EXPERT MEETING ON ACCELERATING ACCESS TO HUMAN GENOMICS FOR PUBLIC HEALTH

29–30 April 2024
Manila, Philippines
MEETING REPORT

EXPERT MEETING ON ACCELERATING ACCESS TO HUMAN GENOMICS FOR PUBLIC HEALTH

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NOTE

The views expressed in this report are those of the participants of the Expert Meeting on Accelerating Access to Human Genomics for Public Health and do not necessarily reflect the policies of the conveners.

This report has been prepared by the World Health Organization Regional Office for the Western Pacific for Member States in the Region and for those who participated in the Expert Meeting for Accelerating Access to Human Genomics for Public Health held in Manila, Philippines from 29 to 30 April 2024.
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**Keywords:** Biomedical Technology / Genomics / Regional Health Planning / Research
Recognizing the historic significance of genomics for public health, especially during the COVID-19 pandemic, the World Health Organization (WHO) Science Council made genomics the focus of its first report in 2022. The report on *Accelerating Access to Genomics for Global Health* provided recommendations for WHO and Member States to expand access to genomic technologies, particularly in low- and middle-income countries and areas (LMICs). The recommendations were grouped under four themes: (1) promotion of genomics through advocacy; (2) implementation of genomic methodologies; (3) collaboration among entities engaged in genomics; and (4) attention to the ethical, legal and social issues raised by genomics.

WHO in the Western Pacific Region is a pivotal player in advancing access to human genomic technologies, with several noteworthy successes in addressing the genomics of complex diseases and implementing large-scale genomic programmes from prominent economies. This progress is driven by strong technical expertise, research infrastructure and robust governance frameworks. The Region’s genomic diversity provides valuable insights into genomics implementation and underscores the need for representation of diverse populations in genomic programmes. To set the regional agenda and find a pragmatic approach for implementing genomic technologies in less-resourced settings, WHO in the Western Pacific convened an expert meeting.

The Expert Meeting on Accelerating Access to Human Genomics for Public Health was held in Manila, Philippines from 29 to 30 April 2024. The objectives of the meeting were:

1. to raise awareness of the benefits and risks of genomic technology implementation by sharing of the Science Council report and initiatives in the Region;
2. to develop a joint vision on accelerating access to human genomic technologies in the Region and define the roles of governments; and
3. to identify the issues impeding the implementation of genomic programmes and plan a stepwise approach for WHO in the Region to coordinate actions that can accelerate access to genomic technologies.

Forty-seven temporary advisers and observers attended the meeting, including members of the WHO Technical Advisory Group on Genomics (TAG-G) from the Western Pacific; senior experts on national genomic initiatives, cancer genomics, rare diseases and congenital disorder genomics, and ethical, legal and social issues; and senior government officials. They were joined by 12 WHO Secretariat members.

On day 1, participants were provided with an overview of the recommendations of the WHO Science Council and the WHO genomics programme. Temporary advisers shared their experiences and perspectives on the accessibility and status of genomic activities in their countries. Participants then divided into three parallel sessions to present initiatives, best practices and national experiences on (1) large-scale human genome programmes, (2) cancer genomics, and (3) rare diseases and congenital disorder genomics. Group discussions explored issues on equity, advocacy and communication, private sector engagement, and workforce development in human genomics. Plenary presentations and panel discussions on day 2 focused on implementation challenges, including strengthening data governance capacity, addressing ethical, legal and social issues, supporting the genomics ecosystem and stakeholders, and making an investment case for human genomics. The expert meeting concluded with a brainstorming session on the next steps to advance genomics in countries and to define the contributions of stakeholders and WHO to these efforts.

The meeting conclusions are grouped under the four themes of the WHO Science Council report.

1. **Promotion of genomics through advocacy**
   - Countries and populations of the Western Pacific Region are underrepresented in large-scale international human genomic initiatives, with far smaller representation from LMICs and disadvantaged groups. Consequently, the beneficial outcomes and implications of genomic
medicine cannot be generalized to these cohorts. This inequity has potentially harmful scientific and clinical ramifications. To address these challenges, concerted efforts to advance genomic literacy are needed. These include (a) generating and presenting local data to identify gaps and opportunities; (b) conducting cost–benefit analyses to overcome hesitancies in adopting genomics programmes; and (c) engaging with patient cohorts and other disadvantaged groups, such as Indigenous populations, in the design, implementation and evaluation of human genomic initiatives.

(2) Implementation of genomic methodologies
- Not all countries in the Region possessed the requisite infrastructure and resources to allow the prioritization of human genomic initiatives over other competing health needs. Building upon the current pathogen genomics infrastructure, which underwent rapid development for numerous countries during the COVID-19 pandemic, may be the pragmatic approach.
- The lack of trained molecular scientists, bioinformaticians and genetic counsellors is a common problem across the Region. Suggested approaches included professional capacity-building through funded training and fellowships and schemes to incentivize the retention of trained genomics professionals within the public sector.

(3) Collaborations among entities engaged in genomics
- Engaging in partnerships with the private sector, with an emphasis on equitable benefit-sharing, was deemed essential because of its potential to yield many advantages. However, some agencies, especially those from less-resourced contexts, require support from more experienced institutions and from WHO in initiating such partnerships.
- Collaborations between countries and institutions were envisioned as levers to increase purchasing and negotiating power when working with the industry, to facilitate sharing of best practices and to accelerate data harmonization and reporting standardization.
- Close partnerships between research institutions and the public health sector were deemed necessary to foster more entry points for the participation of patients and their families.

(4) Attention to the ethical, legal and social issues raised by genomics
- Genomic activities generate volumes of data that require adequate governance, mindful of the need to integrate clinical outcome data and the ethical and regulatory complexities inherent in their use. Enhancing ethical data-sharing among researchers and between researchers and study participants must consider the potential value of the research, the privacy costs to participants and the health system impact.
- While WHO and its partners develop guidance, countries in the Region can share expertise on regulating data-sharing and genomic activities. For instance, the rapid growth of direct-to-consumer genetic testing kits in many countries in the Western Pacific is not covered by prevailing pharmaceutical regulations. Policies must be deliberate yet adaptable to remain abreast with the evolving scientific landscape and the emerging ethical challenges.
- Solidarity and inclusivity are essential for equitable access to the benefits of human genomics. Addressing social issues to ensure the participation of disadvantaged groups, including Indigenous populations, must be part of the national and regional policy frameworks.

WHO is requested to do the following:

(1) Review existing regulatory policies on human genomics in the Western Pacific Region to inform the development of country-level policies pertaining to human genomics.
(2) Develop and promote case studies highlighting the use of human genomic initiatives and best practices in developing investment proposals on human genomics.
(3) Facilitate dialogues between research institutions, government agencies and the private sector to set unified goals for collaborative efforts.
(4) Develop and promote a framework for initiating, implementing and evaluating equitable human genomic programmes, focusing on LMICs in the Western Pacific Region.
1. INTRODUCTION

1.1 Meeting organization

The Expert Meeting on Accelerating Access to Human Genomics for Public Health was held in Manila, Philippines from 29 to 30 April 2024. The full meeting agenda and programme are in Annex 1. Forty-seven temporary advisers and observers attended the meeting, including members of the World Health Organization (WHO) Technical Advisory Group on Genomics (TAG-G) from the Western Pacific; senior experts on national genomic initiatives, cancer genomics, rare diseases and congenital disorders, and ethical, legal and social issues; and senior government officials in the areas of research policy and bioethics policy. They were joined by 12 members of the WHO Secretariat from WHO headquarters and the Regional Office for the Western Pacific. A list of participants is in Annex 2.

1.2 Meeting objectives

The objectives of the meeting were:

1) to raise awareness of the benefits and risks of genomic technology implementation by sharing the Science Council report and initiatives in the Region;
2) to develop a joint vision on accelerating access to human genomic technologies in the Region and define the roles of governments; and
3) to identify the issues impeding the implementation of genomic programmes and to plan a stepwise approach for WHO in the Region to coordinate actions that can accelerate access to genomic technologies.

