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**Panel on Health Services**

**Background brief prepared by the Legislative Council Secretariat  
for the meeting on 12 June 2020**

**Genomic medicine**

**Purpose**

This paper provides background information on and summarizes the concerns of the members of the Panel on Health Services ("the Panel") on genomic medicine.

**Background**

2. Genome is the complete set of genetic material (i.e. DNA) found within a cell. Everyone's genome is unique. Apart from determining a person's physical characteristics, genome provides information why a person is prone to certain diseases and what treatment is more effective to that person. Genomic medicine uses genome data to support clinical treatment to bring the benefits of more precise diagnosis, avoiding unnecessary investigations, more personalized treatment, more prediction of disease development, more chances to explore new medicine and treatment, and more efficient ways to prevent diseases. There is an international trend to introduce large-scale genome sequencing project for clinical and scientific advancement.

3. Pursuant to the announcement in the Chief Executive's 2017 Policy Address that a steering committee would be set up to lead the study on strategies for developing genomic medicine in Hong Kong, the Secretary for Food and Health appointed the Steering Committee on Genomic Medicine ("the Steering Committee") in December 2017. Three working groups were established under the Steering Committee, namely, the Working Group on Laboratory Network for Genetic Testing, the Working Group on Biobank and the Working Group on Hong Kong Genome Project.

4. It was announced in the Chief Executive's 2018 Policy Address that based on the preliminary recommendation of the Steering Committee that a large-scale genome sequencing project should be conducted in Hong Kong with a view to enhancing the clinical application and promoting innovative scientific research on genomic medicine, the Government would provide funding to introduce the Hong Kong Genome Project ("HKGP"). Separately, the Hong Kong Genome Institute ("HKGI"), a limited by guarantee company wholly owned by the Administration, would be established to coordinate the implementation of HKGP and drive the collaboration of existing infrastructure and expertise for maximum synergy and innovation. It was announced in the Chief Executive's 2019 Policy Address that HKGI would be set up in 2020.

### **Deliberations of the Panel**

5. The Panel discussed issues relating to HKGP at its meeting on 21 January 2019. The deliberations and concerns of members are summarized in the following paragraphs.

#### Genome database under HKGP

6. Members expressed support for and urged an early implementation of HKGP which could enhance clinical application of genomic medicine to benefit patients and their families, and promote research in genomic medicine and related field. Referring to the genome studies conducted in the Mainland and other places on Chinese population, some members asked whether the application of genomic medicine could also be achieved by making use of the genome profiles developed under public genome infrastructure platform in the Mainland, or any collaborative studies could be conducted to achieve synergy and facilitate the development of a genome database of Chinese population. There was also an enquiry as to whether the Administration would accede to other places' request to access HKGP's anonymized genome data of the local population for the carrying out of various studies and, if so, whether a fee would be charged.

7. The Administration advised that the transfer of domestic genome data to places outside the Mainland was not allowed under the laws of the Mainland. That said, it was expected that the implementation of HKGP, which aimed to cover 20 000 cases in two phases and sequence 40 000 to 50 000 genomes in total, would contribute to the enhancement of clinical application of genomic medicine, the development of genome profiles on Chinese population and relevant scientific exchanges with other places, including the Mainland.

HKGP would also create synergies with the world-class biomedical technology and information and communications technology clusters to be established in the Hong Kong Science Park.

8. On the privacy-related issues arising from the access to the genomic and clinical data under HKGP, enquiries were made as to whether a regulatory framework or administrative measures would be put in place to protect patient privacy under HKGP and under which circumstances informed consent from participants would be sought and the parties responsible for approving data access requests. There was a particular concern about the privacy of the genomic and clinical data of patients with rare diseases, whom were small in case numbers and hence, could be easily identified.

9. The Administration advised that similar to the practice of some overseas genome projects, a secure database infrastructure platform would be established under HKGP and data access guidelines and protocols would be developed. Informed consent would be sought from participants. Researchers could only access the anonymized genomic and clinical data with the approval of the specific advisory committee and under an ethically approved research protocol. The Working Group on Hong Kong Genome Project set up under the Steering Committee would continue to examine issues relating to patient privacy under HKGP with reference to overseas practices. The view of the Privacy Commissioner for Personal Data in this regard would be consulted.

