

**ASM'S PRECISION MEDICINE INITIATIVE FOR
MALAYSIA
PUBLIC ENGAGEMENT WORKSHOP**

IS PRECISION MEDICINE OUR FUTURE?

WELCOME SPEECH

[TRANSCRIPT]

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**MALAYSIAN SPACE AGENCY (MYSA)
13 JALAN TUN ISMAIL KL 50480**

[SALUTATIONS]

1. Thank you so much for being here this morning. My apologies for being late because in my diary it says 9.30am, but that's okay. I still had the time to listen to Dr Fazilah. And I think I've listened to her twice now so far, once during iConnect™, and one here this morning. And whatever she has to say is very much in line in what we want to do and what we want to discuss.
2. This is the **Academy of Sciences Malaysia's Precision Medicine Initiative for Malaysia: Public Engagement Workshop**. So that's why we have invited all of you here - to help us put up a position paper on precision medicine and how we are going to go about it in the country.
3. It is a pleasure to have all of you in the audience today. We have almost 100 participants this morning. On behalf of ASM, I would like to express our gratitude to each one of you for making your time out of your busy schedule to attend this morning.
4. Now, as Dr. Fazilah had mentioned, previous medical approaches were usually based on policy of "one size fits all" – applying the same treatment to those with same disease. But with the advance of genetic data, with the advance of -omics: genomics, proteomics, metabolomics – we can now classify individuals into sub-populations that differ in their susceptibility to a particular disease, or even their response to a specific treatment.

5. [So] the genetic data obtained will reveal many new and revolutionary insights that are hidden in the human genetic code, and that is a lot more work among the researchers that need to be done. [And] we can now do genetic testing. Whether we like it or not, those who can afford – I know about the 3As – but those who can afford, they will go out there. If you don't have it in Malaysia, they will go out there somewhere and get this thing done.
6. Basically, genetic testing, now especially in overseas, even in Singapore who has already started the precision medicine initiative, is done quicker and it is now cheaper. Once that happens, the opportunity to collect larger volume of data from more diverse patient group now gets to be an opportunity that will now happen.
7. By **combining** the genetic data with clinical, pharmaceutical and socio-economic information, we can now analyse the integrated data and actually observe patterns in the effectiveness of a particular treatment and identify the genetic variation that may be correlated with the success or failure of the treatment.
8. [So] basically now – the difference before was the doctor will be looking at age, gender, physical – all these other paradigms, but now we are looking at the genetic data of the patient. At this juncture, this is where, even myself, get confused between the terminologies of personalised medicine that is now used interchangeably with precision medicine.

9. Today we are talking about precision medicine. And personalised medicine, however, can create an impression that completely individualised treatments are available for every unique patient, which is not the case. [So] this is now a different approach, so we put our mind together now, and concentrate on precision medicine which is basically an emerging approach for disease treatment and prevention that considers the individual variability in genes, environment and lifestyle for each person. Putting it simply, it is about **giving the right treatment at the right time**.
10. One of the first big initiatives for precision medicine came from the UK with the launch of the 100,000 Genomes Project in 2012 and this then was followed by the Precision Medicine Initiative in USA by the past president, Obama, in 2015. And he mentioned that with the launching of the Precision Medicine Initiative in US, we will now have medicine that deliver the right treatment at the right time. So, that was in 2015, and if you were reading the article, it says that by 2015 onwards, they now use the word precision medicine, personalised medicine is now passé. Within the past few years, many of the developed nations have also embarked now on precision medicine.
11. Are we ready? That is the question, and that is the engagement that we want to have after the panellists [session]. Are Malaysians ready to ride on this wave of precision medicine into our healthcare research and initiative?

