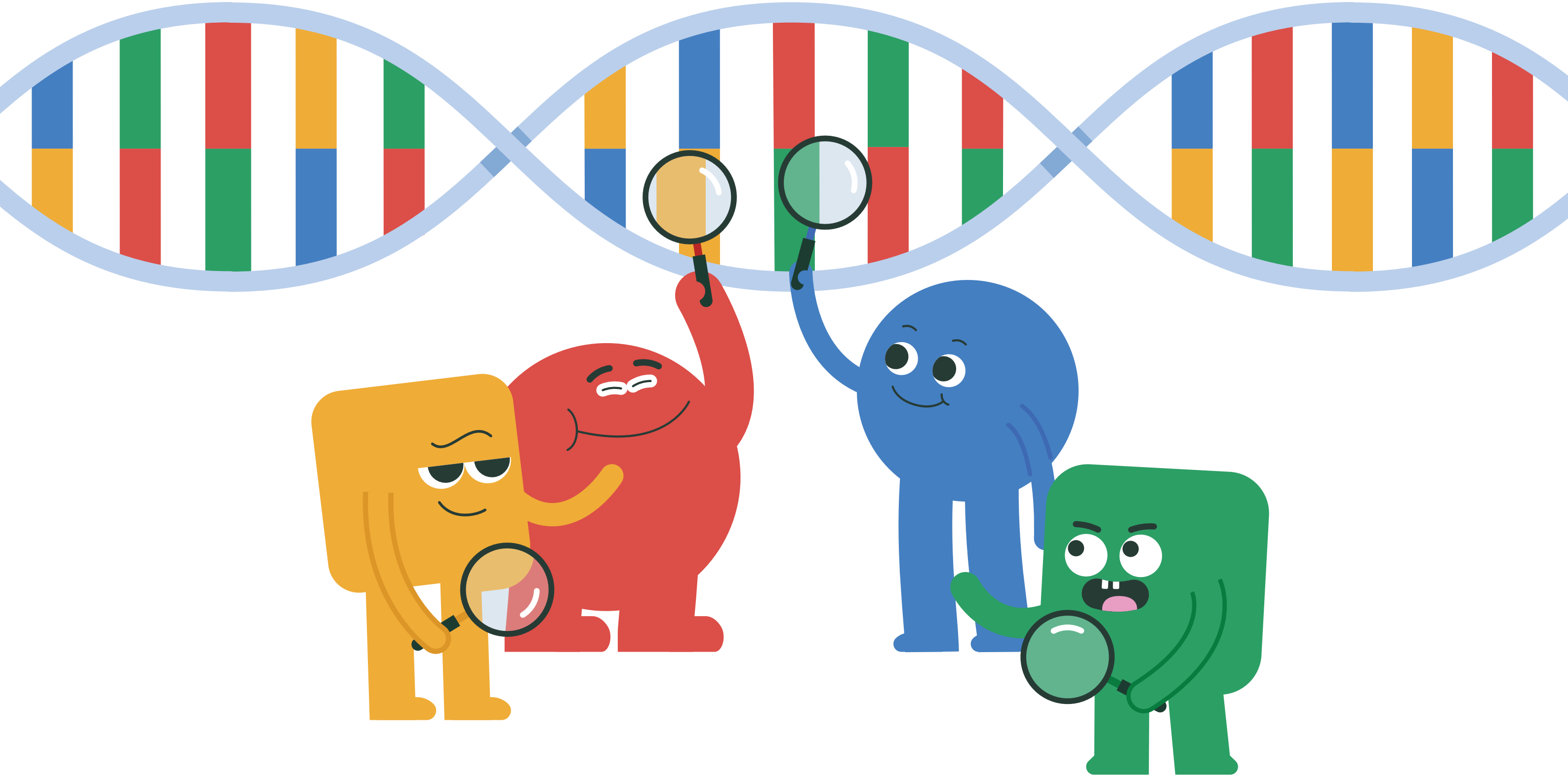

Hong Kong Genome Project Information Booklet

(appropriate for individuals aged 18 or above)

(Version 2.0, dated Aug 2021)

Preface

The human genome[1] comprises over 3 billion DNA bases, the basic unit of DNA. It is tantamount to our "body manual", sorting through the vast number of bases that determines an individual's physical characteristics such as facial features, height and signs for why some people may have or are more susceptible to certain diseases. Whole Genome Sequencing[2] is the technology that enables us to read the sequence of all the DNA bases in the human genome, allowing clinicians and scientists to look for cures for diseases, benefit more patients and propel medical development.

There has been a rapid development in genomic technology in recent years, such as rapid DNA sequencing and data analysis etc., enabling us to make use of genomic data to conduct effective disease diagnosis, surveillance and screening, as well as to develop prevention and treatment schemes. In view of this, the Hong Kong Genome Institute (HKGI) was established by the Food and Health Bureau in 2020 to implement the Hong Kong Genome Project (HKGP) to promote the development of genomic medicine in Hong Kong and advance the health of the general population in the long run.

The HKGI will recruit 20,000 eligible cases, involving around 40,000 to 50,000 eligible patients and their family members whose samples will undergo WGS with their consent. Data obtained from the Project will be used to inform clinical diagnoses and treatments for patients, and be used anonymously for approved medical research under stringent scrutiny. All these will enable clinicians and scientists to better understand the relationship between genomes and different diseases. The knowledge and experience accumulated will play a crucial role in fostering future medical development in Hong Kong.

