at things and issues and get out of boxes and focus on a human being. Focus on a person. We focus on a person, and what's necessary for a person to thrive, develop and become the person they have the potential to be, that's what the Sustainable Developments Goals are about. In many ways, if we look at that world that's changing today, we take that perspective. What do human beings need? What do individual human beings need to thrive and develop? We can have a tremendous future. We can look at the future with challenges, but also see tremendous opportunities.

Now sometimes, when we look forward, it's useful to look back too. There's a lot to look back towards that tells us that we can achieve some pretty extraordinary things. If we look back fifteen years ago - and I'll use HIV as an example throughout this. You could use malaria, you could use poverty, you could use education, you could use a whole bunch of areas, but I'll use HIV, because this is the Joep Lange Institute, and it's an area that Joep spent so much of his life on. I was privileged to work with him on it.

If we look back fifteen years ago, there's a lot of reason to be optimistic. Because what has been achieved in the last fifteen years, fifteen years ago was said to be impossible. And when things were said to be impossible and you achieve them, as we look forward and see challenges, and things might look impossible, we can remind ourselves that we've already achieved the impossible. And so we can achieve the impossible again.

Some of you might not know, looking around the room, some of you were way too young to remember when the Millennium Development Goals were adopted. But the original Millennium Development goals did not have a goal for antiretroviral treatment. It did not have a goal for antiretroviral treatment because people in development and in public health - and in fact it was a prevailing view in public health among experts, that treatment in Africa and treatment beyond high income countries was impossible. It could not be done. People stood on the floor of the UN General Assembly and said it was impossible to do antiretroviral therapy in Africa and low income settings. We achieved that impossibility.

This is not a good thing to say in the room here, in a university hospital - I used to be an expert before I became a bureaucrat. But a former prime minister of the United Kingdom, Lord Salisbury, once said: if history has taught us anything, it's taught us not to trust the experts. And the reason for that is: we as experts are trained to be sceptical. We're trained to come up with a thousand reasons you can't do something. For anything of meaning you can come up with a thousand reasons it cannot be done. And looking forward we could be looking at the world and saying there are a

million reasons it's going to turn out badly. Our challenge is to say: how do we actually make it good? How do we find the opportunities? How do we take what looks impossible today, and the by step make it possible?

And it was made possible in that step-by-step way. President Mogae in Botswana, when the public health experts were saying: it is impossible to do antiretroviral therapy, used his own national money, combined with the Bill and Melinda Gates Foundation, and with Merck, and did prove that antiretroviral therapy was possible in Africa. Brazil was doing the same thing. Then there was Three by Five, an initiative of the World Health Organisation and Jim Kim, a dear friend who gave one of the previous Joep Lange lectures. Then the President's Emergency Plan For Aids Relief, and Global Fund, as Peter mentioned. With those initiatives, and because they supported people in the countries to achieve extraordinary things, what was thought to be impossible has been achieved. You saw on World Aids Day, on December 1, eighteen million people in low and middle income countries are now receiving antiretroviral therapy. Eighteen million. Fifteen years ago, the best anyone thought was a couple hundred thousand, what public health experts were saying was a couple of hundred thousand. And infection rates are declining, but I want to come back to that.

Some of the data that were published, and Deb Birx from PEPFAR published this - looking in communities, not in hospitals but in communities, rural communities, in Malawi and Zimbabwe and Zambia, showed that viral load suppression was ninety percent. In the community. Not in a clinic, in the community. [They actually went out] to the community. So people in the communities are taking their drugs, they're suppressing, for the most part, and I want to come back to that.

But I do think it's worth noting what an extraordinary change we've seen, and how the impossible has actually been possible. It's actually been fun to have been in this for a long time, because when PEPFAR started I was heavily criticised for only caring about antiretroviral therapy. Now I'm often criticised for not caring enough about antiretroviral therapy. Interestingly enough often by the same people.

But what's very important, I think, is that some of us have never changed. It's never been about antiretroviral therapy or condoms or medical male circumcision. It's been about how do you get to ending an epidemic. No matter what it is. And then back up from there. How do you get to ending an epidemic? How do you get to controlling Ebola? How do you get to health? How do you get to universal health coverage? And back up from there. Because if you start with: we're going to increase X, Y or Z, we're going to have coverage rates of X, Y or Z, you will fail. Because you will have missed key pieces. It's only by saying: how do we end epidemics, that we will get to the end of the HIV epidemic, by looking for the pieces that will make a difference.