2. PROCEEDINGS

2.1 Opening session and overview of the WHO Science Council report

Dr Kidong Park opened the meeting and welcomed participants. He introduced the first report of the WHO Science Council, which recommended promoting equitable access to genomic technologies in less-resourced countries to ensure the benefits are fully realized for everyone, everywhere. He emphasized the need to address gaps in financing, laboratory infrastructure and highly trained personnel to achieve this vision. He also explained that the WHO Regional Office for the Western Pacific decided to convene experts in human genomics from diverse backgrounds in the Region as part of the initial actions on this topic.

In her welcome remarks, Dr Susan Mercado highlighted the potential of applying human genomics in the public health setting and the need for collaborative partnerships to accelerate its use within the Region. Dr Greco Malijan led the introductory activity for the meeting participants. Ms Mengji Chen introduced the objectives and agenda of the expert meeting.

Dr Anna Laura Ross introduced the strategic objective of the Science Division at WHO headquarters and the WHO Science Council, which prioritized genomics for global health as the topic of its first report in 2022. The report provided recommendations for WHO and Member States under four main themes: (1) promotion of genomics through advocacy; (2) implementation of genomic methodologies; (3) collaboration among entities engaged in genomics; and (4) attention to the ethical, legal and social issues raised by genomics. Dr Ross highlighted that although activities based on the recommendations started at the global level since the report’s launch, the work programme needs informed guidance from countries and regions, which is facilitated through opportunities such as the expert meeting.
Dr Elena Ambrosino discussed the WHO Genomics Programme of Work. She remarked that one of the earliest activities was the establishment of the Technical Advisory Group on Genomics (TAG-G), composed of 15 experts tasked with guiding current activities, recommending priority activities for consideration, contributing to efforts in convening discussions, and bringing attention to regional and subregional experiences. The Genomics Programme includes strategic actions that support the four themes specified in the first Science Council report. These include developing communication and advocacy tools for different audiences; mapping implementation gaps, opportunities and priorities; engaging stakeholders across sectors and regions; supporting workforce education and training; guiding human genome data access, use and sharing; and supporting equitable genomics research and practice.

2.2 Country profiles of human genomics in the Western Pacific Region

Dr Greco Malijan moderated the session, which began with an informal survey of the availability of technologies, expertise, programmes and regulations concerning different aspects of human and pathogen genomics.

Insights gained from the sharing session included the following:

1. In recent years, there has been growing public and government interest in genomic technologies, beginning with noninvasive prenatal testing for congenital disorders and rare diseases, expanded into cancer medicine and later accelerated by pathogen genomic use during the COVID-19 pandemic.
2. With the expansive growth of human genomic research came the impetus to improve the understanding of genomic diversity at the population level, which was steadily also being recognized by research institutions and governments in the Region.
3. In some countries, health agencies and policy-makers are addressing the economic implications of investing in genomics from a societal perspective to ensure equitable access to these new technologies.
4. Translating advances in genomic research into health outcomes presents challenges, complicating the economic evaluation of emerging technologies and the case for investment, especially amid competing health priorities.
5. Limited government funding and national health insurance coverage exist for human genomic technologies, including diagnostic and prognostic tests in clinical care.
6. There is a need for sustainable training for geneticists, genetic counsellors, laboratory technicians and researchers to support the public sector.
7. Sustaining a national genomics programme equipped with big data management systems and supported by the necessary regulatory frameworks was deemed highly complex, especially in countries with minimal experience setting up human genomics.
8. Regional and national human genomic initiatives in the Western Pacific Region are creating opportunities for learning and collaboration between countries and with WHO.

2.3 Setting-the-scene keynotes for the parallel sessions

Dr Elena Ambrosino moderated the sessions.
2.3.1 Large-scale human genome initiatives

Ms Tiffany Boughtwood, a member of the TAG-G, provided an overview of the global landscape of large-scale genomic initiatives. She highlighted the discrepancies in their distribution globally, in the Western Pacific Region, and even within Australia. Of the nine active, planned or concluded national genomic initiatives in the Western Pacific Region, six were based in high-income and upper-middle-income countries. Multinational and global consortia, such as the Human Heredity & Health in Africa, the Centre for Arab Genomic Studies, and the Global Alliance for Genomics & Health, were formed to bridge resource and technical constraints faced by countries wishing to implement genomic programmes. Recognizing the opportunities of genomics to transform public health, Australian Genomics, a national government-funded initiative, was established in 2016 to support the infrastructure, workforce and research needed to translate genomic activities into healthcare delivery. Its early years centred on demonstrating direct patient benefits using genomic technologies, building the genomic medicine investment case in Australia, developing practical strategies to inform policy-makers, and improving research translation capacity. Ms Boughtwood concluded by underscoring the importance of shared responsibility in overlaying the new genomic ecosystem with the public, the federal government and international stakeholders, given Australia’s highly complex health system.

2.3.2 Cancer genomic programmes

Professor Joanne Ngeow Yuen Yie shared about the promise of the implementation of clinical cancer genomic medicine in Singapore. Using the National Cancer Centre Singapore (NCCS) Hereditary and Rare Cancer Program as an example, she showed how the implementation of cancer genomic programmes may bring about health-care reform – shifting from a reactive model into a model of proactive medicine. By generating impactful data from the national cancer registry and research on the public acceptance of genetic testing, health-care gaps were identified, helping dispel hesitancies in adopting a cancer genomic programme that caters specifically to the local populations’ health needs. For instance, rare genetic diseases such as hereditary breast and ovarian cancer were found to occur in 1 out of 150 Singaporeans, and germline cancer predisposition appeared more common than appreciated in the Region, putting the current screening recommendations for these diseases into question. Professor Ngeow underscored how gathering more local population data would increase genomic representation, enabling more genetic variants to be better understood and classified. However, challenges remained, such as poor cascade testing uptake and trained workforce retention, which may be solved through sustainable scaling solutions and data and resource sharing with collaborators.
2.3.3 Rare disease and congenital disorder genomics

Professor Zilfalil Bin Alwi, a member of the TAG-G, provided an overview of the priorities in rare disease genomics and congenital diseases in Malaysia. He argued that while rare diseases were individually rare, they were collectively common. Thus, genomic and sequencing technologies focused on rare diseases could potentially reduce the length of diagnostic journeys and the costs of treatment. Moreover, while there was a wide range of strategic areas that the Region could address to improve health outcomes in rare diseases and congenital disorders, Professor Alwi underscored that networking and collaboration to accelerate research programmes and to facilitate data-sharing could serve as pragmatic first steps to take together. Such efforts were already in place such as the ASEAN Rare Disease Consortium, which included member organizations from, among others, Malaysia, the Philippines and Singapore. Professor Alwi concluded that building the case for investing in national measures to address the unique challenges of patients living with rare diseases is the biggest challenge in less-resourced settings, which could be tackled partly through meaningful partnerships in the Region.

2.3.4 Economic value of genomic initiatives

Professor Ilias Goranitis provided an economist’s perspective on human genomics. He emphasized how investing in human genomic studies could create direct and indirect opportunities for economic benefits. A practical investment case for advocating for human genomic initiatives would begin by looking at trends in the epidemiology of specific disease states. For example, in the context of cancer, shifting from treatment to a preventive approach by genetically testing high-risk but essentially healthy individuals could potentially result in decreased health-related costs over long periods. The same concept could apply to genetic screening for rare conditions, especially during the preconception or prenatal period. The clinical value of earlier recognition and treatment of such conditions was found to be highly valued by patients, the public and policy-makers in a series of public surveys involving patients and family members in Australia. Performing macroeconomic cost–benefit analyses, reviewing and incorporating published literature, and consulting with health economics experts could help build a strong case for increased investment in public health genomics.