This booklet will provide you with more details about the HKGP. If you have any queries, please feel free to obtain more information through the following channels:

- Visit the HKGP website: **www.hkgp.org**
- Contact the genetic counsellors of the HKGP's Partnering Centres:

Partnering Centres	Phone	Office Hours
Hong Kong Children's Hospital	(852) 5741 3334	9:00am to 5:00pm from Monday to Friday; Closed on Saturday, Sunday and Public Holidays
The Chinese University of Hong Kong / Prince of Wales Hospital	(852) 3763 6069	
The University of Hong Kong / Queen Mary Hospital	(852) 2255 6203	

Note 1- 2 : Please refer to page 7 for explanations of the terms "genome" and "whole genome sequencing".

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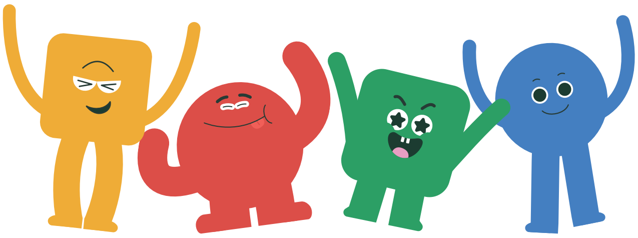


Chapter 1:

Project Overview

① Project Introduction, Objectives and Implementation

1.1. Project Introduction

The Hong Kong Genome Project (HKGP) is a research project. Although it is not a routine clinical service, it may still be helpful to participants regarding diagnosis and treatment of diseases they are living with.

The HKGI will be carried out in two phases, the pilot phase and the main phase. The pilot phase will recruit 2,000 cases of undiagnosed disease and hereditary cancer. Whole Genome Sequencing will be conducted for the patients and their families. After the pilot phase, the scope of the main phase will be expanded to cover other hereditary disorders. The ultimate goal of the Project is to enrol 20,000 cases. Since some cases may involve two or more samples depending on the clinical and research needs, it is estimated that the HKGP would sequence 40,000 to 50,000 genomes in total.

1.2. Project Objectives

- Benefit patients and their families, for examples, by increasing the diagnostic rate of diseases, or by giving cancer patients more personalised treatment;
- Establish a genome database of the local population by integrating their genomic data and clinical medical data to aid clinicians and scientists to understand the links between genome and diseases in order to render more accurate diagnoses and appropriate medical care for patients; and
- Promote the clinical application and research of genomic medicine as well as the medical development in Hong Kong.

1.3. Project Implementation

Overall coordination and execution of the Project is carried out by:

食物及衞生局
Food and Health Bureau

Hong Kong
Genome Institute
香港基因組中心

The HKGI collaborates with various stakeholders* to implement the Project:

衞生署
Department of Health

醫院管理局
HOSPITAL AUTHORITY

CU Medicine
香港中文大學醫學院
Faculty of Medicine
The Chinese University of Hong Kong

HKU Med

For the pilot phase, the HKGI has set up Partnering Centres in three hospitals* under the Hospital Authority to recruit eligible participants to join the Project.

香港兒童醫院
Hong Kong Children's Hospital

威爾斯親王醫院
PRINCE OF WALES HOSPITAL

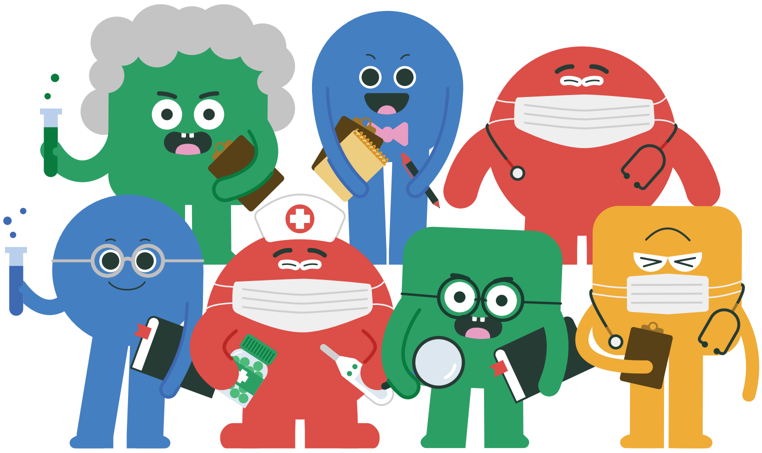
瑪麗醫院
QUEEN MARY HOSPITAL

*Names are listed in alphabetical order

1.4. The Project Team

The project team (referred to below as "we") comprises clinicians, nurses, scientists, bioinformaticians and genetic counsellors. Our duties include:

- Enrolling suitable participants;
- Explaining project details and addressing participants' queries before they sign consent forms;
- Collecting samples, performing Whole Genome Sequencing, and analysing the genomic data;
- Preparing Whole Genome Sequencing results report for participants; and
- Providing genetic counselling and discussing results report with participants.



② "Genome" and "Whole Genome Sequencing"

What is a genome?

"Genome" is a relatively new and significant term in genetics. It refers to all the genetic material in an organism. It is like our "body manual", consisting of over 3 billion DNA bases (A, T, C, G). These bases, being the basic unit of DNA, are like English alphabets in a manual. They convey genetic information through various sequences that determine our physical characteristics and potential risks for myriad diseases.

