Tokyo Symposium on Genomic Med...icine, Therapeutics and Health

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My two labs here. This is Department of Public Policy and it was established in 2007. And my lab is located to the rules where Professor Matt, you sitting there for a reason, right. And I am the new Commonwealth. And we are doing as many kinds of ethical and legal and social implications research and using quantitative research methods and also qualitative research myself. And actually, my background is medical sociology. So, I'm really interested in patient engagement and public improvement issue. And this is a new lab, established last year in weekend, it's called level 2446. and participate in we are now establishing the new rules in weekend. And in of course, we are doing the kind of research of other Biomedical Ethics as well. But also, we have to give some ethical presentation to the researchers. So we can researchers wondering how to get the nice informed consent form. So they are facing the new challenges about the ethical issues, we are open to them, we want to be open to them and discuss, frankly, together. So the two labs progress with various research projects, including viva, Japan, and also jpsc ad, this is a cohort study of dementia, and also a cancer study or Japan environment and children study. This is one of the biggest first cohort study in the world. And also, I have been actually integral advisor against the COVID-19 measures of the Japanese government. So that's why I can move in the vaccine development. So I want to problem with a notice here and institutes of castle here with regard to issues too. And also, basic interests is regarding the patient engagement involved in the decision making process of the research. So I want to introduce some examples or research results. And also, I'd like to add some comments regarding the national new projects, or for whole genome sequencing and conduct quantitative study in Public Housing Survey annually since 2005. And we have always used that same questionnaires to the to understand their attitude perception or risk abilities, genetic research, and here is one of the results. Companies are not the results of the 2017. And the latest one that was finished last month. And you can see that many, many respondents almost 60 or 65% of the respondents, that's a good color, they are very interested in the personalized treatment is agenda acknowledge is in beneficial and understanding towards more provincial results is beneficial. And they will be collaborative to doing advancing science through the new data collection and research is beneficial. And also, the right side says that genic screening during pregnancy as in early disease detection is beneficial to further these are the companies are noted between the seven years but the trend is not dramatically changes. So usually, during their most many years Japanese public 60% or two or Japanese public supportive to the clinical research. That however, great power shows that 70 or 25% of the respondents show whether they're positive or negative attitudes. And these are the results of the negative or risk attitude to solve generic research regarding the discrimination or disadvantages or other things. And when the Emperor shows that concerns about disadvantages in marriage consultancy, or employment insurance, and I don't know Why the percentage is decreasing during the seven years, but nothing has happened during this phase. And so then you really have to look at the gray zone that almost 50 or 45% of respondents didn't show that they cannot understand data risks or benefits or something. So that we have to do some more comprehensive public engagement regarding the genetic research. And then I'm going to introduce the actual plan for a whole genome analysis called AP WGA, led by the Ministry of Health, Labor and Welfare, and that this plan was launched in 2013. And it just before the split of COVID-19. So nobody knows that this had started at the time, but action plans for cancer and infectious diseases were formulated. And then the new committee and roadmap was made in a year or 220 21. And then, two years ago, the actual plan was revised. And maybe in two or three years, is something that the government will suddenly establish the legal entity to manage the data sharing of four game genome sequencing data. And the key color shows that government's plan about legal entity, and they release. This legal entity is similar to the genomics England. And so they often visit to singular data a lot, their experiences. And this management organization has a board, the board, and also Advisory Committee, and they manage their analysis or data center or for genome sequencing for the cancer or rare disease patients. Then up to now, they have already collected samples and data from the patients and I mean, total 25,300. And in almost, I believe that most of the persons from these samples opt out, have opted out for the use of software and data. And since last year, they started to use a new equal present form. And so these consent forms include both academic and commercial use. And then maybe two years or three years after now, they want to move to E consent forms. And so participants can select which data to use for what purposes but we don't have a plan in our detailed plan, what kind of this law what kind of thing is possible. And the ministry decided that LC and PPI PTM is a patient of a movement to be positioned in this action plan. For the first two decades, to recently, the Japanese government's interest in ethical, legal and social integration has been opportunity opportunistic, and these occasional research projects and challenges. It's also today's approach now requiring an explanation from scratch or being forgotten for being wired. The act of personal information protection has been recently amended. So that's why the government only understand that LLC is a personal protection, personal information protection. But we want to explore more more perspectives regarding ethical and legal issues. So I personally worked out that the government decided that this legal entity has a division of LLC and Division of Patient public involvement. And

