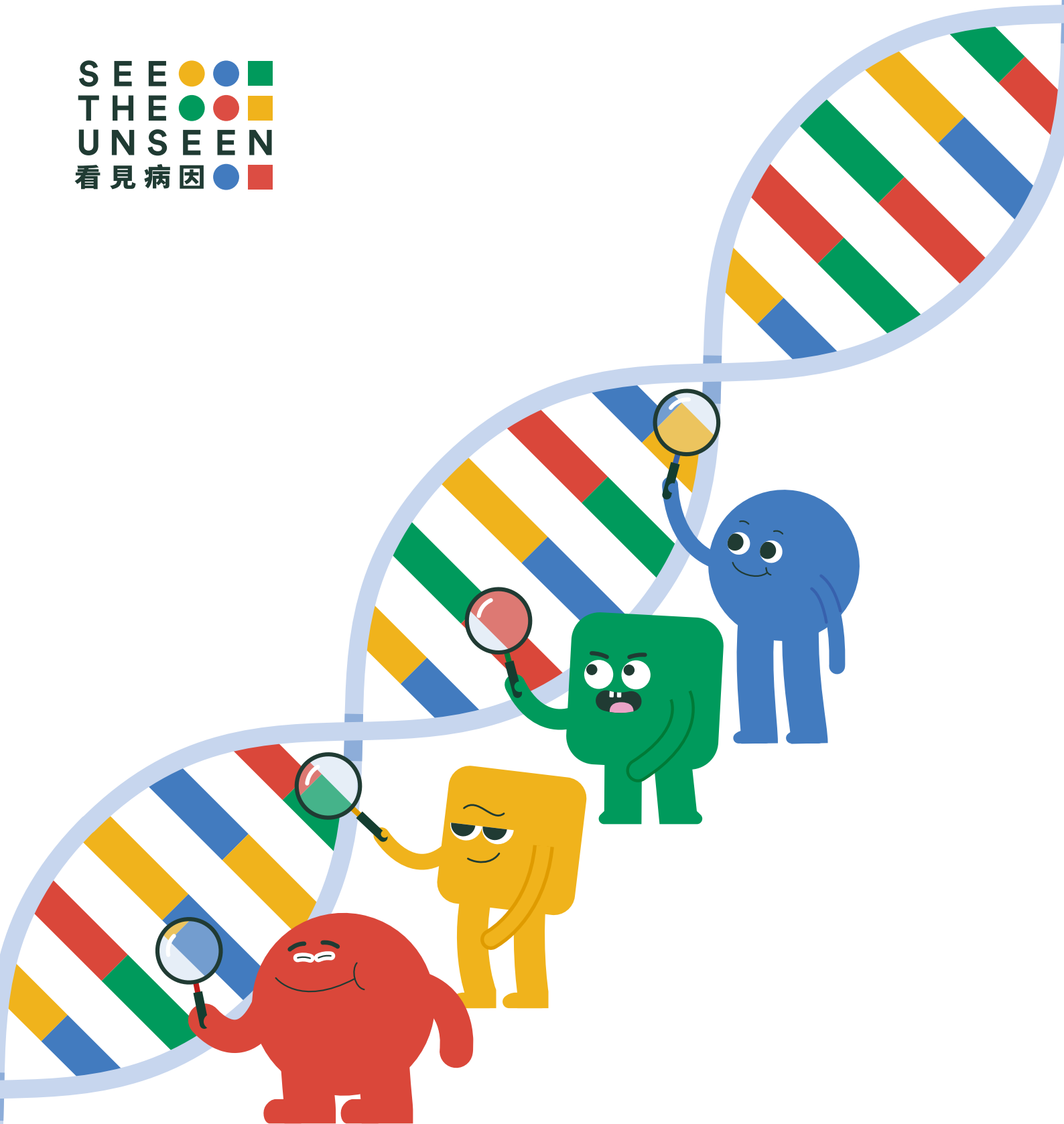


SEE THE UNSEEN
看見病因

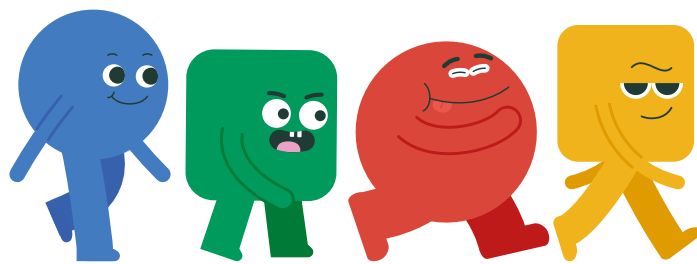


Hong Kong Genome Project Information Booklet (appropriate for individuals aged 12 - 17)

