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Density, Taiwan the role so I also help them Israel health and welfare and Tobin to give some advice on the theory also. So today I'm going to talk about the documents found about accent versus United States. So here you can see roughly around the same time the elbows establish, or this had been discussed to establish in 2004. Actually, we discussed the simple idea in Taiwan. We try to establish a nation of Bell Bell, or we've got population base, a circle called static cocoa. So the government took about July time. It was 20 years ago, is we discuss under the project code about medical technology. I share with the recruitment of the Taliban the targets of two countries size and half the population in Taiwan. So we discuss this idea. The first model we tried to various on the UK, but later we tried to develop a new governance model is actually a little bit different funds in the UK. And we're talking about the per value set. They want to put that on hold the combination of talents. So the first question comes out how do we define what these are? And people understand that I lose people from talent I actually shared genetic overview screen with mallinder on China. So in my time, we try to distinguish four different assets the goods a cop car hobo and Chevy's mandolin they're actually probably share the same genetic orangey only talents operation buco now is 2% of the whole population, Taiwan, they probably are quite unique participant for the Taiwan balls. But that also comes down to some serious discussion about the possible stigmatization because the scoop is far as smoke so tell us about that was operated by the Institute of Biomedical Science. In Sydney calm, we tried to develop with the three different phases The first phase we call the pilot study, which is trying to pass the fire smoke group to see how the sob can be established. Then later we is had the skill to the feasibility study, all the way until 2012, the godfather of spatial information, health and welfare for 10 years including the project to support the project. So actually, the sample collection delay a little bit due to the coffee. So we finally finalized Oh, the central production system last year as to Samsung IP 321. And now we're moving to the to analyze the data and try to do some proper pitch. Because it's just too much so we only try to do self promotional sequency for part of the development data. So as you can see, you guys have actually we establish poverty around the country to 30 different sites for our sample collection. And some several collection sites are located at the eastern part of Taiwan, where the tellers Aboriginal people come from, so later because there are some disputes about this particular group. So the first few centers are looking at the east side how to stop the coast at the very beginning of the central connection, and the east side to the west side of the Taiwan is almost all important hospital inquire into central collection. Analysis How about when the physical storage has been moving to mentality so so you can hide pay? ASAP our technology search bar with the SMS city so we have a huge stores collection for two floors for the retailer. And the Vantage work for the government to think of that we need about the tower especially A nation without that there are two reasons one is that they said we probably have relatively homogeneous population. So if we can use this data to predict something and the potential impact, not only this not only the need to try but we can use this data to to to help the COVID champion Chinese nomination around the world. The other sectors so quite important is that the title what we have is a national health insurance system and the coverage rates more than 198 to 99. So I do want to join is the nation health insurance system allows the reason we have this issue is big data, especially talking about the image stream house or the electronic house record. So in the future, we can link this data it will make the phone call by prefer powerful and resourceful and this is the data stored in retirement. There are two important things to important data is one is about the questionnaire data, because it takes about 40 to 60 minutes for participant to answer all your questions is actually a very very large sophisticated data power that is mostly rely on the self report questionnaire data so the question is a consumer reach. Another interesting data is about the genetic profile. We are still trying to give keynotes they couldn't see this. They had to make the resource for the future based on the concept we can link research NASA data with the National Health Insurance database as well. And now the people in telephony, we try to develop a website because it's how we do so it's just a lifestyle for people to understand what kind of data how many details we have in development. So it hasn't been quoted for us and things have before they briefly survey the formal application to tweet about that. So interesting. Is that possible? How can we say about Instagram more? I can make this about as the be more transparent and honest and responsible. So just back to two years ago. Establish a specific law particular government to allow them I don't know of any jurisdiction use this specific law in order to rapidly allow them for example of some jurisdiction for example in the UK versus rely on the PCT application for and also the humidity should have been terrible and we have this specific angle. And the most interesting is that the specific damage the more you try to get the declination, the weaker the bow bags and also the collection and how we banish them about our course that