12. **Ethics**, I think is a very big problem, because once you have this genetic data, this information now – are we ready with the privacy disclosure and the ethical issues that come in with this privacy disclosure? How sure are we that even if we are doing genetic testing with iPROMISE – I see UiTM iPROMISE here – how do they promise? How do you promise that the data is secured, that you will not now sell the data? Because now you have the genetic information of the individuals, there are a lot of things that can be done with the information – sometimes very good and sometimes very bad. I just finished an ethics conference in USM for FERCAP – and this is a big agenda.
13. With the coming of precision medicine – genetic data – how do we ensure the security of that data? And of course, ethical issues need to be discussed. But as you know, Prof. Dato' Aishah, ethics and policies cannot catch up with the disruptive technology that is going to happen in the future. So, we hope that you are still around after the panel discussion – after lunch – to be continuing the discussion and engagement on this particular topic.
14. So, we have today listened already to **Dr Fazilah Shaik Allaudin**, Senior Deputy Director from the Planning Division, Ministry of Health Malaysia.
15. In our panel, we will hear our panellists share their expertise from the angles of health economics, medical law and the setting up of specialised laboratories plus the requirements for lab accreditation and hopefully touch also on ethic. We

will also hear the experiences and challenges from the view point of an oncologist and a patient.

16. In October 2017, ASM launched its Science & Technology Foresight Malaysia 2050 Report. This flagship study reports the big picture of the future that we desire for Malaysia. 95 emerging technologies mapped on a time horizon had been identified – among them are biomarkers for diseases, gene editing, nano-based drug delivery system and regenerative medicine – all of these are components of precision medicine.
17. Realising the need to **understand the current landscape and challenges** in Malaysia, as well as the **feasibility to mainstream precision medicine** in revolutionising the present healthcare delivery system – by the end of year 2017, the ASM Council decided to embark on a study to address the objectives. A task force called the **Precision Medicine Initiative for Malaysia** led by Professor Datuk Dr A. Rahman A. Jamal., was formed. Nobody until today understand what that A means for A Rahman and A Jamal. I have been friends with him for a long time, still until today he has not told us what the A part is. *(audience laughter)*
18. Professor Rahman, I think, is no stranger in this field both locally and internationally. And of course, Dr Fazilah, being the student of Prof Jamal has already shown what Prof Jamal can do on this aspect. As an esteemed researcher, he pioneered personalised and precision medicine in UKM's Medical Molecular Biology Institute (UMBI). The Former Founding Director of UMBI is also the Principal Investigator

of The Malaysian Cohort study and the custodian of the largest Biobank in the country. So there you are, this is the man whom we already elected him to take charge of this particular aspect.

19. [So] this Workshop will be organised in a **two-pronged** approach.
20. The Task Force is in the process of drafting basically, a **position paper** that will be presented to the Ministry of Health. So Dr. Fazilah, this is something that we hope to be engaging with you. In order to **represent the voices of all the relevant stakeholders** – so if you want to start Precision Medicine, you want to have the position of the various stakeholders, that means the practitioners, patients, researchers, service providers, policy makers, and of course, from the public – [you want to know] what does it (precision medicine) mean – and that's why all of you have been invited today.
21. This is basically your opportunity to **provide sound insights** and be the co-architects with ASM in completing the position paper. That's why just before the researchers getting together, we have a taskforce under Prof A Rahman A Jamal, but you know, we have to have [an] engagement. With any of the papers initiated by ASM, it is very important that we undergo the engagements specially with the quadruple helix – it's now quintuple helix.
22. Anyway, we also hope to **validate** our views and raise **awareness** of such an initiative through this particular

engagement. There is a high possibility that in a not so distant future precision medicine will create a healthcare system which focuses on wellness as opposed to the present system which has to concentrate in sick care. You are looking at potentially saving a whole lot of healthcare cost, if it can be done, and if we have the sufficient number of bioinformatics and all the skilled people that we need, [including] data scientists who can now do a lot of the analytics that need to be done.

23. We have come a long way since the first human genome was sequenced in 2001.
24. With advancement in technology, we are now seeing rapid acceleration in making this process affordable and efficient. Whether that is going to happen in Malaysia, I think Rahman had already put up a paper to say that we need the kind of labs that need to be there, but whether the test is affordable, accessible, available, that is something that we need to challenge with labs that can do this, like iPROMISE, to promise making it cheaper in a long run.
25. I have mentioned earlier the initiatives in the UK and USA. Our closest neighbour Singapore has also implemented a national Precision Medicine Initiative. We have not announced right, Dr. Fazilah? We just have the digital reformation – electronic medical record is already being announced by the Ministry of Health. Whether you like it or not, you have to discuss about the fact that the data [security]. That means you go to MoH, whatever that has been done is now on the EMR. That is data.