After the introductory keynote session, the participants broke into three groups for the parallel sessions.

2.4 Parallel session A: From launchpad to implementation – lessons from large-scale human genome initiatives

Ms Tiffany Boughtwood and Ms Mengji Chen moderated this session.
Dr Syahrilnizam Abdullah shared institutional experiences in establishing the MyGenom Project, Malaysia’s first embarkation into population genomics. With the goal of sequencing 10,000 Malaysian genomes, the project was set up to provide a genomic baseline for future implementation of precision medicine in the country. Dr Abdullah reiterated that much of the publicly available genomic databases have been predominantly contributed by European populations, resulting in documented issues for underrepresented groups, including low diagnostic accuracy and ineffective treatments.

Central to ensuring buy-in from stakeholders were being persistent in proposing the project across funding cycles, aligning the project with national research policies across different ministries, providing a clear vision of capacity and expertise for the country, and drawing inspiration from the rapidly advancing genomic initiatives of neighbouring countries. Dr Abdullah remarked how the project continued to rely on societal readiness and engagement apart from receiving government approval and support to bolster implementation success. The infrastructural barriers to implementation were viewed as parallel opportunities for the improvement of other aspects of the health system. Furthermore, effective oversight and regulations needed to be developed to ensure long-term implementation of the project.

Dr Eva Maria Cutiongo-de la Paz discussed leveraging existing infrastructure and expertise and engaging academic communities and patient advocates to develop the FILIPINOme project, an initiative aiming to sequence at least 10,000 Filipino genomes. The Philippine Genome Center (PGC) was established prior to the FILIPINOme project as a multidisciplinary research unit for agriculture, environment, biodiversity and health sciences. One of its priorities was to promote genomics appreciation for academics and the public alike through roadshows, educational trips and workshops. Continuous engagement with students and early career laboratory trainees in genomics and bioinformatics was effective in promoting genomics literacy and training the workforce. The FILIPINOme project built on the success of the PGC to facilitate the translation of the eventual Filipino reference genome into precision medicine in health care, thereby contributing to the country’s national health agenda.

Dr Tan Ee Shien shared about the country’s National Precision Medicine (NPM) Programme and how population genomics could empower patient care. The 10-year NPM programme, which aims to generate whole genome sequences of at least 1 million Singaporeans by 2027, was developed using a whole-of-government and health care-research ecosystem approach. Pharmacogenomic strategies and focused cancer screening programs (for example, Lynch syndrome and hereditary breast and ovarian cancer) were developed, significantly improving precision patient care in the Region. After sequencing 10,000 genomes, impactful discoveries with public health implications were found. For instance, at least one in five Singaporeans was discovered to have a pharmaco-genomically targetable variant. Dr Tan highlighted the importance of high-
quality national population health data as a health resource and that generating large data could be a powerful tool to increase equity through data-sharing. However, it came with ethical and legal challenges concerning data security. Finally, in recognition of the importance of communicating the results and harnessing them for clinical use, pathfinder projects were created to educate clinicians on cost-effective genomic testing and cascade testing of family members, enabling the integration of genomics evidence into the health-care system.

Dr Hyun-Young Park shared institutional learnings from 20 years of national genomic initiatives in the Republic of Korea. She provided an overview of the human genome research at the Korea National Institute of Health (KNIH), beginning with large-scale cohort studies through the Korean Genome and Epidemiology Study (KoGES), through to the National Bio Big Data project in recent years. KoGES was initiated in 2001 and has been following up with more than 240,000 participants from across the country, targeting major noncommunicable diseases such as cardiovascular diseases, metabolic syndrome and cancer. Other national genomic initiatives followed, including genome analysis projects to build the Korean reference genome (KRG). Through these initiatives, one central biobank and 47 regional biobanks have been working together to build and continually update the KRG bank. The Clinical and Omics Data Archive was created to store and share 6.6 petabytes of clinical and omics data for efficient translational research. Furthermore, the KNIH established a web-based platform to help stakeholders analyse data and view the association of genetic variants with clinical phenotypes. Despite national successes in advancing sequencing technologies, biobanking, linking samples with clinical data, and data analysis, Dr Park identified persisting challenges in the clinical integration of genomic technologies, genetic counselling and education, and the ethical and legal frameworks guiding these activities.

The discussion session included the following key points:

- Most participants noted the lack of national policies for the management of genomics technology and data as a significant implementation gap.
- They also highlighted the importance of leveraging patient advocate groups and relatable patient narratives to increase public awareness and acceptance of genomics activities.
- Some participants shared how building upon existing infrastructures, such as for pathogen genomics, could be a practical entry point for the development of human genomics infrastructure.
- Engaging with the private sector was also deemed important to create more access points to genomic technologies and to potentially scale down costs. However, private sector engagement raised further challenges concerning the regulation of commercially driven genomics activities.
- Finally, the participants echoed the need to create broad but flexible regulations to ensure accessibility and responsible use of genomic testing.

2.5 Parallel session B: How human genomics initiatives can contribute to health systems – lessons from cancer genomics

Professor Joanne Ngeow and Dr Catalina Lopez-Correa moderated the session.

Dr Takashi Kohno provided an overview of cancer genomic medicine initiatives in Japan. The Center for Cancer Genomics and Advanced Therapeutics (C-CAT) was established to aggregate genomic data, store clinical information including drug efficacy and adverse events from trials conducted in the country, and construct a knowledge database for cancer genomic medicine. Since April 2024, 264 core
hospitals in Japan have been offering broad cancer gene panel tests that feed into the C-CAT data systems. With clinical information from over 74,000 patients, C-CAT has been providing data to research institutions and companies locally and overseas through a secure online portal. Its efforts have been instrumental to the development of pharmaceuticals, the improvement of patient eligibility for clinical trials after gene panel testing, and government lobbying and regulatory applications. Dr Kohno attributed the initiative’s success, at least in part, to the political support from the national government and the funding of the cancer genomic medicine platform through the national health insurance system. The recent addition of next-generation liquid biopsy to the reimbursement scheme further bolstered participation. Lastly, outside of C-CAT, Japan has been considering the introduction of whole genome sequencing to cancer care.

Professor Thi Lan Anh Luong discussed how cancer genomics efforts were integrated into the national cancer control strategy in Viet Nam. With most cancer patients being diagnosed in the later, non-curable stages, national efforts to increase the availability and accessibility of hereditary genetic testing, comprehensive genomic panels, and targeted therapies were a priority of the national cancer control strategy. Professor Luong talked about the available gene panel tests for cancer screening in Viet Nam and the potential implementation of multiple early cancer detection systems. Moreover, initiatives in partnership with the private sector, such as the GeneStory, which provided free screening for drug responsiveness among nearly 6000 patients and families necessitating treatment for serious debilitating diseases including cancer, had been instrumental in facilitating collaborations between medical centres in the country. Professor Luong remarked how even small-scale clinical care integration of genomic initiatives could create demand for larger-scale investments in the future.

Professor Sun-Young Kong discussed different national initiatives integrating genomic technology into cancer care in the Republic of Korea. Since a government reimbursement system for next generation sequencing (NGS)-based testing was initiated in 2017, there has been an increase in the availability and affordability of hereditary and non-hereditary genetic cancer testing platforms. A first tier of required genetic tests is required depending on the disease type (for example, hereditary versus non-hereditary) and tumour type (for example, solid tumour versus haematologic) before proceeding to the second tier of more intensive testing. The co-payment scheme has also evolved over the years, reflecting the changing attitude towards genomic technologies. As of 2023, Stage III, Stage IV and non-small cell lung cancers require a 50% co-payment, and all other cancer types and hereditary disorders require an 80% co-payment. Data from clinical NGS tests informed the Health Insurance Review and Assessment Service as well as hospital data, allowing changes in the strategic directions of medical centres and the wider health system. Two programmes using NGS somatic tests were initiated to support precision oncology in the Republic of Korea. The K-MASTER programme is a nationwide, precision oncology screening programme that enrols patients into the most appropriate ongoing clinical trial based on their cancer’s unique genomic properties. The KOSMOS II programme uses the NGS test results in
conjunction with decision-making from the tumour board to select treatment for participants in clinical trials. These efforts have been instrumental in identifying actionable mutations for respective tumour types, leading to improvements in clinical outcomes. Furthermore, to support other oncologists and scientists in large-scale data analysis, all anonymized data from these cancer initiatives have been made accessible to the public through an online portal.