(Version 4.0, dated Feb 2024)



2023 GOLD 金獎
Privacy-Friendly Awards
私隱之友嘉許獎
Awarded by PCPD, Hong Kong
由香港個人資料私隱專員公署頒發



The Privacy-Friendly Award 2023 (Gold Certificate) was awarded to Hong Kong Genome Institute to recognise its efforts in promoting the protection of personal data privacy and championing the importance of setting up a Privacy Management Programme based on the following five assessing criteria:

1. Discussed and recognised the importance of Personal Data Privacy Management Programme (PMP) at senior management meetings.
2. Have established a dedicated department for data protection.
3. Have developed internal policies on personal data handling.
4. Have put in place a data security breach notification mechanism and a written policy.
5. Provided training or education for staff on the protection of personal data privacy.

Preface

Inside our bodies, we have a hidden instruction manual called the “genome”, which is the sequence of all of our DNA. Our unique DNA sequence, also called the genetic code, determines our physical characteristics, such as the size of our eyes and the colour of our hair. It also tells us important health information, including how likely a person is to get certain diseases.

This manual inside us is large and complex, but clinicians and scientists hope to use research to better understand this manual. This knowledge will help to unlock body’s mysteries, unveil clues to cure diseases, and bring better treatments for more patients.

The former Food and Health Bureau (currently the Health Bureau) established the Hong Kong Genome Institute (HKGI), with the aim of implementing the Hong Kong Genome Project (HKGP). The HKGP will help clinicians and scientists better understand how our genome (our DNA sequence) affects different diseases. This knowledge will promote the medical development in Hong Kong.

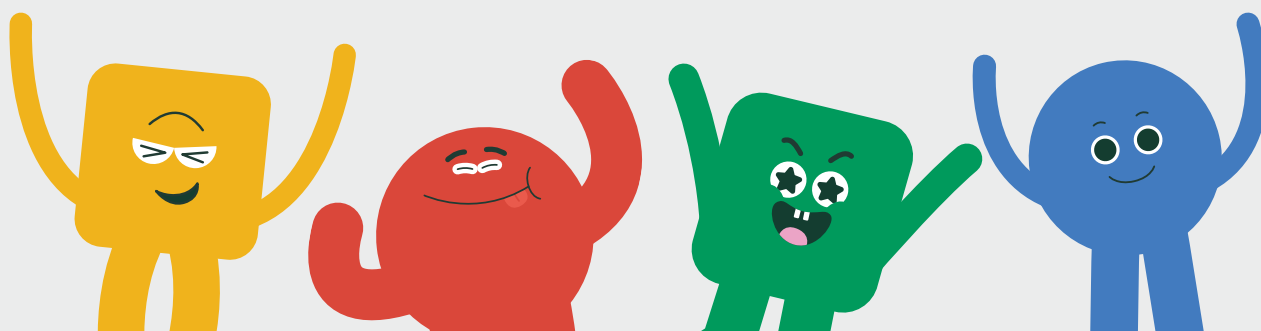
This booklet introduces the Project to you through questions and answers.