One of the fascinating things, and something we've learned, that data have taught us, is there is no such thing as a global HIV epidemic. There never was. There's no such thing as a national HIV epidemic in almost any country. There never was. There are micro-epidemics in every country. Different epidemics with different drivers in different places. Just as an example: if you look in Kenya, there are three different epidemics. In the west, in Mombasa [?], Homa Bay, up around Lake Victoria, the epidemic is largely driven by gender inequality, and I'll come back to that. By adolescent girls and young women having extremely high rates because of their association with older men. In Mombasa the epidemic is largely driven by gay men, men who have sex with men, and by intravenous drug use, or other drug use. And in Nairobi you have a very mixed epidemic. So you have three fundamentally different epidemics in one country. That's what the data tell us. You

wouldn't possibly respond to the epidemic in a national way and expect to succeed. The only way to succeed is to look at each epidemic, understand each epidemic, and then respond to each epidemic in the way that is most likely to be effective, based on the data which are available.

Which brings us back to the Sustainable Development Goals and the focus on a person. Because viruses aren't at risk, people are at risk. People are at risk of a viral infection. So who are the people? And how do we understand the data, and how do we understand the response that will be most effective for a person? It's nice to talk about it theoretically, but it's also useful to focus on a specific area. And I'd like to focus on adolescent girls and young women for a little bit, because it helps us understand the epidemic.

Now you could do the same for any of the traditional key populations. As an openly gay man I get criticised too for talking too much about adolescent girls and young women. But it is truly important because of the demographics I talked about. We will win or lose the global fight against HIV/Aids, based on whether or not we win or lose the battle to protect adolescent girls and young women from HIV. It's really a numbers game. As I mentioned, the growth rate in Africa - we will see a doubling of the population of Africa between now and 2050. That means there will be a lot of young people. Young people are at very high risk of HIV infection. They're the highest risk of HIV infection, twenty-five and older. We will have population - we will have many countries in Sub-Saharan Africa, where sixty, seventy, eighty percent of the population are under thirty to thirty-five years of age. Which means that if we kept the infection rate the same, we would double the number of infections by 2050, because of simple demographics. And what's really frightening, and this again was shown on World Aids Day, in communities that have been studied, even with that great ninety percent suppression, adolescent girls and young women are up to fourteen times more likely to be HIV positive then young men and adolescent boys.

And the reason for that we now understand, and we have phylogenetics and the data are very clear: it's because twenty-five to thirty-five year old men are having sex with fifteen to twenty, twentyfive year old girls. It's for a lot of different reasons, and we've just begun to understand it. But the data tell us that we will win or lose the battle against HIV based on how we respond to adolescent girls and young women.

The phylogenetics tell us what is happening. It tells us scientifically what is happening. But it doesn't tell us about human beings. This is what we're missing. Who are those young girls and who are the older men? Not as statistics, not as members of a randomised controlled trial, but who are they? What are their social and personal characteristics? Why are they at risk? Where are they meeting each other? Why are they meeting each other? We have no idea except for some very sparse pieces of information. What we do know is, it can look very different ten kilometres away from each other. It's a community-by-community, person-by-person thing. That means we have to have the data down to a personal level. On an anthropologic human behavioural level, if we're going to respond.

Because what the data show us: yes, we have ninety percent suppression overall, but in twentyfive-year-olds and under very few know their HIV status, and about twenty-five percent of them are suppressed. Which means if we don't get to them, we will lose them. What the data tell us is they are not coming to the services we are providing. Either those men or the women both are not coming to the services we're providing. So unless we understand them, unless we understand who they are, unless we can design programs that meet their needs as human beings, we will lose the fight against HIV/Aids despite all of the progress. Because of demographics and because of human

beings, because of human behaviour.

So we can either have a demographic dividend that we talk about, or we can have a demographic

disaster. The reality is that those women and men we're losing in HIV services are also not being educated. They're also not participating in family planning. They're also not participating in economic growth and development. Which means we will fail in our efforts to have a growing world, we will fail in taking the opportunity of the changing world and only be stuck with the challenges. We will have a demographic disaster rather than a demographic dividend.