Please scan the QR code to understand the difference between "gene" and "genome"

What is Whole Genome Sequencing?

1. As mentioned, the human genome has 4 DNA bases like alphabets: A, T, C and G. Whole Genome Sequencing aims to read out the order of over 3 billion DNA bases in this "body manual".

2. After obtaining a patient's genomic data from the sequencing, medical professionals and scientists then proceed with data analysis, which is a substantial investment of time and resources, to identify disease-causing variants (pathogenic / likely pathogenic variant). This information can be used to diagnose the patient's condition, and to prescribe appropriate medication or plan for clinical care and management.

③ Target Participants

Currently, the Project is in its pilot phase and is recruiting a total of 4,000 to 5,000 individuals with undiagnosed diseases or hereditary cancers and their families for Whole Genome Sequencing.

If you fulfil any of the conditions below, you may qualify to join the Project.

- You may have a medical condition without a known cause despite a lot of evaluations (refered to as an undiagnosed disease) and it may be genetically linked; or
- Clinical data shows that you may have hereditary cancer; or
- You are a family member of either type of patient.

Eligible individuals must be referred to the Project through Partnering Centres. The project team will then formally assess each individual's situation and determine their eligibility to join the Project.

Please scan the QR code to learn how Whole Genome Sequencing can help these two types of patients

Undiagnosed diseases

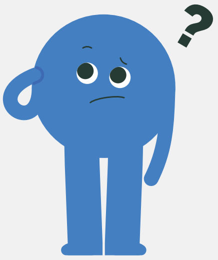
Hereditary cancers

④ Benefits of Joining the Project

If you meet the eligibility criteria and agree to join, we will perform Whole Genome Sequencing for you free of charge. We will also review the results with you to help you and your family members better understand your medical condition and to potentially benefit from this knowledge.

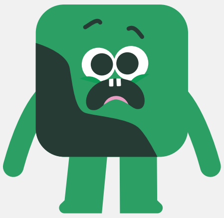
If you are a patient living with an undiagnosed disease, participating in the Project will:

- Assist clinicians to uncover the cause of a disease for you and possibly improve your chances of a correct diagnosis.
- Assist clinicians in devising clinical care and long-term treatment that is more appropriate for you.
- Help you and your family understand the genetic risks to facilitate family planning.
- Potentially inform diagnoses for patients with similar symptoms.



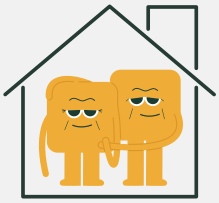
If you are a patient with hereditary cancer, participating in the Project will:

- Help clinicians formulate more appropriate treatment for you.
- Assist scientific researchers and medical professionals to understand the relationships between genetic variants and cancers that you and other patients may be living with.



If you are a patient's family member, participating in the Project will:

- Help us gain insight into the medical situation of your family member by comparing their genome with yours, thus formulating a better care plan for your family member.



5 Project Terms

Joining the Project is purely voluntary. Please consider carefully before deciding to join.

- Participation is free of charge.
- Joining does not involve any remuneration.
- You can withdraw from the Project at any time without giving a reason.
- Whether you join the Project or choose to withdraw after joining will not affect your access to regular medical services.

Chapter 2:

Project Participation

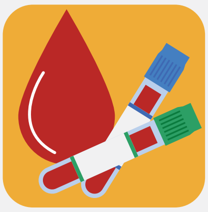
If you decide to participate in the Project, you must sign a consent form to authorise:

- The HKGI to use and store the samples you provide;
- The project team to access your medical records; and
- The HKGI to share with researchers your "de-identified” data (data that does not contain your identifying personal information). Please refer to page 14 for the detailed explanation of “de-identified data”.

⑥ Sample Collection

6.1. What Samples Will the Project Collect?

If you are a patient:



Blood sample

We will need to obtain a blood sample from you (5-10 ml for adults, 3-5 ml for children).

Saliva sample

Depending on your medical condition, we may ask you to provide 3-5 ml of saliva.

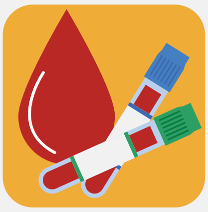
Buccal swab sample

Depending on your medical condition, we may ask you to provide 2-4 buccal swabs. The collection may take a few minutes.

Body tissue sample

For body tissue samples, we will collect them during surgery according to your clinical needs or take them from excised tissues after the surgery. You will not need to undergo additional surgery for us to collect tissue samples for the HKGP.

If you are a patient's family member:



Blood sample

We will need you to provide a blood sample (5-10 ml for adults).

Should specific circumstances arise, such as needing additional amounts and / or alternative types of samples, we will use leftover portions of samples you have previously submitted to the Hospital Authority or Clinical Genetic Service, Department of Health for more precise analysis.

The project team will contact you again if we need additional samples or information from you. You may consider and decide on each new request independently.

Your rights:

- **Providing samples is purely voluntary. You may decide after careful consideration of your situation and when all information is provided.**
- **When you agree to provide us with samples, you are authorising and agreeing the HKGI to use your samples for the HKGP.**

6.2. Sample Processing

After providing samples, the HKGI will extract genetic material from them and carry out Whole Genome Sequencing to obtain genomic data.

The entire process will only be conducted in Hong Kong. The analyses include genomics and other "omics" studies, such as "proteomics" and "metabolomics".