I have to go off these requirements are exactly requires everything. Not only based on information about the older PC space now that operating in the hospital as well to save our IBM documents concert. So later this afternoon on governance council place of law about this issue review. An interesting is that this specific law actually comes before the general personal data protection law. So the older guys very interesting and just waiting with that two years because of the style and the shape if so the government started to eat and not only allow that mention of APA OSA Kuma centerstage and major personal income protection. And as we've sat alone we try to learn from in the UK now in Scotland, the smaller the Osage Nation The new model is because DuraTrac often is smarter. Let me every application to apply as opposed to access the data from the Taliban. They need to go to Google why is that they need to get to their audience to choose our disapproval. In addition to that, we also need to get the EGC that I've been in governance consists of Google, so probably inside sometimes it takes a bit longer. It takes probably four months to six months. If those muesli also at the governance council, the role here place is more than this, there's some concrete cofrac So people say the UK valgus etc is like a critical fan of UK valve and so immortalize places. All at the advisory committee. But you tell why try but you can see they do have a routine power. So they can say

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sometimes they they just just because of some reasons for example, they build a one samples to be sent outside of country or something they can say you're allowed to say they also about a unique struggle is about the concept. So remember, we talk about operational people in Taiwan. So for in particular for this group of here is just short under the About the time this Aboriginal group actually tells us that we're returning just an umbrella term, so they also have their individual group. So for this particular group they need to have this group consent. So we've been discuss for a long time, how do we implement this group consent who can really stand in Congress have retreat group, at least on the one hand, what is either the research protocol that this particular column is telling us operation or we collect sample on this operational area, we need to gather consent in addition to individual consent, and not only talking about the collection of data, even before the research result is published. We also need to get consent the group consent from the some terms of ratio. So now only implementing majors has a enacted quite clearly, it will say so 2016 How can we do so concerned and especially between houses commercial benefi and what kinds of houses we need to put inside to the consent form? So in addition to that, tell us about that after 2019 the governing tower also try to initiate another kind of fall as a working it's just like we have it's just like to try to establish a single single service or a single service provider. So I went stylized, we can make odors entirely easy to share altogether, and also to standardize the SOP. So we establishes the label of coalitional biobank on social timeline. The consortium is virtual biobank. So this In the meanwhile, we try to find a real place to collect all the data, all the data ties together or for the center together. We try to use the common data model to make data to be shared. It's a virtual number. And nowadays we have 63, a hospital disease space now back to our population base, including Taiwan. So again, with the governance framework, so sequential stay Leppings the consumption itself he has the sole central MPO Governor's Council and local for example, the every hospital based on the Beltline mansion, and they also have their etc. So the challenges still allow the efficiency of the review and usually promote a little bit so it takes about six months or so or longer. And as we can see the application process has to there has social without antisocial the consortium case and more to to allocate resources, for example, while case it requires lots and lots of data, and it's a big data, a particular hospital that is paid based on the consortium to decide which hospital to allocate what kind of data how much data they're going to share. And after this decision has been made, this decision will be sent to the central GC of the consortium to pay for accommodation whether it's okay or not. Now we've said the whole package pays to back to the hospital has been allocated and based on these hospitals and the governance council GC to reveal whether it's possible to send a sample or data out. So nowadays we have been discussed how to improve the circle review process to close if researchers know it takes too long they just don't want to use this data. So in the recent our management and revision that we discussed last year, it hasn't really been finalized. We try to make the new possibly simpler to make the central AGC can play your role as a major reviewer. So here it just shows how this common common data model has been established and how this circle of trust was the century in our lives as we establish we think the consumption of the car consumption about following and roughly around the same time to salsa 19 Tao while we initiate another very important macho ricotta Taylor precision imcd che T is somewhat different from the other is more like the US operating the United States is originally we want to target anyone in the town's population and actually recruiting new participants. So we viscerally rely on the relevant data because we decide that based on the research design, you just