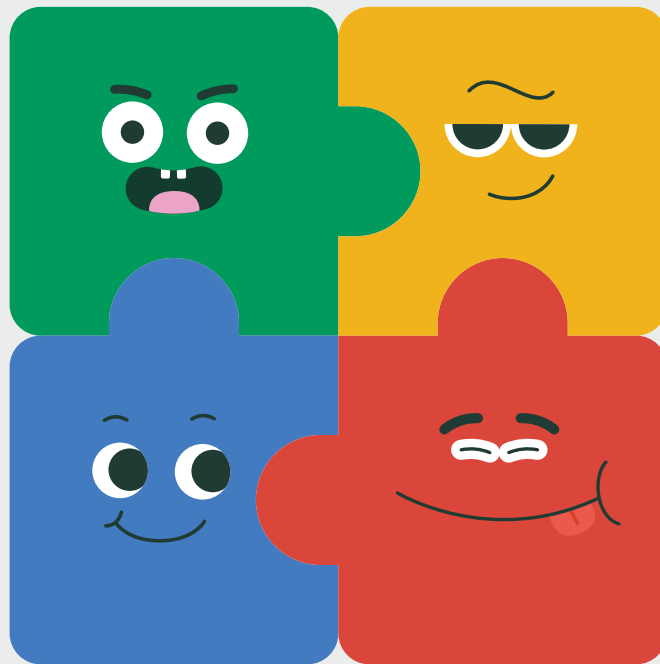


Table of Contents

Preface	1
Chapter 1: About the Project	4
1. What is the Hong Kong Genome Project?	
2. Who are the project team members?	
3. Why am I invited to join the Project?	
4. What are the benefits of being in the Project?	
5. Do I have to join the Project?	
Chapter 2: Joining the Project	7
6. If I join, what will it involve?	
6.1. Accessing my medical records	
6.2. Collecting my samples	
6.3. Processing my samples and analysing my DNA (my genome)	
6.4. Accessing and sharing my data	
7. How will the project team store and use my data?	
8. How will I know my results?	
Chapter 3: Things that I need to know	12
9. What should I know about participating in the Project?	
9.1. Process of providing samples	
9.2. Impact of report results	
9.3. Impact on family	
9.4. Data security	
10. Can I leave after I have joined the Project?	
11. What will happen when I become an adult?	
Chapter 4: Others	15
12. Monitoring of the Project	
13. Compensation and treatment for injuries	
14. Contact information	



Chapter 1:
About the Project



1 What is the Hong Kong Genome Project?

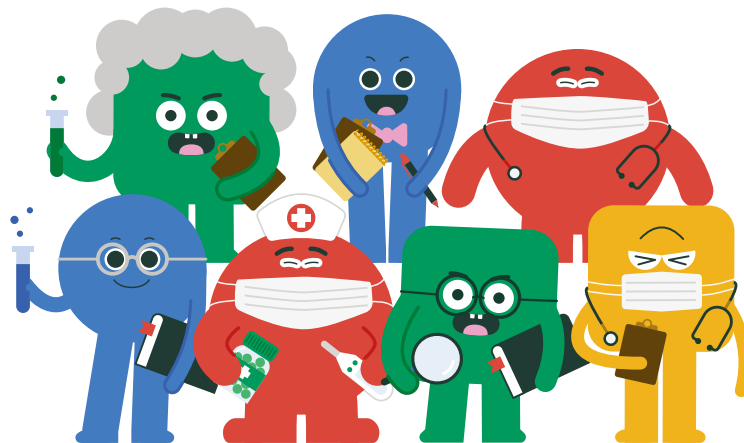
The Hong Kong Genome Project (HKGP) is a research project carried out by the Hong Kong Genome Institute (HKGI). Its primary aims include:

- Helping clinicians to find out the cause of your current medical condition. This could help them to understand your condition more and provide treatments that are better for you;
- Setting up a database of genomic data from local participants. This database will help clinicians and scientists to study the relationship between the genome and diseases, and to develop better treatments for patients.

2 Who are the project team members?

Our members include professionals such as clinicians, nurses, and scientists. We work together to organise the entire Project.

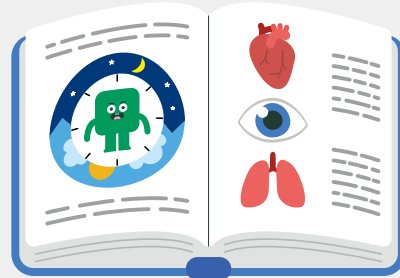
If there is something you do not understand, please feel free to ask us or your parent(s) / legal guardian(s). You can also visit our website to get the latest news from the HKGP: www.hkgp.org



Why are we studying the genome?

The genome is like an instruction manual for the human body. It provides instructions for how to build each part of the body and to help it work well. An error occurring in one step of the manual could cause part of the body to malfunction, causing us to fall ill.

When scientists and clinicians study and research a person's genome, it is like reading the instruction manual thoroughly, hoping to find such errors in the instructions so that they can understand more about the causes of the illness and provide more effective care and treatment for the person.



3 Why am I invited to join the Project?

Clinicians believe that the illness you have may be related to your genetic code, and joining this Project may help with your medical condition.

4 What are the benefits of being in the Project?

We hope that this Project can help clinicians to discover whether the disease that you are living with is related to your genome. Doing so could lead to better medical care and treatment. At the same time, this experience could also help clinicians to find more suitable options to treat other patients living with conditions similar to yours.

5 Do I have to join the Project?

Joining this Project is completely voluntary. You can discuss the details with your parent(s) / legal guardian(s) before deciding to join.

- Joining is free of charge.
- You do not get paid for joining.
- Whether you join the Project or choose to leave after joining, you will still have access to your regular medical services.
- With the consent of your parent(s) / legal guardian(s), you can leave the Project at any time without giving a reason.