Dr Jiao Yuchen shared how workforce professional development must be sustained to properly implement cancer genomic programmes in China. Dr Jiao identified bioinformatics, data validation and troubleshooting of diverse genomic product designs among the most important skills requiring workforce training. Navigating the intricacies of regulations and policies and negotiating with institutions and other stakeholders were also deemed to be important in advancing cancer genomic programmes. Through the continued training of undergraduate and graduate students, the overseas recruitment of skilled workforce and the evaluation and certification of genomics technologies, China has been able to sustain the integration of NGS-based laboratory research and clinical cancer care.

The discussion session focused on the impact of cancer genomics in public health systems.
- The participants highlighted the importance of ensuring the existence of proper governance in the use of cancer genomic technology as well as quality assurance in data collection and interpretation.
- The participants considered it essential that policies be able to cover issues such as possibilities of genetic discrimination or data misuse yet flexible enough to adapt to the rapidly changing landscape of cancer care.
- The importance of workforce development in sustaining the initiatives was also highlighted.
- Finally, the participants underscored the need to improve genomic literacy for future clinicians, including those incorporated into the medical school curricula, and for the public to facilitate participation and dispel hesitancies.

2.5 Parallel session C: Advocacy and partnerships – reflections from rare disease and congenital disorder genomics

Dr Greco Malijan and Dr Elena Ambrosino moderated this session.

Professor Hidehiro Muzisawa shared insights into the establishment of the Initiative on Rare and Undiagnosed Diseases (IRUD). Japan has a long history of tackling undiagnosed diseases, beginning in the 1960s when an undiagnosed disease called subacute myelo-optic neuropathy turned out to be clioquinol intoxication, spurring social movement to diagnoses. Countermeasures have since been developed to prevent similar occurrences. Since its establishment in 2014, IRUD has succeeded in its three main objectives: (1) to utilize technologies such as NGS for specimen analysis, (2) to establish a nationwide, comprehensive system with a specialized diagnostic and clinical committee that facilitates conferences on complex cases and offers genetic counselling and follow-up for patients, and (3) to create a sharable registry. As of 2023, over 47% of families who have undergone whole genome sequencing under IRUD have received specific diagnoses, alleviating their diagnostic odysseys. For
those yet to receive a diagnosis, other tests such as proteomics studies were being done. Professor Mizusawa identified collaboration among institutions, engagement with patients and families, and strong support from the government to be facilitators of these successes. However, he also argued that the needs of undiagnosed diseases remained large, requiring further studies and collaboration with other countries and institutions.

Dr Adiratna Mat Ripen discussed how scaling up accessibility to NGS facilities could also provide the groundwork for improving congenital disease and other health outcomes. Using examples from Malaysia, Dr Mat Ripen shared how understanding the genomic roots of inborn errors of immunity (IEI) in the population shed additional insights into tuberculosis (TB) pathogenesis. For instance, a study examining the clinical utility of whole-exome sequencing for IEI found mutations in the Mendelian susceptibility to mycobacterial disease genes, which strongly correlated with the development of severe TB infections. These findings may facilitate the identification of genetic variants that would predict individual patient responses to standard and biomarker-directed therapy, which remained important in Malaysia, where the prevalence of multidrug-resistant TB remained substantial.

Professor Daniel MacArthur highlighted the importance of data-sharing and inclusive reference data in improving equitable rare disease diagnosis. He echoed how publicly accessible genomic data did not represent genomic diversity. The inclusion of more individuals from underrepresented communities who conventionally had lower diagnosis rates, higher rates of variants of unknown significance, and poorer genomic risk prediction would diversify the genomic reference datasets, allowing for a less biased recognition of unique genetic variants, leading to equitable research and drug development. In Australia, a nationwide, funded project called OurDNA focuses on filling the gap of genomic underrepresentation by collecting genomic data from 10,000 individuals. Priority community engagement with diverse populations allows for the recruitment of volunteers who donate their genomic data and, optionally, receive a return of their results. As the reference dataset grows, continuous re-analysis and reporting of results have also been accomplished. Professor MacArthur remarked that the sustainability of such efforts relied on shared responsibility between academia, the government and nongovernmental institutions. Partnerships with companies such as Microsoft may also increase their capacity to interpret large sources of data through artificial intelligence and machine learning. Lastly, Professor MacArthur identified persisting challenges in the field, including the ability to respond rapidly to external change, retention of talent in data science, mitigation of data security risks without hindering innovation, and models for large-scale, long-term funding.
Dr Carmencita Padilla discussed the role of effective partnerships in advancing investments in rare diseases and congenital disorders in the Philippines. She shared how the enactment of the Newborn Screening Act of 2004 provided the framework for the continued implementation of a fully subsidized national newborn screening programme, which presently screens for 29 newborn metabolic disorders. The creation of continuity and satellite newborn screening continuity clinics also ensured proper treatment and follow-up of patients and their families. The success of the newborn screening programme provided the groundwork for a new national consortium on an integrated rare disease management programme and the eventual passing of the Rare Diseases Act. Supported by government funding, nongovernmental agencies, the media and patient support groups are involved in advocacy and promotion. Research institutions contribute technical expertise, genetic services and genomic advances that support rare diseases.

The discussion session centred on the need to communicate the value of genomics for rare diseases to policy-makers, the government and industry.

- Participants deemed this to be particularly challenging when faced with competing health needs. However, some expressed that carefully highlighting use cases and developing fit-for-purpose messaging could bridge these difficulties.
- By creating effective pilot projects, supporting the commitment of patients and other stakeholders in genomics for rare disorders, and thinking of stakeholders as partners, trust can be built between the public, academia and policy-makers.
- Some participants expressed the need to take a stepwise approach in building genomic programmes. For instance, some agencies may consider beginning with several genetic tests that could be scaled up and evaluated further down the line.
- The participants also noted the need for workforce training in the field. Specifically, they recognized the lack of a clinical geneticist that could support patients and families in navigating the diagnostic odysseys. Facilitation of exchange training programmes was recommended as one way to address this gap.

2.7 Implementing human genomics – strengthening data governance capacity

Dr Mas Rina Hamid moderated the session.

Professor Kazuto Kato, member of the TAG-G, presented updates on the development of the WHO Guiding Principles on Human Genome Data Access, Use and Sharing. The principles applied to all prospective and retrospective collections of human genomic data, while pathogen and microbiome data were excluded. The key principles focused on social justice to prevent discrimination and stigmatization and fostering solidarity to collectively and equitably share the benefits and burdens of human genomic technology. At the time of the presentation, the draft document was open for public comments. Professor Kato remarked how important it was for experts from the Western Pacific Region to provide feedback as the Region contained diverse societies whose voices needed to be reflected in global efforts.
Professor Shoba Ranganathan shared insights into the establishment of bioinformatics and genomic data analysis capacity in Asia and the Pacific. She discussed the challenges of genomic data storage and sharing, which often involve managing huge volumes of data on genetic variants that are associated with small increases in relative risks for adverse outcomes. Professor Ranganathan advocated for extending genomic data storage to a digital biobank, similar to specimen biobanks, to improve equitable access. The identified challenges included the need for interoperability of data formats, reproducibility of methods, and integration of -omic and clinical data. To address these challenges and the inequality in genomic literacy and infrastructure, workforce training efforts such as the Asia-Pacific Bioinformatics Network tutorials and workshops have been established.