26. How do we now secure the privacy of data now if you ever go to Ministry of Health hospitals? At this particular juncture, university hospitals have not yet said 'yes' to join the initiative. So, university hospital is different, and Ministry of Health is different. Electrical medical record [actually] is done within each university hospital, kept within that hospital. We also have not yet formed a consortium among the university hospitals. But essentially – where is all this heading? I think all of us are worried about privacy of the data and how do we now ensure security of our personal data? So that is something we need to address.
27. Both researchers and patients around the world are already benefiting from genome sequencing – some patients have been receiving improved diagnosis and treatment while researchers are discovering more and more about the genetic variations that cause diseases. But whether you do this, because now we have another problem, usually this is in consultation with the doctors or with the genetic counsellors that you do this genetic testing. But now with the availability of this by companies – that can afford – people are directly going without any advice, any counselling, and then find out later what is wrong with you, and how are you going to cope with that? Of course, the problem with insurance, now that they know that you are going to suffer from X, or Y or Z, why would they now cover you? So there are a lot of things that you actually need to discuss this afternoon.
28. As the field of precision medicine grows, significant impact has been seen in areas of oncology as Dr. Fazilah has mentioned, and in several rare diseases. However, the

journey is at its infancy. The scientific community is just beginning to understand the manifestation of diseases at the molecular level. There are more discoveries waiting to happen.

29. No doubt that the genomic revolution has paved the way for the practice of medicine to be personalised, predictive, preventive and participatory. But precision medicine is also not all about the genes. Because all of us are also wearing wearables, how many of you have this iWatch? If not iWatch, Tag Heuer, Fossil, Micheal Khor has also come out with all these wearables. I think Dr, Fazilah also mentioned that we are going to wellness paradigm. Therefore, now when you wear this iWatch – you know this iWatch tells you ‘get up, you are sitting too long’, it tells you on the phone. And all the activities of the week are now displayed to you, but tomorrow it goes into a receptacle that is probably organised by a company and this company will now be analysing this precisely for you – because each one of us have a different way different lifestyle, so it is not a one size fits all. So that is how now Asma manages her health. This is where you pay the company.
30. But to do this, the company and the algorithm is reading you. So basically, with the algorithm now being available with all the Instagram and Facebook – as Dr. Fazilah has mentioned, social media – so we have now algorithm that is actually reading all of you. That is why now on your hand phone, you now receive advertisement precisely on what you want, and you look for, and it is not just any rubbish advertisement now.

31. So this is now the kind of security we now need to know, because every time we register for something, 'either you want to buy WhatsApp or whatever, you know they say, please agree to the term of agreement, whether you like it or not, you tick agree because you want to go forward. You got this? But they have done the test, and they say 'okay, do you agree that...' – because the test showed that most of us no longer read what we agreed to – they say, 'you agree to give your first born child away', 98% of people agreed. This is now what is happening in the world. You are so getting used to go forward so you have to say agree, so you are being forced to agree. So I think [Dato'] Aishah, you need to discuss something about this as well. This is as correctly mentioned, the data ownership and management of this data, this needs to be resolved. Issue around the world—this privacy thing, I think we all need to look into.
32. Can Malaysia make the big leap in the next few years to join the 'big boys' by leveraging on the breakthrough discoveries and our strengths? The ethnic diversity within our population will definitely provide a valuable resource for research in terms of the novel genetic variants that are yet to be discovered and the vast opportunities to link various genotypes with disease phenotypes. What are some of the structural and institutional barriers stopping us from doing so? There is certainly a need to look at the readiness of our laboratories as well as the human capital particularly in bioinformatics and data analysts, in addition to scientists and researchers.

33. Being here shows that you are interested, you want to know more about this, you want to hear about the panellists. Each of them will be discussing what is this all about. We hope to awaken the visionaries, dreamers and risk takers in you today to chart a strategic direction in the discussions planned for this afternoon.
34. So I hope that you don't go away after the panel discussion. Because a lot of the time, people are here, they want to hear what the key note speaker have to say, the panellist have to say, and then after lunch, there are very few people left. I hope that you are here, you are engaged, you want to do more, and you want to give your inputs to make sure that A Rahman A Jamal's paper is intact as we go into the ministry of health. With that **ladies and gentlemen**, it gives me great pleasure to officiate this workshop. I wish you all a fruitful session.
35. Thank you.

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