Chapter 2: Joining the Project

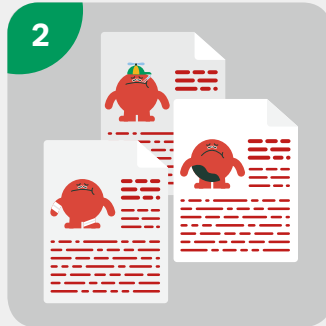


6 If I join, what will it involve?

If you join the Project, we will:



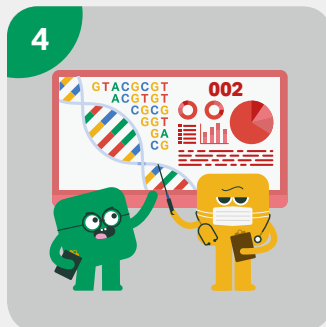
1 Collect samples from you (such as blood, saliva, buccal swabs or body tissue samples)



2 Access your medical records



3 Try to find the genetic cause of your medical condition by looking at your genome and medical records



4 Share your "de-identified data" with scientists and clinicians for research



5 When you reach 18 years of age, we will ask you again if you consent to continue to stay in the Project

Note 1: Unless you withdraw from the Project after joining, you will remain in the Project.

What is "de-identified data"?

"De-identified data" is data that is devoid of information such as your name, date of birth, identification document number, sex, hospital number, and contact particulars. These details have been removed by the HKGI and replaced with an identification code.



6.1. Accessing my medical records

Your medical records can help clinicians and scientists to better understand how your genome (your DNA) affects your medical condition.

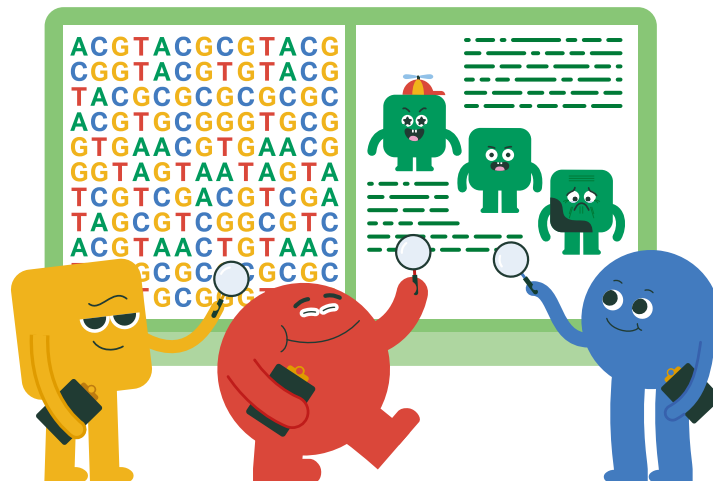
The human body grows and changes as you get older. To understand how this affects your medical conditions over time, we need your medical records from different times in your life for our continuous analysis, including those from before your birth (that is, during your mother's pregnancy) until you grow up.

The types of medical records that we will collect include:

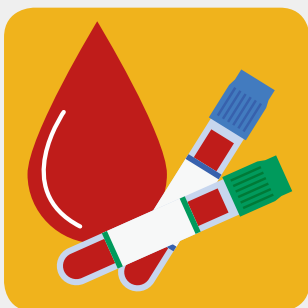
- Files on hospitalisation or clinic visits;
- Clinical records and laboratory test results; and
- Radiology and imaging records such as magnetic resonance imaging (MRI) scans, X-rays or clinical photos, etc.

To further understand the impact of your condition, we will also invite you to fill out questionnaires. You may decide at that time if you would like to provide the required information.

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



6.2. Collecting my samples



Your body's cells contain the DNA we need for analysis. To collect enough DNA to analyse your genome accurately, we will collect a small sample of blood (about 3 to 5 ml) from you and extract the DNA from it for analysis.

Depending on your condition, we may need other samples from you:



Saliva sample



**Buccal swab sample
(cells from the cheek)**



Body tissue sample

If we have to collect body tissue samples, we will collect them during surgery if it is already part of your treatment plan; or get them from tissues that were already removed from you during the surgery. You will not need to have an extra surgery for the HKGP.

6.3. Processing my samples and analysing my DNA (my genome)

All testing and analysis will be done only in Hong Kong. We will send your samples to the laboratory and extract the DNA needed to sequence your genome, and then analyse them together with your medical records.

The rest of your samples and genetic material will then be stored safely in the HKGI's Biobank at the Hong Kong Science Park so that, if new tests need to be done in the future, you will not need to provide blood samples; they can just use the samples you gave earlier. This way, it is unlikely that you will need to give your specimens multiple times.

6.4. Accessing and sharing my data

Only authorised people from the project team can see your medical history, medical records, identifying personal information, genomic data and reports, for your clinical diagnosis, medical care and research².