want to include a new participant about what to do with the based on the budget restriction, and how this year we already stopped the recruitment and now we reach 53,000. Everything doesn't have population is one. So the total precision vaccine initiative, the purpose is to try to establish the polygenic risk score for the CC 10 one and also try to to set up the hospital clinical timeline about how to use this parents school. So different different phones, the telephone lines, or the TPM Bipasha. We've probably three channels. They're also post some discussions in Taiwan. So we can see that because the purpose for the cell PPMI is that we try to use the scientific evidence and to make the base happy in between companies. So now we've been finalized the recruiter were moving to the second phase about the validation of the price. Here shows this table shows us the difference between the TPM y and the talent now that both of the project have been operated by fmsc comp, and GVR ally also collaborate with 16 has because you have a major big brain so tell us about the some of the thoughts and some of the TPM is based on the specific concepts. So that's also been criticized quite happily recently, because we can talk about specific concern with the Intel at China securities have been have been corrected. And the goal is for at least two projects are so very different. So for telehealth, I don't have a specific goal. Now that gonna go to PMI and we survey somebody who was such a researcher. And just recently, the doctor took about two weeks. Imagine that the father back in Taiwan it would be cool if you can identify. So because of this particular project, we have tried to read the five other repos out there. So now he's not only talking about the central mass data, the peer database in south central can also be regardless of now then on the validation errors so the TPM like always to recalibrate itself for based on the consent form, we already say there's no more return you'll yourself. Follow this established probably about five years ago. So the profile thinks about whether we need to repeat the sign Did you consent form sample your way through to participate in as many stakeholders? So TJ, I, by the way, have the Calvary salary set, we're still trying to develop ATP. So everyone they can not only save up currency to know themselves. And because it's just a research set, we don't want the participant to have a misunderstanding. To trigger TPM is that Gnosis with clinical evidence? Show we only use the Kathy line to show the possible routes. So we still have a specification for them to understand that if the senior employees they rely on your mobile app, they have to go back to the doctor so you need to double check so the challenge of our telephony stuff.

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So where can we draw your line between the research and clinical application is actually not very easy, especially for these research projects because we have some really finalize their validation theories. So we have to save here your model for the width of the prediction model. Also, because in parallel, we have already established the genetic counseling system. Now we presumably have additional examination for the search method constantly to be certified. So both of the implications rely on a family or a friend with motivation. They play a role. So how can we do a responsible return especially for kind of genomic research for itself should we return for how to return? We did researchers may be to provide updated information all the time in the future they have we find these all these discussions have been going on, along with the TPM project. So I think the secret of our project is a little bit challenging because we decided to be set up everything clearly at the very beginning. So we just tried to start to make things to be precise about we have room to discuss and he also has some public concern, to be honest. So another major issue about the Precision Medicine precision house nowadays in Taiwan. This goes back to how do we allow secure use of national health insurance data? We kind of lost the Showhouse foundation of nation house insurance data with the bankers original purpose for collecting data is for house reimbursement. So if we want to use this rich data, to risk to research actually, we need to find another legal basis for further processing of data. So each one of these three major laws involving opposition and circumcision house of God and most of the case the research project based on the tumor software research, there are some explosive the case actually the sample be collected with this specific concern. So that makes us different use of they have the characteristics and sometimes we goes back to the inception for the person become a patient for example, we have done the research in the UK for the Center for US East action in Taiwan, because at that reception, so as some research was increased autonomy or second section, actually we can based on the Personal Data Protection Act and see whether we use a spreadsheet, which is corporate analysis of data. So time actually practicing. Why is that? Because the nation has insurance database, because everybody requires a big concern. Because the data just overlaps with the outermost into the central interface for the reverse multi purpose. They start with their problem now that we put that database on the consent model. So most of the cases that if we want to use the same time for second use we just space on the so called the identification so it isn't really have often said we also doesn't really have the option opportunity. So based on that we have the potential cost which