Professor Masayuki Yamamoto shared institutional experiences in establishing a large-scale genomics initiative following the Great East Japan Earthquake in 2011. He remarked that beyond the need for physical repair, the health and longevity of the population most affected by the tsunami were top priorities, leading to the establishment of the Tohoku Medical Megabank (TMM). Professor Yamamoto highlighted the stark difference between generating data for a biobank and maintaining high-quality data over time that could be pooled to properly inform policy and practice. As an example of epistemic justice, TMM serves as the world’s first integrated biobank, linking biospecimens and genomic data with clinical information for over 10 years. With government support and oversight from professional societies, the sustainability of storing and updating large genomic data was made possible. Long-term data management was made possible through investments in safe data storage and supercomputers, including a paradigm shift to data visiting. However, a significant challenge encountered was the return of genetic results to participants. Health-risk information was being shared with otherwise healthy, unaffected individuals in Japan, typically in their middle age. Professor Yamamoto noted that TMM remained aware of the potential unintended consequences of these efforts and that close clinical follow-up was being conducted with the Tohoku University Hospital.

Professor Hannah Kim discussed the challenges of ethical genomics data governance in the era of artificial intelligence (AI). Using prevailing issues in rare disease genomics as an example, Professor Kim highlighted key concerns such as data protection and long-term data oversight when integrating AI into genomic data systems. She recognized the growing research potential when AI models are applied to large genomic databases but noted the accompanying risks, including genetic discrimination in areas such as health insurance. Professor Kim advocated for prioritizing the ethical and legal governance of AI technology in a timely manner to ensure the responsible conduct of researchers and stakeholders from industry and government. Supporting the public with AI and genomics literacy programmes was deemed necessary to sustain societal support.
Key discussions centred on the utility of comprehensively reviewing regulatory policies of various countries on genomics data.

- Participants agreed that genomic data tend to move and be used much faster than other components of the genomics ecosystem.
- The importance of reviewing and co-developing regulatory policies between countries in the Region was emphasized, as it would facilitate knowledge-sharing on current best practices.
- Some participants noted that asymmetries in data-sharing, including variable quality of data, had previously led to unsustainable collaborations.
- There was recognition of the need for an international, third-person entity to facilitate such collaborations moving forward.

2.8 Implementing human genomics – ethical, legal and social implications

Professor Kazuto Kato moderated the session.

Professor Angus Dawson discussed the importance of translating ethical values into health policy in human genomics. He explained that public health ethics should be distinguished from medical ethics, as it is informed by population data and motivated by a set of relevant values to the community. Public health ethics also has different aims and values compared to conventional biomedical ethics. To build towards health equity, human genomics activities must consider inherent inequities in risks within and between populations. Universal health care principles can guide how health-care systems respond to genomic data.

Professor Ock-Joo Kim discussed the ethical and legal framework of genomics research and its repercussions in the Republic of Korea. Over several years, bioethics regulations for human genomic data have been revised to include strict and specific clauses and corresponding punishments. Any activities not in accordance with National Bioethics and Safety Act are considered criminal. However, these regulations have been found to slow the pace of genomic research that is physically based in the Republic of Korea, despite the country having adequate genomics and bioinformatics expertise and technology. Professor Kim advocated for the modernization and adaptation of these laws and regulations to be deliberate and created with foresight to enable accelerated research and technological development.

Mr Steve Waldegrave highlighted similar challenges in regulating human genomics in New Zealand. He provided an overview of the complex array of laws that indirectly regulated genomics in health care.
The regulatory approach has not kept pace with technological advancements and could potentially exacerbate inequities, as genomic testing and treatments would remain costly without proper regulation. For instance, the current regulatory act in New Zealand, shaped over 15 years and passed in July 2023, is set to be repealed due to a new government. Therefore, all-encompassing, dynamic policies and regulatory frameworks that offer basic protections while promoting progress in health and technology should be highly considered. Mr Waldegrave reiterated how policy-making and regulation are inherently political processes, making it essential to gain a broad social license for regulation.

Professor Alexander Brown shared insights into empowering Indigenous communities in genomic medicine. He highlighted the distinctions between precision health and population health, arguing that mere inclusion in genomic programmes does not constitute equity. While human genomics has long been framed as a means to prevent and reduce existing inequalities, building trust among Indigenous populations remains a challenge due to generational disadvantages. Despite a global push for diversity in genomics, there are concerns that this effort could become a form of bio-colonialism. Professor Brown shared examples of initiatives in Indigenous genomics, including the development of the National Indigenous Genomics Agenda, built on Indigenous leadership for complex diseases of importance to Indigenous communities. Other activities include the National Health and Medical Research Council Synergy Grant for Empowering Indigenous Communities in Genomic Medicine, which explores Indigenous knowledge systems and builds a pan-genome reference with unique variations. Lastly, Professor Brown shared a vision for equity in genomics founded on the principles of trust, empowerment and respect.

2.9 Implementing human genomics – ecosystems and stakeholders

Professor Ock Joo Kim moderated the session.

Dr Daniel Tan discussed equitable partnerships in lung cancer genomics in Asia and the Pacific. Drawing from experiences in lung cancer research in Asia, Dr Tan introduced the Asian Thoracic Oncology Research Group (ATORG) as facilitator of translational research in the Region. The central agency began coordinating multi-centre clinical trials and other collaborative studies that benefited patient subgroups from countries and areas such as Australia, China, Hong Kong SAR (China), Japan, Malaysia, the Philippines, the Republic of Korea, Singapore and Viet Nam in 2016. The initiative began with stakeholders from academia, but after securing the commitment of principal investigators from different institutions across these countries, clinical trials were implemented. Furthermore, molecular profiling projects and continuing education programmes have accelerated the development of expertise within the Region. Multiple entry points for collaboration
with private industries and academic societies have also enabled the completion of multiple drug development projects.

Professor Sean Grimmond discussed the need for the alignment among government, academia and industry to advance precision cancer care. In 2020, The Advanced Genomics Collaboration (TAGC) was launched as a university-industry-state government initiative to expand Australia’s capacity for genomics research, communication and commercialization. Academia and health-care institutions are expected to foster future workforces, while industry partners supply equipment and innovative technology, and reduce costs in research. For such public–private partnerships to be successful, they need to be principle-based and led by strong governance. Professor Grimmond emphasized that promoting genomics for health would require involvement from more government agencies beyond the Ministry of Health. He also noted that researchers and governments should recognize that the industry partners are not limited to providing reagents and equipment.

Professor Maui Hudson emphasized the need for culturally informed and inclusive biobanking. He echoed that biobanks and data repositories are essential infrastructure for genomics, and that the principles of responsible research and innovation require stakeholders to bring diversity to research infrastructure. Hence, engaging underrepresented populations to ensure inclusivity and diversity is equally important. This approach not only builds individual interest but, more importantly, creates a collective interest in human genomics initiatives, thereby gaining community trust and ownership.

Professor Hudson shared an overview of the He Tangata Kei Tua Guidelines for biobanking with the Māori and provided examples of key cultural values and concepts relevant to genomic research. He remarked that Indigenous data sovereignty was about a discourse on rights and interests that involves data for governance and governance of data. Therefore, culturally informed and inclusive biobanking requires a reconsideration of current structures to ensure inclusive governance, guidelines, capacity-building and services, while being respectful of the level of control, comfort and integrity of Indigenous populations.

The participants echoed the importance of a trusted third party such as WHO to protect countries from further inequity.

- WHO was viewed as a source of governance and practical guidance for countries in the process of developing their national genomics initiatives and fostering collaboration between countries and with the private sector.