The other reason to focus on adolescent girls and young women is the impact on development more broadly. These numbers are kind of frightening and should be really embarrassing to all of us who are men. What happens with a girl to become a woman of opportunity, or conversely, what happens to a girl so that she doesn't become a woman of opportunity? Well, one of the most interesting things is a girl who stays in school through secondary school is much less likely to become HIV infected. So we're actually investing in HIV programs to keep girls in school. They could be as much as sixty percent less likely to be infected, which is probably an exaggeration of a study, but many studies have shown a benefit.

What else happens as the girl stays in school? Well, not only will the HIV rate be lower, but she's much less likely to be a child bride, she's much less likely to get pregnant early, she's much more likely to have fewer children, and she's much more likely to have an income. When a woman has income, when a mother has income, she will spend about eighty percent of it to feed, educate and provide health care to her child. Men, we men, will provide about a third of it.

So you can actually have a huge change in development just by keeping a girl in school as a response to a HIV epidemic. It's a pretty extraordinary interchange of opportunity. It's an extraordinary opportunity for us. One of the great things about the demographic, the great change in the birth rate is a huge opportunity. In your culture and my culture and most cultures it took three, four generations to have gender equality. And we're still struggling with it. Or other types of equality. And that's because – and there's a great Roman saying: there is hope in death. As older people go and die their thoughts and beliefs go with them, and younger people tend to be a little more forward leaning and their ideas take over. But it can take generations. But if you have that demographic change, where sixty, seventy, eighty percent of the population will be thirty-five and under, if we get gender equality right now, we can actually change the gender dynamic in a generation, not three, four, five generations. And that would change the world. What an extraordinary opportunity that would be.

So we have the opportunity to look at the world in a different way, to look at the data, to look at the challenges, but also to look at the opportunities. But to do that requires us to focus on the data. Data, data, data. To look at data is more than we learned, or at least I learned, in medical school. More than randomised controlled trials, more than assuming that if we come up with a medical solution people will do it, more than treating them as lab animals and saying: we think you should be on treatment, so you'd better be on treatment, or we think you should use PrEP, so you're going to use PrEP, and understand human beings. Understand the anthropology, which is a science. Understand behavioural science. Understand human beings. And as the SDG's tell us, focus on a human being and all the data derived around that. If we do, we can actually respond to the changes in the world and have better human beings.

Now one of the themes about the Joep Lange Institute is a hugely important one, which is innovation and technology. If we could switch to the slide - financing is important too. I just want to look to the future a little bit, to see where we're going. And I'll talk a little bit about innovation, and

Now I know a lot of activists, and there is some in the room, get really upset when I show this slide. But we have to actually focus on reality. The reality is that - the red line shows over time, and I'm not giving a time line, that's short, medium, long term, external resources for development, for global health will trail off. And the reason for that is that economics and economic growth is occurring in most countries. The World Bank predicts that about eighty to ninety percent of the currently low income countries will be in middle to upper middle income within the next thirty years. Twenty-five to thirty years. And development agencies were not built to provide funds to middle and upper middle income countries. You cannot explain that to your tax payer. So over time we will see a decline in external financing for development, including global health.

But there are growth opportunities if we focus on different approaches and not just do things the way we used to. So what could the role of development be, what could the role of an organisation like the Global Fund, or this university, or the Joep Lange Institute be over time, as external resources are decreasing? Technology, innovation, and exchange of technology and innovation. Including global public goods. I can tell you, whether it's China, India or Mexico, they are hungry for technological exchange, innovation exchange. Not us coming and saying: hey, we designed this, you should use it, but: what are you learning, how do we learn together, how do we grow together, how do we innovate, how do we create, where are the ideas? And I don't just mean technology. When we hear innovation, everyone runs to new technology. And we absolutely need new technology. We need new data systems. We need new abilities to aggregate and use data, and I'll come back to that. But a lot of innovation is human innovation. Technology is wonderful if it's used. There's many, many advances in technology that have never been used or never will be used, because we haven't looked at the human use of them. We haven't looked at whether or not a human being wants to use them or whether or not the technology was designed for them.

And if we create global public goods, and I know there's a disagreement about that definition, but let's just say it's something that can be used to cross space and time in a non-protected way, a non-overly protected way, that brings value to humanity, that is a resource and a growth potential that is enormous and that will shift us from a demographic disaster to demographic dividend. That can shift us from changing the flux, and changing the world, to something that's challenging, to a massive opportunity. There are a couple key areas, whether it's procurement or supply chain, and these are areas that we are all working on together. We've done some amazing innovation in it.