1 The HKGI will extract genetic material from the samples provided by the participants

2 Carry out Whole Genome Sequencing

3 Obtain genomic data

4 Carry out analyses with samples and medical records

Your samples will be stored in the HKGI's Biobank at the Hong Kong Science Park. The HKGI will abide by strict guidelines and management processes to handle the samples. Your samples will be stored for seven years after the completion of the Project. If a longer duration is required to complete the Project, the HKGI will seek endorsement from relevant research ethics committees.

In addition, when necessary, some samples may be kept in the Partnering Centre's laboratory for clinical use.

⑦ Access to Medical Records

Whole Genome Sequencing can help clinicians diagnose, understand and treat diseases, and your medical records are a crucial and accurate source of information about your medical condition. To enable us to carry out analysis in understanding the relationship between genome and disease, we have to refer to both your health and genomic data.

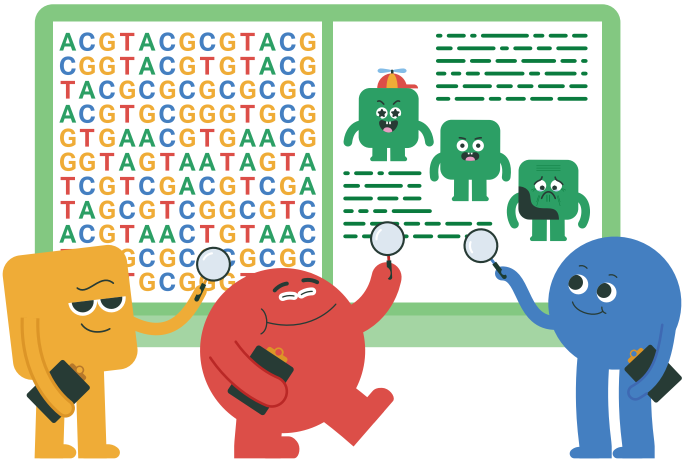
The HKGP is a long-term project, and the medical conditions of participants will change over time. These changes may bring new research insights, so we need participants' medical records at different time points for sustained analysis.

After obtaining your consent, we will, when necessary, access and analyse your medical records in the Hospital Authority and Clinical Genetic Service, Department of Health, including:

- Records of hospitalisation or clinic visits;
- Clinical records and laboratory test results; and
- Radiology and imaging records such as magnetic resonance imaging (MRI) scans, X-rays or clinical photos, etc.

Moreover, if necessary, we will contact you to collect more information, such as your health records that is kept at other medical institutions. We will explain and invite you to sign extra consent forms if needed. You may decide at that time if you wish to provide additional information.

If you withdraw from the Project, we will stop accessing your medical records.



8 Handling Participants' Data

The HKGP greatly values the privacy and the security of every participant's data. The collection procedure for all personal and genomic data complies with the Hong Kong law, Personal Data (Privacy) Ordinance Cap. 486, and all data will be kept strictly confidential.

8.1. Data Storage

The HKGI will classify your personal information, medical records, and genomic data as confidential material, and properly store it in the HKGI's database located in Hong Kong. The HKGI fully owns and manages the database. It will enact data security and privacy rules on par with international standards.

8.2. Access to Data

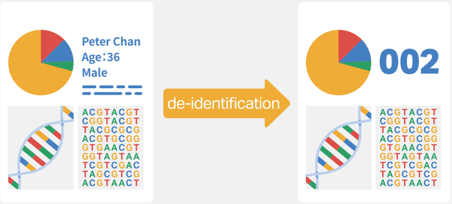
Only authorised designated project team staff can access and use your medical history and records and genomic data, for analysing your situation and preparing reports. The personal data that can identify you will only be used for your clinical diagnosis and care.

The HKGI will share only your de-identified data (data that does not include personal information) for research purpose. Qualified research organisations and researchers must seek approval from the HKGI's Institutional Review Board to view and to analyse de-identified data on the HKGI's designated platform.

You can also request to the HKGI to access your genomic information.

What is "de-identified data"?

"De-identified data" is data that does not contain any of your personal information (such as name, date of birth, identification document number, hospital number, and other personal details), which will have been removed by the HKGI and replaced with an identification code.



What is the Institutional Review Board (also known as Research Ethics Committee)?

When a researcher or research institution applies to the HKGI for the use of relevant data for research, the Institutional Review Board will examine and approve the study based on relevant guidelines, mainly predicated on ensuring the benefits to patients or to Hong Kong's future medical development. Eligible research institutions and personnel (local and non-local) may include:

- Non-profit bodies (such as universities, research organisations); and
- Commercial enterprises (such as pharmaceutical manufacturers).

8.3. Use of De-identified Data

To give impetus to the future development of genomic medicine in Hong Kong, the HKGI will collaborate with local and international medical and scientific research institutions.

Under no circumstance will the HKGI disclose your personal information to any researcher without your consent. Your de-identified data will only be shared with:

- **Approved local and international research institutions and researchers**
    - Eligible research institutions and relevant researchers must obtain approval from the HKGI's Institutional Review Board before using your de-identified data. If your health care providers/clinicians wish to use your data for their own scientific and medical research, they must also apply through the Institutional Review Board.
    - If any research institutions and researchers submit an application to download participants' data, the HKGI will entail them to ensure the confidentiality and safety of the data they obtained.