**2.10 Implementing human genomics – making an investment case**

Dr Lock-Hock Ngu moderated the session.
Dr Erik Karlsson shared insights on defining the downstream benefits of genomic programmes in less-resourced contexts, particularly Cambodia. He emphasized the importance of increasing sequencing capability and capacity for endemic and emerging diseases unique to Cambodia. Through multiple public–private partnerships and investments, sustainable funding for machine maintenance costs and local capacity-building was possible. Drawing from experiences during the COVID-19 pandemic, Dr Karlsson shared examples of how Cambodia has been leveraging increased pathogen genomic capacity by applying expertise to agricultural diseases, other vector-borne diseases and human seasonal diseases. Specifically, current platforms are being used to understand the genomic epidemiology of influenza A (H5N1) human infections in the country, highlighting the downstream benefits of genomic technologies.

Dr Jianchao Quan discussed the benefits derived at different stages of implementing national genomic initiatives. Using the multidimensional evaluation of the Hong Kong Genome Project (HKGP), which was launched in 2018, Dr Quan shared insights into the structure, process and outcome evaluation of the programme. The building blocks needed to facilitate the sustainability of this project included (1) building capacity, such as improving IT systems and bioinformatics systems, nurturing talents and expertise in genomics and enhancing genomic literacy of stakeholders; (2) involving government officials in the publicity of new technologies; (3) enhancing clinical services to deliver the downstream benefits of the project directly to the patients; and (4) continually engaging the public and policy- or decision-makers. While establishing the economic value of the HKGP was still in its very early stages, there were indications that these building blocks had benefits for other aspects of the health system in Hong Kong SAR (China).

Participants agreed that, broadly, a good investment case for human genomics would be building upon the infrastructures that were already present and working efficiently.

- For instance, it may include acknowledging the success of COVID-19 and pathogen genomics initiatives, especially in less-resourced settings.
- Small case studies within countries and from comparable countries could also serve as invaluable resources to share with policy-makers.
- Linking the health benefits of human genomic initiatives to the overall health of the country and its economic growth may be considered as a strategy to engage with government officials.

### 2.11 Charting the way forward with WHO

Dr Catalina Lopez-Correa moderated the session. Some meeting participants suggested that a regional set of guiding principles for establishing genomic initiatives would be foundational. Despite genomic diversity, many countries in the Region shared values that could serve as a basis for collaboration. Others suggested developing frameworks to incorporate genomic programmes into universal health care goals to ensure equitable access for all.

Moreover, meeting participants agreed that the Region should lead in promoting and implementing equity in genomics, drawing from the rich experiences shared in the meeting. The framework was envisioned to include a discussion on not only the potential benefits but also the potential risks.
The participants agreed that the two-day meeting reflected the intentions and vision of the WHO Genomics Programme and viewed the Western Pacific Region’s diversity as a key strength. Collaborations with patient organizations, professional societies, research institutions, government offices and the private sector were viewed as accelerators to advance human genomics capacities, especially in less-resourced countries.

Finally, value-networking could be a means to understand the different stakeholder perspectives on integrating human genomics into public health.

Dr Elena Ambrosino, Dr Anna Laura Ross and Dr Kidong Park delivered the closing remarks and thanked participants for their active contributions, particularly for sharing their experiences, insights on the advancement of human genomics initiatives in the Western Pacific Region.

3. CONCLUSIONS AND RECOMMENDATIONS

3.1 Conclusions

Several key points emerged from the discussions. The main conclusions of the meeting are grouped under the four themes of action specified in the WHO Science Council report.

(1) Promotion of genomics through advocacy
- **Advancing genomic literacy.** Countries and populations of the Western Pacific Region are underrepresented in large-scale international human genomic initiatives, with far smaller representation from lower- and middle-income countries and disadvantaged groups. Consequently, the beneficial outcomes and implications of genomic medicine cannot be generalized to these cohorts. This inequity has potentially harmful scientific and clinical ramifications. To address these challenges, concerted efforts to advance genomic literacy are needed. These include (a) generating and presenting local data to identify gaps and opportunities; (b) conducting cost–benefit analyses to overcome hesitancies in adopting genomics programmes; and (c) engaging with patient cohorts and other disadvantaged groups such as Indigenous populations in the design, implementation and evaluation of human genomic initiatives.

(2) Implementation of genomic methodologies
- **Building upon existing infrastructure.** Not all countries in the Region possessed the requisite infrastructure and resources to allow the prioritization of human genomic initiatives over other competing health needs. Building upon the current pathogen genomics infrastructure, which underwent rapid development for numerous countries during the COVID-19 pandemic, may be the pragmatic approach.
- **Capacity-building and incentives.** The lack of trained molecular scientists, bioinformaticians and genetic counsellors is a common problem across the Region. Suggested approaches included professional capacity-building through funded training and fellowships and schemes to incentivize the retention of trained genomics professionals within the public sector.

(3) Collaborations among entities engaged in genomics
- **Engaging in partnerships with the private sector** with an emphasis on equitable benefit-sharing was deemed essential because of its potential to yield many advantages. However, some agencies, especially from less-resourced contexts, require support from other more experienced institutions and from WHO in initiating such partnerships.
- **Collaborations between countries and institutions** were envisioned as levers to increase purchasing and negotiating power when working with the industry, to facilitate sharing of best practices and to accelerate data harmonization and reporting standardization.

- **Partnerships between research institutions and the public health sector** were deemed necessary to foster more entry points for the participation of patients and their families.

(4) **Attention to the ethical, legal and social issues raised by genomics**

- **Ethical data-sharing.** Genomic activities generate substantial volumes of data that require adequate governance structure, mindful of the need to integrate the clinical outcome data and the ethical and regulatory complexities inherent in their use. Endeavours to enhance ethical data-sharing among researchers and between researchers and study participants must consider the potential value of the research, the privacy costs to participants and the health system impact (for example, sharing of genomic risk scores to healthy participants and consequences for further screening and management).

- **Regulation of genomic activities.** While WHO and its partners develop guidance, countries in the Region can share expertise on regulating data-sharing and genomic activities. For instance, the rapid growth of direct-to-consumer genetic testing kits in many countries in the Western Pacific is not directly covered by prevailing pharmaceutical regulations. The policies therefore need to be deliberate yet adaptable to remain abreast with the rapidly evolving scientific landscape and the attendant ethical challenges that arise.

- **Participation of disadvantaged groups.** Solidarity and inclusivity are essential for equitable access to the benefits of human genomics. Addressing social issues to ensure the participation of disadvantaged groups, including Indigenous populations, must be part of the national and regional policy frameworks.

### 3.2 Recommendations for WHO

WHO is requested to do the following:

1. Review existing regulatory policies on human genomics in the Western Pacific Region to inform the development of country-level policies pertaining to human genomics.
2. Develop and promote case studies from the Western Pacific Region highlighting the use of human genomic initiatives and best practices in developing investment proposals on human genomics.
3. Facilitate dialogues between research institutions, government agencies and the private sector in the Western Pacific Region to set unified goals for collaborative efforts.
4. Develop and promote a framework for initiating, implementing and evaluating equitable human genomic programmes, focusing on the needs of lower- and middle-income countries in the Western Pacific Region.
**ANNEXES**