In program quality - program quality is a huge area right now, that people are taking very little interest in, but that has an enormous amount to do with access. There is no reason not to have high quality care in a village just like you do in a city. It doesn't have to be the same care, but it has to be high quality care. To do that, you need a system, you need a data system, you need a human resource system. You need people trained from the local level to the national level, and they need data from the local level to the national level that they will use.

You know, if you waited, if every time we waited when a house was on fire, for a mayor to give the order to put the fire out, most cities would have burned down a long time ago. If we wait in a health crisis, whether it's an HIV epidemic or ebola or the next influenza outbreak, for a response from a

health minister, or the World Health Organisation, by the time we get that response we will have lost. If we build, from the ground up, from the communities, from community health care workers, to everyone they are engaged with, a system of data collection that they can use<sup>6</sup> and respond to

while they're reporting, they're an empowered health care worker that will detect and respond to what comes next. And we will have sound systems. But that requires understanding human beings, that requires understanding each community, and building a system that they can use.

That's technology, but it's differentiated technology. It's not us coming up with a technological solution we give them, it's them coming up with solutions that work for them and modifying it as we go along. It's developing health insurance systems that work for people at a community level. PharmAccess, and the Joep Lange Institute, has a huge opportunity to work on that. It's new products, but it's new products that are responsive to individuals.

For those of you who have not read Bill Foege's "House on Fire" - does everyone in this room know who Bill Foege is? A lot of people are young enough. Bill Foege designed the approach that led to the end of smallpox. He bucked the global health system, the public health system said what he was doing was crazy. What he did was say: we have to stop just increasing vaccine coverage rates, and go to each community and find out where the new infections are, figure out why the infections are spreading, respond at the community level, and we'll end the epidemic. It's a fascinating book. It's only ninety pages. I strongly encourage you to read it. He spends more time on cultural human responses than he does on scientific responses on the vaccine. But he also says something hugely important relating to technology: they modified the tool that delivered the vaccine based on the response from the community. It actually had to do with the way it was hooked. In some communities they wouldn't use it. So they had to actually change the technology to respond to the community.

Technology and community, and response in community, and innovation in community, are intimately linked. If there isn't an interchange back and forth it won't work. So as we develop new technologies, whether it's digital or otherwise, if we're responding in that community base, in that constant interchange back and forth, using all the areas of science, we will actually respond, and accelerate the response, to have a remarkable, remarkable future.

Now I want to end – you know, one of the things about having done PEPFAR and the Global Fund and going back to academics, is you get some time to think. We will end the HIV epidemic. We'll end it by using data and innovation and technology, and getting back to incorporating all the [scientism], focussing on people, understanding each micro-epidemic, who's at risk, why are they at risk, develop responses for them, develop technologies for them. We will get to the end of the HIV epidemic as an epidemic. And when we have a vaccine we will end the epidemic. And when we do, that will be an extraordinary success in global health. But the response to HIV has been a somewhat unique response, relative to an infectious disease. I think there will be some legacies beyond the end of an epidemic. Beyond the end of what we all – some of you have never known a world without HIV. The historic nature of that we cannot underplay.

But there are a few other things that happened in the response that might help us as we try to look at responses to other things, and grow out to achieve universal health coverage. A couple of legacies that I think were largely driven by the HIV epidemic, and I admit I am a bit biased. The first is data, and the insistence on results. It is extraordinary for those who were around - that was fifteen years ago - if you asked anyone fifteen years ago: what are we doing in the HIV response, what are we doing [in] global education, what are we doing in nutrition, what are we doing in pretty

much anything, the answer would have been: we're spending X amount of money. It wouldn't have been: we're focussed on achieving these results and we're reporting them – it would just have

been: we're spending this amount of money. HIV really flipped that, and said: we're going to spend money, we're going to spend billions of dollars, but we're going to get results. And we're going to go in and create the data systems and collect the data.

Now we still have massive data gaps. But what we know about HIV – we know more about HIV in communities in Africa than we know about HIV in communities in the United States. The insistence on data, the accountability, the responsiveness, the need for results, really was driven in a large part by HIV. I know this, because when we created PEPFAR and we put out very specific prevention, care and treatment goals, we were heavily criticised by the global health and development community. I remember the criticism. They said: development is too complicated to set specific goals. That's absurd. Now there isn't anyone who doesn't talk about results-based development, results-based global health and collecting data and results. That did not exist fifteen years ago. And that is a massive and important legacy of the HIV response. Because without data, without accountability, we can achieve nothing, including achieving the demographic dividend.

