For discussion
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Legislative Council Panel on Health Services

Genomic Medicine

Purpose

This paper briefs Members on the Report on Strategic Development of Genomic Medicine in Hong Kong submitted by the Steering Committee on Genomic Medicine[1] (the Steering Committee) to the Government.

Background

2. The rapid advancement in genomic medicine[2] has presented huge potential in accurate diagnosis, personalised treatment and efficient surveillance of diseases. In view of the importance of genomic medicine to future medical development, the Secretary for Food and Health appointed the Steering Committee in December 2017 to lead the study on strategies for developing genomic medicine in Hong Kong.

Gist of the Report

3. The Steering Committee and its three Working Groups had a total of 17 meetings in the two-year-term. In December 2019, the Steering Committee concluded its discussions and submitted a report to the Government for consideration[3]. The report gave a detailed account of

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[1] The Steering Committee is chaired by Professor Raymond Liang Hin-suen and comprises members from academia, professional bodies and experts in genomic medicine. The membership list is at Annex.

[2] A genome is the complete set of DNA found within a cell. Genomic medicine uses genome data to support clinical treatment.

[3] The report is available at

the current landscape of genetics and genomics in Hong Kong, examined key issues to be addressed and proposed eight recommendations on further development of genomic medicine in Hong Kong. A summary is set out in the ensuring paragraphs.

(a) Overview of Genetics and Genomics in Hong Kong

4. The Steering Committee recognised that with the dedicated work of passionate clinicians and researchers in the past few decades, high quality clinical services and impressive research outcomes on genomic medicine have been developed organically, benefiting many patients in Hong Kong. Meanwhile, the opportunities presented by recent scientific breakthrough require a clear policy to steer and coordinate the efforts of various institutions, notably the Department of Health (DH), the Hospital Authority (HA), local universities, professional bodies and the private sector, in order to bring the development of clinical application and research in genomic medicine in Hong Kong to the next level.

(b) Key Issues to be Addressed

5. The Steering Committee identified the following four key issues which ought to be addressed through a comprehensive strategy –

(a) ***standardised clinical service provision*** – a need to explore a more standardised and coordinated clinical pathway for genetic and genomic services in Hong Kong, so that patients can access to clinical genetic and genomic services on a fair and equitable basis;

(b) ***more efficient laboratory services and translation of new technology to clinical use*** – a need for a well-established mechanism to evaluate the clinical validity and utility of new genetic and genomic tests developed by different institutions, which will also facilitate transfer of new technology into clinical use;

(c) ***enhancement of training and establishment of clear career***

https://www.fhb.gov.hk/en/press_and_publications/otherinfo/200300_genomic/index.html

paths – a need to train more healthcare professionals specialised in genomic medicine and enhance genomic literacy among general healthcare professionals; and

(d) ***ethical, legal and social implications*** – a need for proper regulatory and educational measures to address potential discrimination by insurers and employers based on genetic information and prevalence of direct-to-consumer genetic tests (DTCGTs), etc.

(c) Eight Recommendations

6. The Steering Committee proposed the following eight recommendations to guide the long term strategic development of genomic medicine in Hong Kong.

Recommendation 1: Launching the Hong Kong Genome Project

7. In order to significantly advance the development of genomic medicine in Hong Kong, the Steering Committee recommended that a large-scale genome sequencing project should be introduced to serve as a catalyst and anchor for showcasing the clinical benefits, piloting related new policy measures, building up talent pool and testing clinical protocols. With reference to international experiences, such project can also provide the essential data for researchers to conduct genomic researches focusing on local population, bringing benefits to patients of our community.

8. At the recommendation of the Steering Committee, the Chief Executive announced in the 2018 Policy Address that the Government would launch the Hong Kong Genome Project (HKGP), which aims to sequence around 40 000 to 50 000 genomes in the next six years, with a budget of $1.2 billion allocated in the 2019-20 Budget. Brief details were reported to this Panel in January 2019. The Hong Kong Genome Institute (HKGI), which is a company limited by guarantee wholly owned by the Government, was established in May 2020 to take forward the HKGP in partnership with HA and universities. Recruitment of senior

management is underway. The latest plan is to start recruiting patients for sequencing in mid-2021.

Recommendation 2: Enhancing clinical services in genetics and genomics

9. The Steering Committee supported HA's Strategic Service Framework for Genetic and Genomic Services announced in October 2019, which aimed to provide structured and coordinated clinical services in genetics and genomics in HA.

10. In particular, the Steering Committee recommended that designated posts for clinical geneticists, pathologists, genetic counsellors and bioinformaticians should be created in HA to establish clear career paths for these professions. The Hong Kong Children's Hospital (the Hospital), a tertiary referral centre for complex paediatric cases, should play a key role in enhancing service collaboration and research translation in genomic medicine among HA, the Clinical Genetic Service of DH and universities. The Hospital would also serve as a major training ground for genetics and genomics. In addition, the genetic and genomic test formulary should be enhanced with clinical guidelines to ensure the standardised use of genetic and genomic tests, while the mechanism for evaluating the introduction of new genetic and genomic tests in clinical service should be as efficient and flexible as possible.

Recommendation 3: Nurturing talents in genomic medicine

11. The Steering Committee recommended that the Government should estimate the manpower requirement for professionals in genomic medicine to facilitate programme planning of universities, and to attract prospective students and overseas talents. The Hong Kong Academy of Medicine has been invited to coordinate with relevant colleges on enhancing training in genetics and genomics of clinicians, including issuing relevant ethical guidelines.