Annex 1. Programme of Activities

<table>
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<tr>
<th>Day 1 Monday, 29 April 2024</th>
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<tr>
<td><strong>Time</strong></td>
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<td>08:30 – 09:00</td>
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| **Session 1** Expert Meeting Opening and Overview of the WHO Science Council report  
MC: Dr Kidong Park, WHO WPRO | 09:00 – 09:35 | Welcome remarks | Dr Kidong Park (WHO WPRO) |
|  |  | Opening remarks | Dr Susan Mercado (WHO WPRO) |
|  |  | PRSEAH Announcement | Video |
|  |  | Introduction to meeting participants | Dr Greco Malijan (WHO WPRO) |
|  |  | Introduction to meeting agenda and admin announcement | Ms Mengji Chen (WHO WPRO) |
| 09:35 – 09:50 | Recommendations of the WHO Science Council in accelerating access to genomics for health | Dr Anna Laura Ross (WHO HQ) |
| 09:50 – 10:00 | WHO Genomics Programme of Work | Dr Elena Ambrosino (WHO HQ) |
| 10:00 – 10:30 | Coffee break and Group Photo | |
| **Session 2** Country profiles of human genomics in the Western Pacific Region  
Moderator: Dr Greco Malijan, WHO WPRO | 10:30 – 10:45 | Mapping the landscape of genomic activities across the Western Pacific Region | Dr Greco Malijan (WHO WPRO) |
|  | 10:45 – 11:45 | Country situation sharing | Expert Meeting Participants |
| 11:45 – 12:45 | Lunch break | |
| 12:45 – 12:50 | Announcements and instructions for the afternoon session | |
| **Setting-the-scene keynotes for parallel sessions**  
Moderator: Dr Elena Ambrosino, WHO HQ | 12:50 – 13:30 | Building large-scale human genome initiatives | Ms Tiffany Boughtwood  
Australian Genomics  
Australia |
|  | Implementation of cancer genomic programmes | Prof Joanne Ngeow Yuen Yie  
National Cancer Centre  
Singapore |
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<tr>
<td>13:30 – 13:40</td>
<td>Mobility break</td>
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**Parallel Session A** From Launchpad to Implementation - lessons from large-scale human genome initiatives

**Moderator:** Ms Tiffany Boughtwood, Australian Genomics

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<tr>
<td>13:40 – 14:55</td>
<td>MyGenom Project (10k Malaysian Genomes): Enablers, Execution and Barriers</td>
<td>Dr Syahrilnizam Abdullah</td>
<td>Malaysia Genome &amp; Vaccine Institute</td>
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<td>Leveraging existing structures and collaborations and community engagement to initiate the FilipiNOME project</td>
<td>Dr Eva Maria Cutiongco-de la Paz</td>
<td>National Institutes of Health</td>
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<td>Overcoming implementation challenges to genomic programmes through PRECISE-ASEAN</td>
<td>Dr Tan Ee Shien</td>
<td>Precision Health Research</td>
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<td>Learnings from the 20 years of national genomic initiatives in Korea</td>
<td>Dr Hyun-Young Park</td>
<td>National Institutes of Health</td>
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<td>14:55 – 16:30</td>
<td>Group discussion</td>
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**Parallel Session B** How can human genomics initiatives contribute to health systems - lessons from cancer genomics

**Moderator:** Prof Joanne Ngeow Yuen Yie, National Cancer Centre Singapore

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<tr>
<td>13:40 – 14:55</td>
<td>Initiative on cancer genomic medicine in Japan</td>
<td>Dr Takashi Kohno</td>
<td>National Cancer Center</td>
<td>Japan</td>
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<td>Integrating genomics into cancer control programmes in Viet Nam</td>
<td>Prof Thi Lan Anh Luong</td>
<td>Hanoi Medical University</td>
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<td>Governance structures in the national initiatives to implement genomic technology for cancer care in Korea</td>
<td>Prof Sun-Young Kong</td>
<td>National Cancer Center</td>
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<td>Workforce development to enable widescale implementation of cancer genomic programmes in China</td>
<td>Dr Jiao Yuchen</td>
<td>National Cancer Center</td>
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<td>14:55 – 16:30</td>
<td>Group discussion</td>
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**Parallel Session C** Advocacy and partnerships – reflections from rare disease and congenital disorder genomics

**Moderator:** Prof Zilfalil Alwi, Universiti Sains Malaysia
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<tbody>
<tr>
<td>13:40 – 14:55</td>
<td>Establishing the Initiative on Rare and Undiagnosed Diseases in Japan</td>
<td>Prof Hidehiro Mizusawa, National Centre of Neurology &amp; Psychiatry Japan</td>
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<td>Integrating genomic data into clinical practice for congenital disorders</td>
<td>Dr Adiratna Mat Ripen, National Institutes of Health Malaysia</td>
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<td>The importance of data sharing and inclusive reference data for equitable rare disease genomics</td>
<td>Prof Daniel MacArthur, Centre for Population Genomics Australia</td>
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<td>The role of effective partnerships in advancing rare disease and congenital disorder genomics investments in the Philippines</td>
<td>Dr Carmencita Padilla, University of the Philippines Manila Philippines</td>
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<td>14:55 – 16:30</td>
<td>Group discussion</td>
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<td>16:45 – 16:55</td>
<td>Call to Action Feedback</td>
<td>Dr Elena Ambrosino (WHO HQ)</td>
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**Session 3 Sharing of parallel session outcomes**

_Moderator: Ms Mengji Chen, Team Lead, Innovation and Research, WPRO_

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<tr>
<td>16:55 – 17:25</td>
<td>Parallel A Group discussion leads</td>
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<tr>
<td>18:30 – 20:30</td>
<td>Dinner reception</td>
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**Day 2 Tuesday, 30 April 2024**

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<tr>
<td>08:30 – 08:35</td>
<td>Overview of the Day</td>
<td>Ms Mengji Chen (WHO WPRO)</td>
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<tr>
<td>08:35 – 09:35</td>
<td>Updates on the development of the WHO Guidance Principles on Human Genome Data Access, Use and Sharing</td>
<td>Prof Kazuto Kato, Osaka University Japan</td>
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<td>Supporting the establishment of bioinformatics and genomic data capacity in the Asia-Pacific</td>
<td>Prof Shoba Ranganathan, Macquarie University Australia</td>
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<td>Challenges and opportunities in sharing data with study participants in the Tohoku Medical Megabank Project</td>
<td>Prof Masayuki Yamamoto, Tohoku University Japan</td>
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<td>Advancing ethical genomics data governance in the era of artificial intelligence</td>
<td>Prof Hannah Kim, Yonsei University</td>
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<td>09:35–10:00</td>
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**Session 5** Implementing human genomics – Ethical, legal and social implications  
**Moderator: Prof Kazuto Kato, Osaka University**

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<tr>
<td>10:30–11:30</td>
<td>Translating ethical values into health policy in human genomics</td>
<td>Prof Angus Dawson</td>
<td>National University Singapore Singapore</td>
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<td>Ethical and legal framework of genomics research and their repercussions in Korea</td>
<td>Prof Ock-Joo Kim</td>
<td>Seoul National University Republic of Korea</td>
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<td>Regulating genomic technology in New Zealand</td>
<td>Mr Steve Waldegrave</td>
<td>Ministry of Health New Zealand</td>
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<td>Engaging indigenous population in human genomics research</td>
<td>Prof Alexander Brown</td>
<td>Australia National University Australia</td>
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<td>11:30–12:00</td>
<td>Panel discussion</td>
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<td>12:00–13:00</td>
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**Session 6** Implementing human genomics – Ecosystems and stakeholders  
**Moderator: Prof Ock Joo Kim, Seoul National University**

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<tr>
<td>13:00–13:45</td>
<td>Equitable partnerships in lung cancer genomics in Asia-Pacific</td>
<td>Dr Daniel Tan</td>
<td>National Cancer Centre Singapore</td>
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<td>Aligning government, academia and industry for Precision Cancer Care</td>
<td>Prof Sean Grimmond</td>
<td>University of Melbourne Australia</td>
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<td>Culturally informed and inclusive biobanking</td>
<td>Prof Maui Hudson</td>
<td>University of Waikato New Zealand</td>
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<td>13:45–14:00</td>
<td>Panel discussion</td>
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<td>14:00–14:30</td>
<td>Coffee break and Mobility Break</td>
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**Session 7** Implementing human genomics – Making an investment case  
**Moderator: Dr Lock-Hock Neu, Hospital Kuala Lumpur**