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for the participants who don't know about the patient and public involvement in research, this is a definition research that is done. We saw by the pulpit close to about four for them. And maybe more than is also different performance engagement, which is when information and knowledge about research is shared with the public, but that if you finish on the wages, and the reason Canadian definitions are a little bit different, they say, PPI is meaningful and active cooperation in governance from the sitting conducting research. gentleness translation, depending on the context, patient oriented research may also encourage people who prefer to bring their collective voice over specific affected communities. And so, now Japanese government is thinking about their research patient about the pain patient have a format right now. And I want to introduce some examples of genomics England. How do they do about the process about the involvement? Genomics England has the participant to follow in 23 participants contributes to this pattern. And they meet four times a year to extend views and how data is being handled. And also, are they some they sit on the committees and boards such as access review committee or is it of advisory committee. And also, all of us first frankfurters a very famous that 43 participants contributes to the these committees, including the steering committee, executive committee and advisory panel and principal advisors. And they were recruited from the information side. And these individual help support the program's design implementation, the programs including the FBI serving our communities. And I heard that the UK Biobank last year, they started to recruit members of the participants advisory group. According to the website, according to the website, can you get back when participants from across the UK of different ages, genders and ethnicities have been enrolled, and when they will come up, welcomes applications from participants who have led a lot of interaction with them over the years, and those who have had very little as well. And they don't ask any request, any experience of committee membership or public involvement research is necessary. And they present themselves will be paid some money for a three hour meeting, and also in each of the population posts will be covered. And I heard application was opened up the last year in September. But I don't know the final results. So if if anyone out from the UK marathon faces, we'll have the results. In the VA, the Japanese AAP WGA LCPA team is planning to recruit the patient's participants from the cancer or with these realities. And this is a very important agenda. And we are thinking that the participants of the AP WGA, or their relatives from across Japan have different ages, genders and ethnicities can apply starts at a different point is we include the relatives or family members as well, because most of the research participants of this whole genome sequencing project have very severe disease. And so at this moment over a sample set of participants have already passed away. So that's why we want to include their relatives as well. And we fought, we don't request any committee membership or public involvement in research. And also we will pay some money from them and also any cost we interest, but just be a fine. So we have to we have to present the session to open the recruitment. Then, two months ago, the this action plan has had a first open forum, the workshop in Tokyo. We had a one hour lecture about the genome sequencing action plan and voting for pre registered participants available but we are not sure how many participants are really there to see it online. And immediate poll survey showed that 64% Only to support the project and statistics going to support but also had concerns and less than 1% per person and couldn't support this project. So so many so many audience very supportive. So it's really valuable to the patients and family members and citizens. And I I remember some of the comments in the survey, immediate survey that one respondent said that he or she understood the difference between whole genome analysis and cancer gene testing and the usefulness and another option but it was a variable opportunity because Ideas have the chance to learn about the thoughts and future prospects of the pharmaceutical companies regarding genome data using. And last one, he was she said that many local medical professionals and supporters don't understand voting with sequencing. And even if they are interested, they don't have anyone here by to ask questions or seeks advice. So many people are living in the city, big city, like Tokyo and Osaka are really similar

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situation that some people don't don't know anyone who knows much about forging or sequencing.