12. The Steering Committee recognised the important roles of genetic counsellors and bioinformaticians in genomic medicine, and

recommended that universities and academic institutes should be encouraged to offer relevant postgraduate-level programmes which benchmark international qualifications.

13. The Steering Committee considered that clear career path is one of the keys to building up a talent pool for genomic medicine in Hong Kong. In this regard, HA and DH should actively explore the creation of dedicated posts for genetic and genomic services with clear promotional prospect to attract talents.

14. The Steering Committee recognised that the genomic literacy of clinicians, nurses and allied health professionals in general should be enhanced. The proposed HKGP will play a catalytic role in enhancing the genetic and genomic knowledge of healthcare professionals and attracting both local and international talents.

Recommendation 4: Enhancing public engagement in genomic medicine

15. The Steering Committee considered that there is a need to enhance public engagement in the potential and limitations of genomics on healthcare decisions, the proper use of genetic and genomic tests, as well as the relevant ethical implications. FHB, together with DH, HKGI and other stakeholders, should tap on the opportunity of the HKGP to promote public understanding on the above issues.

Recommendation 5: Enhancing the laboratory network with effective referral mechanism and centralisation of advanced genetic and genomic tests

16. The Steering Committee recommended that a referral mechanism on genetic and genomic tests should be established among laboratories in HA, DH, universities and the private sector, and that the provision of advanced genetic and genomic tests supported by public funding should be centralised where appropriate. The proposal could synergise expertise, unify laboratory standards, optimise the use of public resources and allow patients to have more equitable access to appropriate genetic and genomic tests.

Recommendation 6: Facilitating the establishment of a biobank network for genomic research

17. The Steering Committee considered that instead of establishing a centralised biobank, the Government should explore measures to facilitate the establishment of a network of biobanks across institutions, in order to enable the sharing of de-identified biospecimens and associated data for future genomic research. To this end, there is a need to develop a standard protocol on consent-taking, protection of privacy, etc. which will be piloted in the HKGP. The Steering Committee recommended that the Government should consider making participation in the biobank network as one of the conditions for future genomic research projects to receive government funding (e.g. the Health and Medical Research Fund).

Recommendation 7: Enhancing the regulation on use of genetic data for insurance and employment purposes

18. The Steering Committee noted that in addition to the Disability Discrimination Ordinance and the Personal Data (Privacy) Ordinance, more specific regulatory measures on genetic discrimination in the context of insurance should be explored. In view of the rapid development of genomic medicine, the Steering Committee considered that it would be more pragmatic and flexible to enhance regulation through an updated Code of Practice issued by the Hong Kong Federation of Insurers (HKFI). The Government should continue to review the situation and consider introducing legislative measures as and when necessary. Meanwhile, public education should be enhanced on anti-genetic discrimination in employment for employers and employees.

19. Taking into account the recommendation of the Steering Committee, the HKFI has updated the Best Practice on the Use of Genetic Test Results, which took effect on 1 June 2020. In gist, members of HKFI will not require applicants to undertake genetic testing for underwriting purposes nor asking for results of genetic tests which were performed in the context of scientific research, including that of HKGP. Insurers may only ask for a limited list of predictive genetic test results when the applicant applies for Life Insurance or Critical Illness /

Dread Disease policies over defined protection limits, i.e. $5 million and $1 million respectively. For medical indemnity insurance, no predictive genetic test results will be asked regardless of the sum insured.

Recommendation 8: Promoting the proper use of genetic and genomic tests

20. The Steering Committee considered that as DTCGTs have become popular outside the clinical setting, there is a need to introduce suitable measures to address related healthcare and ethical issues. Since many of the DTCGTs could be obtained overseas through online purchase, the most pragmatic approach is to enhance public education on making informed decisions. In particular, consumers should be advised, before taking the genetic tests, to consult healthcare professionals and to understand the clinical validity and utility of the tests, the privacy and ethical implications, as well as the limitations of the test results.

21. For health-related genetic tests, the Steering Committee considered that additional regulatory measures should be introduced, as a test result without proper counselling and professional advice may cause anxiety or false reassurance and would in turn lead to unnecessary investigations or delayed health care. The Steering Committee noted that the Government has been working on a statutory control framework for medical devices, which would cover human genetic tests in vitro that meet the definition of medical devices. The professional qualifications for conducting genetic and genomic tests should also be reviewed.

Way Forward

22. The Government accepted the recommendations of the Steering Committee in full. The Food and Health Bureau, supported by the DH, will implement the recommendations in collaboration with the HA, universities, and all relevant stakeholders. The HKGP will serve as a catalyst to take forward the recommendations.

Advice sought

23. Members are invited to note the content of this paper.

Food and Health Bureau
June 2020

Annex

Steering Committee on Genomic Medicine
Membership

Chairman

Professor Raymond Liang Hin-suen

Expert Members

Dr Derrick Au Kit-sing
Dr Joseph Au Siu-kie
Professor Stephen Lam Tak-sum
Professor Lam Tak-wah
Professor Lau Yu-lung
Professor Leung Tak-yeung
Professor Dennis Lo Yuk-ming
Professor Sham Pak-chung
Dr Mary Tang Hoi-yin
Dr Wong Kit-fai

Institutional Members

Representative from Hospital Authority
Representative from Hong Kong Academy of Medicine
Representative from The Chinese University of Hong Kong
Representative from The Hong Kong University of Science and Technology
Representative from The University of Hong Kong

Ex-officio Members

Under Secretary for Food and Health or representative
Commissioner for Innovation and Technology or representative
Director of Health or representative