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<tr>
<td>14:30–15:00</td>
<td>Defining downstream benefits of genomic programmes in less-resourced contexts</td>
<td>Dr Erik Karlsson</td>
<td>Institute Pasteur of Cambodia Cambodia</td>
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<td>Benefits derived at different stages of implementing national genomic initiatives</td>
<td>Dr Jianchao Quan</td>
<td>Hong Kong University</td>
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<td>15:00 – 15:15</td>
<td>Panel discussion</td>
<td>Hong Kong</td>
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<td>15:15 – 15:45</td>
<td>Group discussion (Facilitated by WHO secretariat)</td>
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<td>15:45 – 16:00</td>
<td>Report back (Group facilitators)</td>
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<td>16:00 – 16:15</td>
<td>Revisiting the WHO Genomics Programme of Work (Dr Elena Ambrosino (WHO HQ))</td>
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<td>16:15 – 16:25</td>
<td>Closing remarks (Dr Anna Laura Ross (WHO HQ), Dr Kidong Park (WHO WPRO))</td>
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<td>16:40 – 20:00</td>
<td>National Museum of Fine Arts Tour and Dinner</td>
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Annex 2. List of Participants

TEMPORARY ADVISORS

Ms Tiffany Frances Boughtwood, Managing Director, Australian Genomics, Australia
Prof Alexander Brown, Professor of Indigenous Genomics, Australian National University and Telethon Kids Institute, Australia
Prof Sean Grimmond, Director, Centre for Cancer Research, University of Melbourne, Australia
Prof Ilia Gorantis, Associate Professor in Health Economics, University of Melbourne, Australia
Prof Daniel MacArthur, Director, Centre for Population Genomics, Garvan Institute of Medical Research, Australia
Prof Shoba Ranganathan, Honorary Professor of Bioinformatics, Macquarie University, Australia
Dr Mas Rina Wati Haji Abdul Hamid, Associate Professor, PAPRSB Institute of Health Sciences, Brunei Darussalam
Dr Noraslinah Ramlee, Consultant Physician and Head of Early Detection and Cancer Prevention Services, The Brunei Cancer Centre, Brunei Darussalam
Mr Savuth Chin, Deputy Chief, National Public Health Laboratory, National Institute of Public Health, Cambodia
Dr Eric Karlsson, Deputy Head, Virology Unit, Institute Pasteur of Cambodia, Cambodia
Dr Yuchen Jiao, Director and Investigator, Laboratory of Molecular and Cellular Biology, National Cancer Center, China
Prof Wenming Zhao, Vice Director and Professor, Beijing Institute of Genomics, China National Center for Bioinformation, China
Dr Jianchao Quan, Clinical Assistant Professor, School of Public Health, University of Hong Kong, Hong Kong Special Administrative Region (China)
Prof Kazuto Kato, Professor, Department of Biomedical Ethics and Public Policy, Osaka University, Japan
Dr Takashi Kohno, Director, Center for Cancer Genomics and Advanced Therapeutics, National Cancer Center, Japan
Prof Hidehiro Mizusawa, President Emeritus and President Special Adviser, National Center of Neurology and Psychiatry, Japan
Prof Masayuki Yamamoto, Executive Director and Professor, Tohoku University, Tohoku Medical Megabank Organization, Japan
Dr Syahrlinizam Abdullah, Director, Malaysia Genome and Vaccine Institute, Malaysia
Dr Zilfalil Bin Alwi, Consultant Pediatrician and Clinical Geneticist, University Sains Malaysia, Malaysia
Dr Adiratna Mat Ripen, Head of Cancer Research Centre, National Institutes of Health, Ministry of Health, Malaysia
Dr Nor Fariza Binti Ngah, Deputy Director of Health, Ministry of Health, Malaysia
Dr Lock Hock Ngu, Clinical Geneticist Consultant, Hospital Kuala Lumpur, Ministry of Health, Malaysia
Dr Ganzorig Dorjdagva, Expert in Charge for Health Science and Research Planning, Ministry of Health, Mongolia
Dr Erkhembulgan Purevdorj, Head, Ulaanbaatar City Health Department, Mongolia

Prof Maui Hudson, Director, Te Kotahi Research Institute, University of Waikato, New Zealand
Mr Stephen Waldegrave, Associate Deputy Director-General, Strategy, Policy and Legislation, Ministry of Health, New Zealand

Prof William Pomat, Director, Institute of Medical Research, Ministry of Health, Papua New Guinea

Mr Pio Justin Asuncion, Chief Health Program Officer, Health Research Division, Department of Health, Philippines
Dr Sonia Bongala, Chairperson, Philippines Health Research Ethics Board, Department of Science and Technology, Philippines
Dr Eva Maria Cutiongco-De la Paz, Executive Director, Institute of Human Genetics, National Institutes of Health, University of the Philippines-Manila, Philippines
Dr Carmencita Padilla, Emeritus Professor, Department of Pediatrics, University of the Philippines-Manila, Philippines

Dr Dahye Kim, Deputy Director, Division of Bioethics Policy, Ministry of Health and Welfare, Republic of Korea
Prof Hannah Kim, Research Associate Professor, Department of Medical Law and Ethics, Asian Institute for Bioethics and Health Law, Yonsei University, Republic of Korea
Prof Ock-joo Kim, Chair and Professor, History of Medicine and Medical Humanities, Seoul National University, Republic of Korea
Prof Sun-Young Kong, Professor, Cancer Medical Science, National Cancer Center, Republic of Korea
Prof Beom Hee Lee, Professor, Pediatric, Asan Medical Center, Republic of Korea
Dr Hyun-Young Park, Deputy Minister, Korea National Institute of Health, Republic of Korea

Prof Angus Dawson, Professor of Bioethics, Center for Biomedical Ethics, National University of Singapore, Singapore
Prof Joanne Yuen Yie Ngeow, Head of Cancer Genetics Service, National Cancer Centre Singapore, Singapore
Dr Daniel Tan, Senior Consultant, Department of Medical Oncology, National Cancer Centre, Singapore
Dr Ee Shien Tan, Deputy Chief Medical Officer, Chief Medical Officer Office, Precision Health Reasearch, Singapore

Prof Thi Lan Anh Luong, Medical Doctor and Senior Lecturer, Department fo Medical Biology and Genetics, Hanoi Medical University, Viet Nam

OBSERVERS

Dr Fan Man Lo, Consultant in Clinical Genetics, Department of Health, Hong Kong Special Administrative Region (China)
Dr Lam Man Yu, Senior Medical Officer for Disease Prevention, Department of Health, **Hong Kong Special Administrative Region (China)**

Mr Philip Depatilo, Senior Research Science Specialist, Philippine Council for Health Research and Development, Department of Science and Technology, **Philippines**

Ms Heo Nan, Division of Bioethics Policy, Ministry of Health and Welfare, **Republic of Korea**
Dr Mi-Hyun Park, Senior Staff Scientist, Division of Genome Science, **Republic of Korea**

**SECRETARIAT**

**WHO Regional Office for the Western Pacific**

Dr Susan Mercado, Director of Programme Management
Dr Kidong Park, Director of Data, Strategy and Innovation
Ms Mengji Chen, Technical Officer, Innovation and Research
Dr Rolando Enrique Domingo, Coordinator, Management of Communicable Diseases
Dr Rajesh Narwal, Coordinator, Universal Health Coverage
Dr Julienne O’Rourke, Technical Officer, Office of the Director, Programme Management
Dr Greco Mark Malijan, Consultant, Innovation and Research
Ms Dayoung Song, Consultant, Innovation and Research
Ms Ma-ann Zarsuelo, Consultant, Universal Health Coverage

**WHO Headquarters**

Dr Anna Laura Ross, Unit Head, Emerging Technologies, Research Prioritization and Support
Dr Elena Ambrosino, Consultant, Emerging Technologies, Research Prioritization and Support
Dr Catalina Lopez-Correa, Consultant, Emerging Technologies, Research Prioritization and Support