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And we have also a three year invitation only workshop after that. The title is benefits and concerns of the process of transplant. And we invited 27 members from patients that don't see eye to eye posts for cancer and rare diseases. And they discuss for two hours and finally show their diverse opinions regarding benefits. So they have a including PowerPoint, that these persons with fire can provide guidance in an easy to understand manner for patients, or these panel can suggest centers where education opportunities that meet the needs and understanding of patients and families. So this is a secret that researchers want to educate them what they want to keep. But patients want to understand in the easier way. So maybe the participants of Fido will be helpful. And another opinion said that the participants can and can communicate about the importance of the fourth of May the research results in a more accessible way to the public. And the final one is amazing. But he was she said that the public can collaborate with international participants panels, for example. So genomics England, so that's a wonderful opinion, I thought about concerns, panel members may be concerned that their opinions may not be useful, or that they are not knowledgeable enough. So these are common concerns that they involve. And also for the members who are fighting recovering from a disease be uncertain about whether an environment can be created in which they can openly express their opinions to professionals. So we need to think about the cycles for a safe and viable environment. And one comment that I remember, he was really serious about whether people can really apply these positions, given the social influence of the world, the humidity, and the daily suffering of patients and family members due to the lack of understanding the prejudice of society and politics. So a few members, few participants of that workshop said that the participant of Human Genome Research Project means that I have some negative genetic chair to the point or feature in it. So maybe, if I if I join your partner, and many, many people know that the name of the panel members, and that will be because of prejudice or discriminatory movements towards patients who are relatives. But I want to introduce a new law in Japan that's for the promotion of genomic medicine, and 2023. And the act, we requested signatures from over 250 patients disabilities, academic pharmaceuticals and portion rotation and lobby all political parties in Japan two years ago, and which resulted in the enactment of this Act last year. And this Act requires the government to draw up a basic plan and implement policies to promote and make medicine as well as this force against gender discrimination, environmental issues such as genome editing, in the first basic plan will be drafted based on this act will come out during this year. I thought I think so this is almost a final slide and I think two there are two challenges in the actual talent for genome sequencing in Japan. First of all, phonemic versus commercial. I think there is a clear distinctions in the data protection rules between the exemption for academic and public health use and exemption. An exemption for the industry of use And there is no exemption for industrial use. And so if people are able to use a stored samples or data for all, not only for an industrial use, they have to report that donors and get another function from them. So this is looseness of the Personal Protection Act. And is this dichotomy effective to degenerative data ecosystem and genomic medicine, and wondering how the industry needs to improve efforts and communication to gain the trust of patients and the public. And then you you or the industry have to get the power to change the law. Because it's quite difficult to get to it, it's quite difficult to first facilitate the genomic medicine without a opting out system. I think that's a different one in the patients from enrollment, genomic research, I think not me, Japanese researchers or not only Japanese researchers, I'm not sure what they are not aware of the importance and value of epi. And some researchers, we experience, patient and public involvement as a part of their research project. They are really happy because they find they can find the public perspectives of patient perspectives, and then change the research plan for protocols. And so I want to introduce this system into the portal or symptom symposium. And I think it's important to overcome the stigma together. And because people who are willing to contribute and create a safe environment to discuss these professionals and establish a successful example of how to get people to become partners. And the ecosystem I have envisioned here is not larger as a documentary footage social media has pointed out, but under Japanese law, those Academy Regino databases and also DTC testing companies are formulated to cooperate to a certain extent by voice power. And in addition, Japanese law treats genetic sequencing synchronous data itself as personal information, as it's socially accepted, so not scientific, but they say, the law says socially accepted. So this may be based on the fact that the multiple databases are close in the future, and it will be possible to identify individuals, but I'm up against the position of the Japanese Euro European Personal Information Protection System. Anyway, now we want to discuss this all the scientists to cooperate with a new future of medicine. So thank you very much.

23:07

Two questions.

23:16

Thank you for doing that. My name is David Cameron from famous American, I sort of said that there was. So within this seven years, the public domain has hasn't changed much. And I can understand that because I never talk about it because my friends have research community, and they don't even know what machine dnn is. So I think it's important for us to involve the interest in public about the research itself in general, not just particular data sharing, but how how can we do that I interest.

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Thank you very much for your question.

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We have we have to do everything from now, globally aggregation to elementary school students will also is quite important to improve the older population. So, we will help you if you want to talk with at the time to be perfect or conform with the public. And so please let us know. And these are small activities mean very important in Japanese society. So not easy. We have to watch

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the question is gets back to your new GDPR agenda. As you mentioned, Oh is probably two three, I think Japan is the first country they shall be recognized as the sea view, which is one of the reasons we did this awesome visitor's center reception or discuss the center reception for the personal protection was huge to assess the situation now. Quick question, Should

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I even have enough knowledge to cover the recent situation, but, definitely saw the condition of the personal information predictions have now been invited to scientists by law and this law is general as you know, so, the scientists and the researchers community trying to set up the news special role to leave from the personal protection role. But I think that that kind of movement is happening in Europe because no one knows. So it is quite difficult to harmonize with general no personal information protection when you when we go to promote those results.

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Thank you Dr. Mountain for it. So the presentation