A second and I think hugely important piece, which is related to the first, is shifting from a paternalistic approach in development to a partnership approach in development. We're still in that process. But for many, many years development was largely: we are the smart, important people, generally white, from the North, who are going to come and tell you how to do things. How to run a program, what you're going to implement, how you're going to do it, what data you're going to collect, what data system you're going to use. That's the way we did development.

And you could do that, actually, when you were doing pilot projects, which is the way we used to do development. Because there wasn't enough money. But when we said we were going to support national systems, we couldn't do that anymore. The only way to support national systems was to have data and accountability, but to shift the accountability and responsibility to a mutual accountability and responsibility, to true partnership.

And this was actually codifying the Monterrey Consensus. Any of you interested in this area? Highly recommended. You go read the Monterrey Consensus. It's about four pages. It lays all this out. It was from 2001. It was wonderful, because it was the first document, so it's only four or five pages. Since then, we have had the Paris Declaration, the Accra Accord, Busan, those are like four hundred pages, because that's what we do as bureaucrats. The first one was only four to five pages, and it lays out this principle that we have to move from paternalism to partnership. But it really was HIV/Aids, because of the national response, that did it first, and was the trailblazer.

Paul Kagame said something once, the president of Rwanda, immediately after PEPFAR was created, or soon after, when I was there. I will never forget. He said: this is the first time someone has held us accountable enough - someone has respected us enough to hold us accountable. It's a pretty extraordinary statement. It's the first time someone has respected us enough to hold us accountable. Which links the data and results with the shift from paternalism to partnership.

The third, and this is the one that in some ways gets me the most excited, and that relates to the adolescent girls and young women, to the key populations we talk about so much. You know, most infectious diseases are great equalisers. Which I know right now, because I was around a bunch of kids and on airplanes, and I'm sick because I was on an airplane and around a bunch of kids, as were many other people. Generally, if you come into contact with something, you are as likely as this

person next to you, unless you're severely immunocompromised, to get sick. You're as likely to

recover, or not recover, depending on what the disease is. The black death was a great equaliser.

HIV/Aids is a rather unique disease. It's a rather unique infection. Because it actually lives in the shadows. The people in the shadows, the people most marginalised and vulnerable in the society, have been the ones most susceptible to HIV. Whether it's gay men, the LGBTI community, transgender - what's happening with transgender communities is absolutely appalling around much of the world, and the risk of HIV, people who inject drugs, prisoners, urban poor, people that live in poverty. And in the case of many parts of the world, not just Africa, in Southeast Asia and Latin America, adolescent girls and young women.

So it's something extraordinary about HIV. We actually can't end an epidemic, the HIV epidemic, unless we become better human beings. It's a pretty extraordinary thing. Not very common in infectious diseases. We cannot end the epidemic unless we become better human beings. If you look over the last fifteen years, where we were fifteen years ago and where we are today, and we still have a long way to go, the shift in rights has in many places had a foothold in HIV/ Aids. If we look at adolescent girls and young women in Africa, and in parts of Latin America and Southeast Asia, if we do it right, what will drive gender equality will be the response to HIV/ Aids, and that's a pretty extraordinary thing for an infectious disease.

And the last thing is hope, which goes along with all of that. You know, we talk about the number of lives saved, we talk about – because we should. But I've been privileged, as many in this room have, to literally go to the same village, to the same clinic, fifteen years ago and today. The same community fifteen years ago and today. I lived in San Francisco when basically it was a death zone, but it was nothing compared to what was happening in Africa. Entire communities were being wiped out. There was no hope. It's impossible to describe it unless you saw it. There was absolutely no hope. Everyone in that community was absolutely convinced they were going to die, their spouse was going to die, everyone in their family was going to die, their children were going to die. You could see it in their homes, because they buried them all in front of their houses. There was absolutely no hope.

If you think you're going to die, if you think everyone around you is going to die, are you going to invest in education? Are you going to try to get a job? Are you going to reach out to your community and respond in your community? No way. It was actually hope, and the restauration of hope, that is one of the greatest legacies of HIV/Aids. And to see communities come back to life, literally come back to life, and believe they can do anything, because they tackled this epidemic, is extraordinary. It will drive enormous change around the world. That legacy of hope is one of the great legacies of HIV.