- **International scientific databases**
    - Some international scientific databases will collect de-identified data from different research projects and organisations to facilitate international scientific and medical research. Each database has its own rigorous application procedures, and researchers must seek approval to use the relevant de-identified data.
    - Before sharing the data, the HKGI will carefully check and review the data security and safety policy of the relevant scientific databases.

8.4. How Will the HKGI Follow Up on Research Findings Pertaining to Participants?

Your de-identified data will be used for various scientific and medical research related to other diseases, not only to the disease you have.

Even if researchers make new and important discoveries about your disease or condition, the HKGI will not reveal your personal information to researchers without your consent. If the researchers wish to contact the participants, they must notify the HKGI in compliance with relevant rules and procedures. The HKGI will evaluate their request and contact you to ask if you are willing to share your contact information with the researchers. Only when there is a clinical need, for instance, when new research insights might lead to improved treatment plan for the participant, will we grant approval for designated personnel to proceed.

Chapter 3:

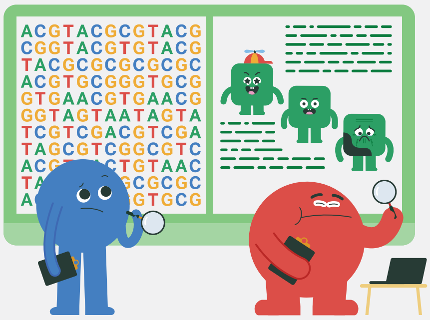
Sequencing Results and Reports

9 Reporting of Main Findings

9.1. Main Findings

The HKGI will prepare for you a detailed report to aid in the clinical diagnosis and care for your family member's or your condition. We call this type of report a "Main Findings" report. It includes genetic variants that are classified as pathogenic/likely pathogenic according to the latest international guidelines.

Location - HKGI

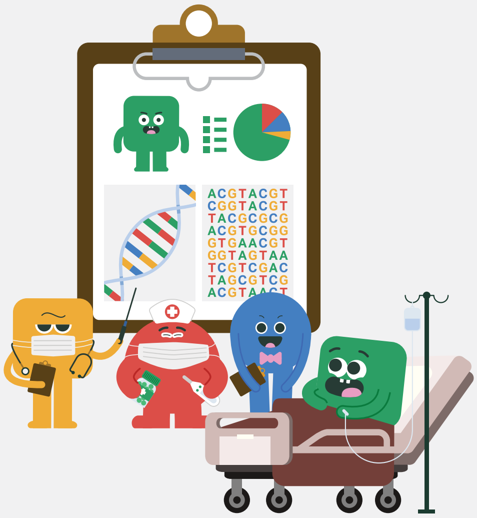


1 The HKGI completes analysis of genomic data

2 The project team evaluates the analytical results based on your medical condition

3 The project team summarises the results into a report

Location - Partnering Centres



4 The project team explains the report to you and arranges follow-up treatments

9.2. Notification and Follow-Up

After the project team evaluates the result, a doctor or genetic counsellor will explain the report to you. If necessary (for instance, further clinical investigations are required), we will provide follow-up or refer you to the appropriate clinical services.

We understand that participants would like to have results as soon as possible. To bring you accurate and reliable results to the best of our capabilities, the project team will take the time that is necessary to analyse the data and interpret the results carefully and thoroughly. For these reasons, it is hard for us to set a time limit on completing the report. We appreciate your patience and understanding with this matter.

Please note that while the report might provide useful insights concerning the medical conditions of you or your family members, it is possible that no new insights will be revealed through the analysis of your samples.

We acknowledge that clinical treatment of certain diseases, such as cancer, is time-sensitive. However, analysing and interpreting findings from Whole Genome Sequencing takes considerable time and resources, and the results may not have a decisive impact on clinical treatment. Unless the analysis definitively provides new directions, the clinical treatment plan will not change.

⑩ Reporting of Additional Findings (Optional)

10.1. Additional Findings

In addition to the Main Findings mentioned above, genomic analysis will also identify vast numbers of genetic variants, leading to a cornucopia of information related to genetic diseases and health risks. This additional information is called the “Additional Findings”, in which the identified variant is not related to the participant's primary health concern but has adequate scientific evidence showing that there is a high risk in causing other diseases.

We will only list those variants that have high pathogenic risks in the Additional Findings Report. The HKGI will draw up a list of Additional Findings exclusively for this Project based on the latest international research results. The HKGI will also regularly review the content of the list and update it when necessary.

Please scan the QR code to view the latest Additional Findings list

10.2. Choosing Whether to Receive Additional Findings Report

You can choose whether to receive Additional Findings report.

- **If you choose to receive them:**
  - You may gain early insight of your potential health risks. Such information might enable you to follow up promptly about the pertinent disorders.
  - However, such results might also impact you psychologically.

- **If you choose not to receive them:**
  - The report will only indicate the Main Findings related to your family member's or your condition.
  - Even if the analysis shows that you have potential health risk, you will not be informed.

10.3. Notification and Follow-Up

If the HKGI finds that you have a variant that is on the Additional Findings list and you indicated that you wish to receive your Additional Findings report, we will notify you and arrange an appointment for a doctor or genetic counsellor to discuss the report with you.

If the report shows the need for further clinical investigations, the project team will first discuss this with you and advise you accordingly. We will refer you to the appropriate clinics under the Hospital Authority if you agree to perform those clinical investigations.