10. On members' concern about the timetable for the implementation of HKGP, the Administration advised that the plan was to commence the pilot phase of HKGP, which would cover 2 000 cases of undiagnosed disorders and cancers having clinical clues linked to possible hereditary genetic components, in 2020. Participants who were referred by the Hospital Authority ("HA") and the Department of Health ("DH") for participation in HKGP would not be required to bear the expenditure arising from genome sequencing. Some members opined that more cases of undiagnosed disorders and cancers should be covered under HKGP for achieving the objective of enhancing clinical application of genomic medicine, in particular the diagnosis of uncommon disorders and the provision of more personalized treatment for cancer patients. In addition, the sample size or case selection for whole genome sequencing had to be of statistical significance to achieve the aim of enhancing genetic diagnosis of rare diseases. The Administration advised that the number of samples collected from each case might vary. It was estimated that the pilot phase of HKGP would sequence 4 000 to 5 000 genomes in total.

## Funding and agent for the implementation of HKGP

11. There was a concern about the funding requirement for the implementation of HKGP. The Administration advised that \$1.2 billion had been earmarked for the implementation of HKGP, which included a non-recurrent provision of \$682 million to meet the project cost of HKGP and a subvention of about \$87 million per year on average for six years starting from 2019-2020 to support the operation of HKGI.

12. On the Administration's plan to task HKGI with the responsibility of coordinating the implementation of HKGP, question was raised as to whether it was common in other places for the Government to set up an agent to deliver the genome projects. The Administration advised that the genome projects of Singapore and the United Kingdom were respectively led by an institute and a company set up by the Government. The setting up of HKGI would enhance the flexibility and efficiency in the implementation of HKGP. The operation of HKGI would be bound by a Memorandum of Administrative Arrangement, which would incorporate important checks and balances to ensure transparency and public accountability of HKGI on the use of public fund.

## Development of genome medicine

13. Concerns were raised over the sufficiency of local experts in the sphere of genomic medicine, and whether the development of genomic medicine in the long run would involve the controversial issue of human genome editing technology. According to the Administration, there were experts in genomic medicine or related field working in HA, DH and local universities. The implementation of HKGP would not only facilitate the enlargement of the talent pool, but also enhance the diagnostic rate of uncommon genetic disorders, enabling more targeted clinical management which ranged from targeted diagnostic testing, medication, surgical procedures, surveillance to lifestyle changes.

## **Recent developments**

14. The Steering Committee concluded its discussions and submitted the Report on Strategic Development of Genomic Medicine in Hong Kong to the Administration in December 2019.<sup>1</sup> In May 2020, the Administration announced that it had accepted all the recommendations put forth by the Steering Committee, among which HKGP was accorded the top priority.

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<sup>1</sup> The Report is available at the Food and Health Bureau's website at [https://www.fhb.gov.hk/download/press\\_and\\_publications/otherinfo/200300\\_genomic/SCGM\\_report\\_en.pdf](https://www.fhb.gov.hk/download/press_and_publications/otherinfo/200300_genomic/SCGM_report_en.pdf).

15. The Administration will brief the Panel on the Report on 12 June 2020.

**Relevant papers**

16. A list of the relevant papers on the Legislative Council website is in the **Appendix**.

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**Relevant papers on genomic medicine**

<b>Committee</b>	<b>Date of meeting</b>	<b>Paper</b>
Panel on Health Services	16.10.2017 (Item IV)	<a href="#">Agenda</a> <a href="#">Minutes</a>
	15.10.2018 (Item III)	<a href="#">Agenda</a> <a href="#">Minutes</a>
	21.1.2019 (Item III)	<a href="#">Agenda</a> <a href="#">Minutes</a> <a href="#">CB(2)1842/18-19(01)</a>
	21.10.2019 (Item I)	<a href="#">Agenda</a> <a href="#">Minutes</a>

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