So those legacies of data and results, switching from paternalism to partnerships, the requirement that we become better human beings to end the disease, and hope, are pretty cool legacies for an infectious disease. If we keep that response going, those will grow, and we'll have grace from grace.

I'd like to end where I started. We are in a time of massive flux. We are in a time of massive change. We have gone through these periods before in history, and we have a choice before us, as we've had before in these times of massive change. There's a natural human instinct in time of change, in times of massive flux, in times of insecurity, to look backwards, to look inwards, to look with fear, and fear's constant companion: hate. When we've done that in the past, we've done some pretty

horrific things. But there is an alternative path when we're facing flux, when we're facing change,

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when we're facing insecurity. It's to look outward and forward and with hope. We also know from history that when we do that, including a response to HIV/Aids, we can do extraordinary things. We can actually achieve the impossible. We can give flight to the better angels of our nature. So the question before us is: which path will we take? And that path will be taken person by person, community by community, country by country. I hope we all take the outward, forward, hopeful approach. If we do, what seems impossible will be achieved. And we won't be facing challenges. We'll be facing opportunity and an extraordinary future.

## Thank you.

Peter van Rooijen: Thanks, Mark. Thanks for - sort of a recurrent theme, I'm thinking, in everything you said, was the need to bring human beings, or the human being, back in the discussion and thinking about data and innovation. But also a call on all of us to be better human beings - which I, as you know, I'm a fan of that line of you. I've seen you pushing this with donors in very chic environments, and I thought it was right between the eyes. You did it again. So thank you.

We have fifteen minutes, I think. Is that ok? Oh, a bit more. Ok, good. Because we have way too many questions. And probably the room is inspired by everything you said, and there will be more questions. So let's see how far we get. But I'll kick this off, and let's see, as I said, how far we can get in those fifteen, twenty minutes.

So let me start off with, and I'm going to ask people to raise their hands if we build on one of your questions. I have a question – it's basically a combination, from Heleen Borleffs. Are you in the room? Heleen, hello. And Henk, I've seen Henk. Let me pull them together. This is a question about - it relates to data. And in the end I hope we will have some questions about the Global Fund, and the future. Because you're leaving and we want to benefit from the moment of having you here.

Heleen and Henk. What insights, derived from data analysis do you see as most impactful for innovative solutions in global health? You spoke to some of it, but maybe you want a little bit more. And, this now becomes more specific, what data do we need in particular to promote local sustainable supply chains? I know you're a big fan of improvements of supply chains and procurement and all those issues.

Mark Dybul: Highly complicated questions. It's very hard to pinpoint specific data. It's so different depending on the disease you're in. So let me just give generalities. The most important data you can get relates to the micro-epidemic of anything you're dealing with. Whether it's diabetes, hypertension, cancer, HIV or malaria. These are not general things. They actually happen to human beings. And human beings live in environments. Unless you understand why someone's at risk, you cannot respond. Not only why they're at risk, but what are their health seeking behaviours, or non-health seeking behaviours? What will they respond to or will they not respond to?

Again, as an example: we are missing young people. Young people are not coming to the HIV service. If you build it, they will not come. Why? What are they afraid of? Or what don't they care about? What isn't resonating? How are we not reaching them? So the most important data are around the human beings and the data in terms of what they are and are not seeking. Now, that's for delivery. You need the data for randomised - you need the data in the laboratory, to understand what you're trying to respond to. You need the data from the human body to know what there is being assaulted by whatever disease it is.

So you have to go from the basic science – I'm sorry for the lozenge, but as you can tell I haven't much of a voice left. You have to go from the basic science through to the human science. And in each case, that cascade is going to be different. Now it's not so complicated that you have to do it for each human being, but you have to do it in a coherent way. One of the great concerns, I think, around how to use data, is: people tend to pick the data in their area and ignore all the rest. I think we've got in this problem with HIV big time. So we've gone down several rabbit holes of silver bullets. You know, this is going to solve the Aids epidemic, and we move massive resources and research, and we've solved that problem and we still have the epidemic. People tend to just look at the data in their area, not see the data cascade. That doesn't mean you have to be an expert in it, you can't be an expert in it. But if you're not conscious of it, you cannot possibly respond.

Supply chain is a little bit the same way. We're actually doing in-depth analyses now of fifteen countries. And I can tell you, each one of them is in a very different place, in terms of where their supply chain has developed, and what they need right now. So if we just said: supply chains are probably going to invest in this way, we would really mess it up. You have to go: in this country, where is the supply chain, what are the big gaps and why, who are the players in the country, and how do you fix it? Without that kind of analyses you're just flying blind. And you're going to blow it.