Since we will prioritise the analysis of the Main Findings, you may not be able to simultaneously receive the reports on Main Findings and the Additional Findings.

⑪ What is Excluded from the Report

Whole Genome Sequencing studies yield an abundance of information. Based on global experiences in other genome projects, project participants may feel overwhelmed if bombarded with a large amount of complex information in a short period of time. The HKGI is following the practices of other international genome projects by not listing the following findings in their research reports.

11.1. Variant of Uncertain Significance (VUS)

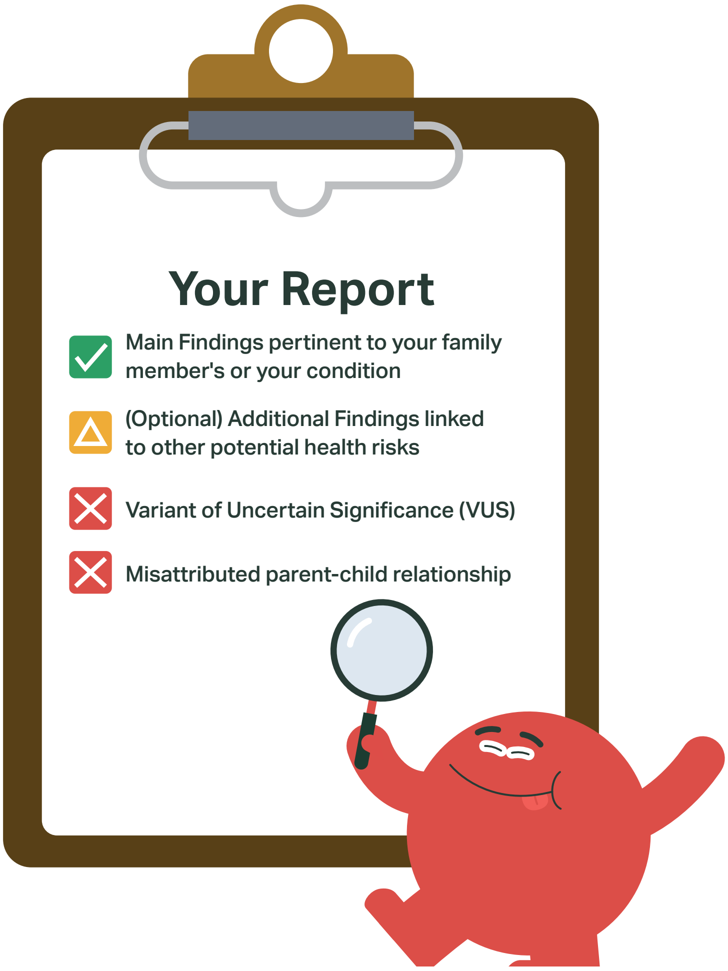
VUS refers to genetic variants that are found in the genome, but, with our current knowledge of genetics, we are not sure if this variant has any clinical impact on health.

Except for special circumstances, these VUS will be excluded from your report.

It is possible though, that with exponential advances in sequencing technology and genomic medicine, we may gain new insights into how these VUS may be useful for understanding and treating diseases. Therefore, in the future, the HKGI may find it useful to analyse your genome again. Once new results appear, we will contact you and discuss with you the updates of the report.

11.2. Misattributed Parent-Child Relationship

Genetic tests might reveal the biological relationship between parents and children. However, as this is not the purpose of the HKGP, the report will not include any such discoveries.



Your Report

- ☑ Main Findings pertinent to your family member's or your condition
- ⚠ (Optional) Additional Findings linked to other potential health risks
- ☒ Variant of Uncertain Significance (VUS)
- ☒ Misattributed parent-child relationship

Chapter 4:

What Participants Need to Know

⑫ Process of Providing Samples

- While drawing blood, you may experience bruising, mild discomfort or feeling anxious, which have been reported by a small proportion of individuals who have experienced this procedure previously.
- If it is necessary to collect buccal swab samples, the process may cause mild discomfort or anxiety, as reported by a small proportion of individuals who have experienced this procedure previously.
- If saliva samples are needed, the whole collection process is simple and safe.
- If body tissue samples are needed, we will collect them only when you clinically require a surgery, or from excised tissues after you have had your surgery. Collecting tissues for the HKGP will not require additional surgeries nor add risks to your treatment plan.

⑬ Impact of Report Results

The Project aims to help clinicians understand, diagnose, and address patients' conditions. However, it is possible that the results from Whole Genome Sequencing analysis may not lead to definitive identification of the cause of illness. Even if a cause is identified, it may not immediately result in better treatment options. Therefore, some worry and anxiety may be arisen from the report results.

⑭ Impact on Family

Each person is unique, but your genome contains some sequences that are shared with other individuals in your bloodline, such as parents, siblings, and children. So, your report results may reveal insights about your family members' health and genetic risk factors.

Although the thought of sharing these findings might make you and/or your family members uneasy, your family members may actually want to know these results so that they can make their own informed decisions about whether to conduct further tests or follow-up. If potential risk factors are found, the HKGI will notify you through the Partnering Centre. Only then will you have to decide if the project team can disclose the results to your family.

⑮ Data Security

As mentioned earlier, the HKGI will deploy all practical and feasible steps to safeguard the privacy and the security of all participants' data. All analysis results and personal data will be processed and monitored according to international standards, to guarantee that the data is protected by rigid confidentiality measures. (See "Handling Participants' Data" on page 14-15 for details.)