is the interest. So many challenges talking about because we recently had a fierce outline about the big are how can we treat as they have the identifier? anonymize. So people start talking about all we rely on we rely on the data the patient is probably not enough. Because data security, same problems and privacy protection. So just recently, about two years ago, we have a quiet important constitutional court decision. And based on my decision, actually, Mensa is our priority on this decision. As simple as that decision, saying only based on the Personal Data Protection Act and Section, especially SME sectors now and he says is described. So we need to have a specific more particular focus on securing use of house data and we know we need to allow ourselves to have this relates to so is the constitutional court case about three years time to allow the government to opt into it as a news specific role or to revise the personal data protection rule. And now the government tries to the the faster you roll the code the secondary use of house data, and knowing has been discussed that has already been finalized within this is just the average. So in order to think about the possible consequences about the alcohol, especially for the Taiwan and showing the visa studies. We also try to learn if that's the case and one of the five maturity models in the UK itself. And how can we improve the transparency and other models? So this is a paper by Hassan I published a few years ago, and in this paper we tried to establish a new possibility especially consider just a different kind of of ages and what kind of anonymization we use for data so that we can decide whether we allow for all or we rely on the AVI model. So for example, if you were to send a survey and so we use this house, a concrete to do the survey, and we tried to try to say about that questionnaire to distinguish academic research and commercial research and participating as a customer we sell and we get to ensure people are able to offer additional health insurance database and we can see actually equalize my say, well the whole way essentially are quite reasonable but we ourselves don't worry about that because it is clear to the UK. The UK already is now or to 5% and what is likely followed with commercial use or we have severally communicate quite clearly our country about the updated value for insurance database that will always be bipartite. And there's also trade off between the process and because you have to and we don't want to stay this a couple months database as a consequence of this is also where some stuff is shows that in probably increase the quality to house care, especially for our particular group. They're the kind of spy stuff has now school may be easier to choose to allow conversation house issues database. So I think the conclusion is that it's always talking about what how can we establish a circle to draw this model for each and every restriction and talking about the documents from walk? We need to balance between individuals all the way I also 30 confused and now I'm telling is that we're trying to move a little bit especially based on this country for the organization. We move a little bit from the so called accommodation all the teams at least we focus only on the data potential with the identification itself. And to the extent that he's more focused on the controlling autonomy, but that's that base that how can we move from consent to accountability? So I think that requires more engagement we increase public trust especially the transparency and responsibility for these problems. So thank you so much, and I look forward to your question

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all the time for one quick question. Fantastic. Talk because so many interested in joining the ministry great to see how five honestly thought of this question, as it was setting up the Bible thing. I was fascinated by the points around the return of results. Then I wanted to learn a little bit more about the strategy that we are using for personalized medicine. More recent research, you were saying that we were returning the result and that it was accompanied by political and I was curious, first of all, is there any person that is involved or it's simply returned through

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an online sort of tool

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that people can access? If that's the case, I did just quite interesting because that reminds me a bit of what direct to consumer genetic testing sometimes will do to to communicate results. And I was quite curious about how this was received by the population to get any feedback or whether you like it, then the point is the convenient way of moving forward. Thank

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you so much. It's fantastic question as you were trying to establish a VP that it hasn't really been established comprehensively. So now the returning oversell stuff was back to to printing we will only retail resell to factories that make that purchase to our retail results with patients. So also now, most people talk about this a PP where they really feel good way or not if we used to save up we sell either question. I don't know. So we probably post some brochures there. But I think we spelled it out updated. Yeah, it's just that all we need more consideration weighted which How can you tell yourself to be more responsible way when we use them when our chapters so we just make everyone try to ask this isn't really what they think it is that we allow patients to assess their well being. It just can see the light but they you give a very good as hobbyists that