The last thing I would say on this is: science and data, and the use of data, is as much a science as an art. You have to make judgements. And when you make judgements, you have to follow them to make sure they were ok. And then correct them if they're not. And we're not very good at that either. We tend to say: this is it, and I'm just going to do it, and no one puts their head up for ten years, and then we do an evaluation and find out we really messed it up. And we do this over and over again.

So, it's that cascade, it's that understanding of where something is along that cascade, what the response is, and then really intensively following what you do and how you intervene. Because you're making a judgement. No matter what, you are always making a judgement when you use data. To monitor it, to study it, and to course-correct rapidly.

That's a general answer, but I don't think there is any specific way to answer without falling into the trap I just mentioned.

Peter van Rooijen: Thanks. Anke. Please, there's a mike, right – Anke, raise your hand please? Anke van Dam. A question about data and the Global Fund, or what an institution can all do with data.

Anke van Dam: Hi, my name is Anke van Dam and I work for AFEW International. That is an organisation that works in Eastern Europe and Central Asia. As you know, there are some countries in that region that do not take care of their citizens. So what is the role of data in global health to convince authorities, local governments, to take care and take responsibilities for their citizens?

Mark Dybul: Data is the only way to do it. But you have to have someone who cares to be responsive to the data. I'm afraid in that region, and actually not just in that region but in a couple of others, there are leaders who functionally don't care. I mean, we've shown them all the - they have all the data. They make up their own data when we show them the data. They come back literally the next day, with a graph that's the exact opposite of the graph we showed them, [and said:] well, these are our data. So, you're beginning with an assumption that someone cares. If

someone does care about their people, then data are the only thing that's going to move policy.

But it's not just scientific data, and I think this is something that excites me about the Joep Lange Institute. You know, the reality is, and this is something I learned not easily at the beginning, is, you know, you get fifteen minutes with a head of state in general, you get half an hour with a minister. As soon as you walk out the door, there's someone else walking in for fifteen minutes or a half hour with their issue and their data. And they have pretty good data too. And there's a finite budget. So it's not just the scientific data and the impact data, it's actually the financing data and the value-for-money and return-on-investment data. And very importantly, can you do anything about it? So, you know, problems are – and this is absolutely true, they get problems every second.

What they are looking for is a solution, not a solution of: I can spend this much money, a solution of: this is what we can do in this way, and I'll report back to you in four months, and six months, and twelve months, and two years, and this is the pathway we're going to be on. And I'll tell you when we're having a problem and why. So it's not just the upfront data on: we could save this many lives, or upfront data on: look, this intervention is more impactful than that intervention. How much does it cost? What's the cost difference between those two? Can I afford it? What's my five year savings if I move in one way or the other?

You know, I used to get people at NIH upset when I was there. I actually think doing a scientific study now on an intervention, without doing cost and cost effectiveness analysis is almost useless. It's just publishing a paper. It's not going to impact policy at all.

So, that's a little bit beyond what you're asking. But you have to start with someone who cares. And if they do care, you have to present the data in a way that's going to compel them to act on what you're presenting, rather than what they're going – and literally they will have six more meetings in a day, on six other topics. So just saying: this works better than that, you should do it, isn't enough.

Peter van Rooijen: You just need to be extremely convincing, and sexy. Christine. I have two more questions, so Christine? Introduce yourself please, Christine, and - I think Mark spoke to your topic, but if so, let's see what, you know...

Christine: Yeah, I'm Christine, I'm a research master student in global health. Maybe I'll start with this question first. What role do civil society organisations play in data and global health, in your opinion?

Peter van Rooijen: Or should. Do or should, right?

Mark Dybul: I think this is one of the areas where we've lost a little bit. I mean, whether we're in San Francisco or here in Amsterdam, or in rural Uganda, the original responders were civil society. Government wasn't responding to HIV for example. It was civil society that engaged. First as advocates. But now civil society implements. And only civil society can implement. If you get to a human focus, you know, governments don't do that, you have to act - to get into the community you need civil society. You need - and the breadth of civil society. It's not just advocacy community, it's the implementing community, community-based the organisations, the faith community, the private sector. The private sector has a huge role to play in development. That was one of the key insights of the Monterrey Consensus. I think we kind of lost that. We got very medicalised, we got very government-focussed, we've lost that what started in the Aids epidemic,

and every other successful response. So without civil society we can't do anything basically. All we can do is open a clinic. You've got to have the civil society engagement. But it can't just be advocacy, it can't just be implementation. It's got to get to the core of the person. And the only person that's going to reach a person is another person. And that's basically civil society.