However, with rapid technological advancement, it is possible that the de-identification technology could be decoded in the future. Although we will continuously update our security measures to protect participants' privacy, we cannot eliminate the very minimal chance of a data breach or leak. In case of data breach, the HKGI will follow prevailing guidelines from the Office of Privacy Commissioner for Personal Data and inform the affected participants.

If any person/organisation/company deliberately breaches your data, or intentionally identifies you from the de-identification data, the HKGI will ban them from using the HKGP's data again. If the breaching actions are illegal, the HKGI will report the matter to relevant law enforcement agencies.

Chapter 5:

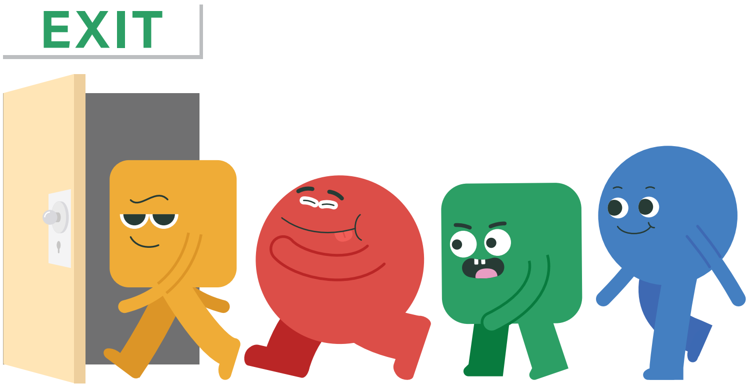
Withdrawal from the Project

You can withdraw from the Project at any time without giving a reason. To withdraw from the Project, you only need to contact the project team of your Partnering Centre.

Your withdrawal from the Project will not affect your access to or the quality of medical services you regularly receive. In addition, you will not receive any new results or reports in the future, including Main Findings and Additional Findings.

⑯ Application for Withdrawal

You can contact your affiliated Partnering Centre team (telephone numbers are listed on page 1) if you want to withdraw from the Project. The genetic counsellor will explain to you in details. When the HKGI receives your withdrawal application, an acknowledgement receipt of withdrawal will be sent to you by mail or email.



17 Sample and Data Processing

17.1. Sample Processing after Withdrawal

When you decide to withdraw from the Project, you may request the HKGI to destroy your biological samples (such as blood samples, etc.) and the genetic materials taken from them. If you do not request your samples to be destroyed, the HKGI will store your samples with those of other participants until the Project ends, and then dispose them all together.

17.2. Data Processing after Withdrawal

Withdrawal implies that:

- We will not use your data for any additional analysis or research;
- We will cease using your data for clinical diagnosis and medical care purposes; and
- Qualified research institutions and personnel will not be able to access your de-identified data.

Your genomic and personal data has to be archived for the following reasons:

- **Ongoing research studies are using your de-identified data**
    - Ongoing research studies refer to research studies that have started but not completed analysing your data before your withdrawal. Qualified research institutions and personnel have read and analysed the data via the HKGI's designated platform. To maintain scientific research integrity and consistency, they need to continue using the same set of data. Deleting your data will affect the results of these research projects. However, after your withdrawal, new research studies cannot utilise your data.

- **Completed research studies have already used your de-identified data**
    - We must safeguard the integrity of the findings of completed research studies. Missing data will affect the credibility of the results.

- **Audit purposes (for instance, to provide a record that you once participated in the Project)**
    - To meet the requirements for auditing, the HKGI will access minimal information from archived data. This may include your name, date of birth, ID number, address and contact information. Only staff authorised by the HKGI can access and use information from archived data. Information used for the audit will be classified as confidential.

The HKGI will scrutinise and record the use of such data to guard against improper usage.

During the Project	After withdrawal from the Project
	
▪ We will analyse your data for clinical diagnosis and medical care purposes. ▪ Approved research institutions and personnel can only access your de-identified data for scientific and medical research.	▪ Your data will be archived by the HKGI. ▪ We will no longer analyse your data for clinical diagnosis and medical care purposes. ▪ Your de-identified data will not be used in any new research studies.

Chapter 6:

Others

⑱ Loss of Decision-Making Ability or Death

The HKGP is a long-term research project. We need participants' medical records at various times to enable us to continue with the genomic data analysis. Therefore, consent forms to join the Project must remain valid even in the unfortunate circumstance that participants lose the ability to make decisions on their own or pass away, so that we can access the relevant participants' medical records, including information added after the loss of decision-making abilities or death.

Should a participant lose the ability to make decisions on their own or have passed away before receiving their report, we hope to contact a designated person to inform him/her of the participant's result.

As HKGP participant, you may choose to provide the contact information of the designated person, so that we can try to contact and inform him/her about your result when necessary (including the Main Findings and Additional Findings report).

⑲ Latest News about the HKGP

If the HKGP has any updated information that may influence your decision whether to continue participating in the Project, we will notify you in time. You may then need to sign a new consent form stating that you have received this pertinent new information.

⑳ Participants' Rights and Other Precautions

- **If you have any comments or complaints during your participation in the Project, please contact the HKGI:**

Phone: (852) 2185 6700
Email: enquiry@genomics.org.hk

- **This Project has been approved by multiple research ethics committees, including the Hospital Authority Central Institution Review Board, The Joint Chinese University of Hong Kong – New Territories East Cluster Clinical Research Ethics Committee, and Institutional Review Board of the University of Hong Kong / Hospital Authority Hong Kong West Cluster, to conduct the Project in each of the Partnering Centres (Hong Kong Children's Hospital, Prince of Wales Hospital and Queen Mary Hospital).**

- **If you have any queries about the Project, please call the genetic counsellor(s) of your affiliated Partnering Centre.**

Hong Kong Children's Hospital	Phone: (852) 5741 3334
The Chinese University of Hong Kong / Prince of Wales Hospital	Phone: (852) 3763 6069
The University of Hong Kong / Queen Mary Hospital	Phone: (852) 2255 6203

- **For any enquiries about the rights of Project participants, please contact the Institutional Review Board or research ethics committee of your affiliated Partnering Centre.**

Hospital Authority Central Institution Review Board	Phone: (852) 2300 8527
Hong Kong Children's Hospital Research Ethics Committee	Phone: (852) 3513 3193
The Joint Chinese University of Hong Kong - New Territories East Cluster Clinical Research Ethics Committee	Phone: (852) 3505 3935
Institutional Review Board of the University of Hong Kong / Hospital Authority Hong Kong West Cluster	Phone: (852) 2255 4086

- **Collection of Personal Data**

The HKGI will access, use and retain your personal data in accordance with the consent form for project participation. Personal data collected will be kept for seven years after the completion of the HKGP. Afterwards, the personal data will be deleted.

According to Hong Kong "Personal Data (Privacy) Ordinance" Cap. 486, you have the right to keep your personal data confidential, including those kept by or related to the HKGP, their collection, retention, control, usage (including for analysis or comparison), transfer into or out of Hong Kong, non-disclosure, elimination and / or the right to handle or dispose of in any manner. If participants would like to access/correct any personal data held by the HKGI, they can apply by contacting the genetic counsellor in respective Partnering Centre.

In addition, relevant research ethics committees and the regulatory authority(ies) can access your data for verification of the research, pursuant to the relevant legal or statutory basis, as the case may be.

If you have any queries, please contact the Office of the Privacy Commissioner for Personal Data to ask about proper handling of personal data.

Phone:	(852) 2827 2827
Fax:	(852) 2877 7026
Email:	communications@pcpd.org.hk

- **If you wish to apply to access your genomic data, please contact the project team of your affiliated Partnering Centre. The HKGI will process your application according to standard procedures.**

- **Will joining the HKGP Affect Personal Insurance?**

In May 2020, the Hong Kong Federation of Insurers launched the "Best Practice on the Use of Genetic Test Results" (referred to below as the "Best Practice"). Under no circumstances will insurance companies demand any type of genetic test results related to the HKGP for underwriting purposes.

For details of the "Best Practice", please scan the QR code below to visit the Hong Kong Federation of Insurers website

- **Genetic Discrimination in the Workplace**

According to Hong Kong “Disability Discrimination Ordinance (DDO)” Cap. 487, a disability includes one that presently exists, previously existed but no longer exists, may exist in the future, or is imputed to a person. Therefore, congenital genetic conditions and genetic predispositions are included as "disabilities" under the DDO.

An employer must have reasonable grounds and justification to require an employee to provide relevant medical reports. For example, such grounds and justification may include helping the organisation determine if the employee’s disability will preclude him from meeting the intrinsic requirements of his job, or helping the organisation consider accessible accommodations and facilities. Otherwise, it is illegal for employers, as a form of discrimination against employees, to request or require employees to submit medical information, including genetic and genomic information.

- **Compensation and treatment for injuries caused by participation in the HKGP**

  Participating in the HKGP will not expose you to extra risks, so the HKGI will not provide compensation nor additional treatment.

- **Termination of Research**

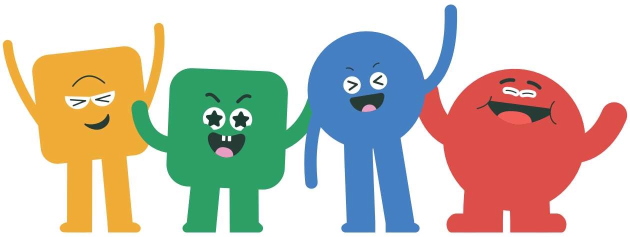
  Currently, the HKGI has no foreseeable plan to terminate the Project.

㉑ Joining Future Research Outside the Scope of the HKGP (Optional)

One of the project objectives is to drive research in genomic medicine and related fields. After examining the de-identified data generated by the HKGP, research entities may wish to invite individual participants to join additional research studies, such as clinical trials for drugs.

You can decide if we may contact you in the future and ask if you are open to taking part in other research outside the scope of the HKGP. This decision is voluntary and separate from your decision in joining the HKGP. Whether you agree to future contact from us will have no impact on your participation in the Project. The HKGI will not transfer your contact information to other research institutions/personnel without your consent.

If you do agree to being contacted about future research studies, the HKGI will use the information provided to contact you should the occasion arises. You can then decide whether to participate in further research. If you agree to this option of future contact in the consent form, but later decide to exit the HKGP, you will not receive further invitation on research outside the scope of the HKGP.



Thank you for supporting the Hong Kong Genome Project

Please visit our website for further details:

Hong Kong
Genome Institute
香港基因組中心