Peter van Rooijen: Thank you. I'm sorry, the downside of having a great speaker is that he's a great speaker. And you know, they take time, and they give excellent answers also, you know. So there are thirty questions at least unanswered. I wanted to finalise with one question, which came from Anne Dankert, you're not here, right? You are here. Are you willing to put your question forward? Come on. Because it's a question we all struggle with. It's a very Dutch question. You spoke a little bit about it. But you're coming from the United States, you're just back, so you've sort of warmed up, I think, to answer maybe this question. Do you remember your question?

Anne Dankert: No I don't. I know it was something about middle income countries.

Peter van Rooijen: No, it was about our elections.

Anne Dankert: Yeah, it was. Please remind me.

Peter van Rooijen: Ok. You know, we went through all these questions and we loved this one. Within a few months from now, there will be national elections taking place. What's your view on how to engage the right-wing populist parties in our work? And maybe: what's your experience, Mark? Thanks Anne, sorry to put you on the spot unexpectedly.

Mark Dybul: This relates a little bit to what I was talking about. There is a global movement, which is not surprising, for those of you who also read a lot of history. Whenever we have a lot of change, whenever there is insecurity, there is always populism and nationalism. Always, always, always, I'm not just talking about the last century. For the last millennia we have had these types of cycles. But we're a much more connected world than we've ever been before. It was much easier in the past to just isolate things. We're a much more connected world than we were before. And there's a lot more sophistication, there's a lot more connectivity of ideas. So I would say, particularly around development and health, you cannot have - the most persuasive people I've ever heard in development are actually commanders from the field. There's a reason Al Qaeda builds schools and provides health care. There's a good way to get people behind you.

If we're going to move forward, and if we're going to have a secure world, and if we're going to have a productive world, you need health and education. That's always been the case. You need economic growth. It's always been the case. And in the connected world we're in today, that's going to be – that is going to determine whether or not the population of this country, the population of the United States, the population of any country, has an economic future. It's not easy to make those arguments. You have to spend some time on them. To be honest, we have not been good at collecting the data to show that. But the data are there.

And we also have to engage others. When global health and development people go in to a policy maker and say: you need to do global health and development, they say: yeah, of course that's what you're telling, you're a global health and development person. When a general goes in, or when a CEO goes in, and says: I need a healthy educated population for jobs and for people who are smart enough and make enough money to buy my stuff, that starts to change things.

When we started PEPFAR, it was actually that coalition that built the support that was necessary for us to begin. Now since then, it's been highly bipartisan, and it's relatively easy to raise money. But we can't just assume people care in the way we do or see things in the way we do. It does take some reflection, and listening. You know, they're human beings. I've met a lot of politicians. The one thing I will tell you is the public perception of most of them is dead wrong. That they are human beings. They have families. They care what their kids think. They care what their families think. They care about their families. They generally care about their communities. Faith leaders care about their congregations. When you start talking about people, about congregations, about their family, about – and I've done this with [Michelle ...], watched them do it, asking very conservative heads of state in Africa: what would you do if your daughter were a lesbian? How would you respond to that?

Make it personal. And then link it to a global personal narrative. And you can get pretty far. But we have to think differently, talk differently. We talk to ourselves, right. So we expect everyone to listen to what we say, but we have to learn how to listen too. I can tell you from having done it, and seeing people change, there is a very different response when you talk differently.

And the last thing I would say is take them to another environment. Take them to an environment where services are being provided and lives are being transformed. I've never seen someone come back, the most conservative, fiscally conservative, I've never seen one of them come back and not say: we should be doing something about this.

Peter van Rooijen: Thank you, Mark. There are drinks waiting outside. And we've come to the end of what I thought was a great lecture. Thank you so much. And a great exchange. I think we're very privileged to have you as part of our collective effort, and build a global effort. Which I think is a nice summary of all the stuff we discussed. This is our thank you. You know, we're modest as the Joep Lange Institute, right? I thank you for this effort, and, ladies and gentlemen, your applause please for [...]. Thank you.