Other than that, we will share only your de-identified data (please see page 8 for details) with approved scientists and researchers for scientific and medical research.

7 How will the project team store and use my data?

Your personal information, medical records and genomic data are confidential and will be properly stored in a database located in Hong Kong. The HKGI fully owns and manages this database, and will ensure its data security and privacy rules are in line with international standards.

Only authorised person from the project team can see and use this confidential information to analyse your situation and to prepare reports.

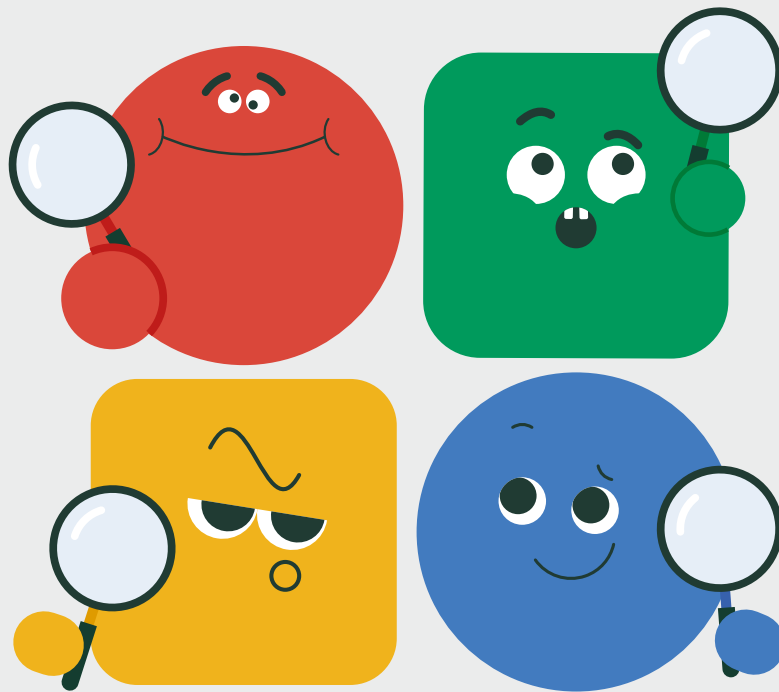
The HKGI will monitor and record when anyone accesses or uses your data, to prevent anyone from using your data in any other way.

8 How will I know my results?

We will prepare a detailed report with your results to help clinicians with your diagnosis and to plan treatment that is suitable for you. The project team will discuss your report with you and your parent(s)/legal guardian(s) and answer any questions you may have.

Note 2 : In the context of enhancing medical knowledge, where the referring clinician(s) need(s) to include identifiable, individual-level genomic and clinical information of the patient(s) in case report / case series publication, he / she should follow the prevailing practice in the clinical setting, to obtain separate consent from the patient(s) concerned for the restricted use.

Chapter 3:
Things that I need to know



9 What should I know about participating in the Project?

9.1. Process of providing samples

- While drawing blood, a very small number of people have reported having bruises, mild discomfort or anxiety.
- When collecting buccal swab samples (brushing of the cheek cells), if needed, a small number of people have reported feeling mild discomfort or anxiety.
- Saliva samples, if needed, are collected in a simple and safe way.
- If body tissue samples are needed, you do not have to undergo extra surgery, and this will not increase your surgical risk (as described in section 6.2).

9.2. Impact of report results

We hope that the Project can help clinicians to understand, diagnose and improve your condition. However, the results may not find the cause of your illness or health condition. Even if the report does lead to a diagnosis, it may not immediately lead to a better treatment plan. Therefore, some worries and anxieties may be arisen from the results.

9.3. Impact on family

Although each person has a unique genome, your genome is more similar to those who are related to you (such as parents, siblings) than to anyone else's. Therefore, your report may also give clues about your family's health risks.

9.4. Data security

The HKGI will use all the ways it realistically can to keep your data safe, secure, and private. However, with quickly developing technology, it is possible that the de-identification technology could be decoded in the future. We will keep updating the security measures to protect participants' privacy, but we cannot rule out the very small 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 affected participants.

If any person / agency / company deliberately leaks your data, or intentionally identifies you from de-identified information, the HKGI will prohibit them from deploying the data again. If the relevant actions are illegal, the HKGI will report the matter to relevant law enforcement agencies.

10 Can I leave after I have joined the Project?

After enrolling in the Project, you can change your mind at any time and leave the Project without giving a reason.

If you are ever thinking about leaving the Project, please discuss the details with your parent(s) / legal guardian(s) first. Your parent(s) / legal guardian(s), upon understanding your thoughts and feelings, will make a final decision jointly with you.

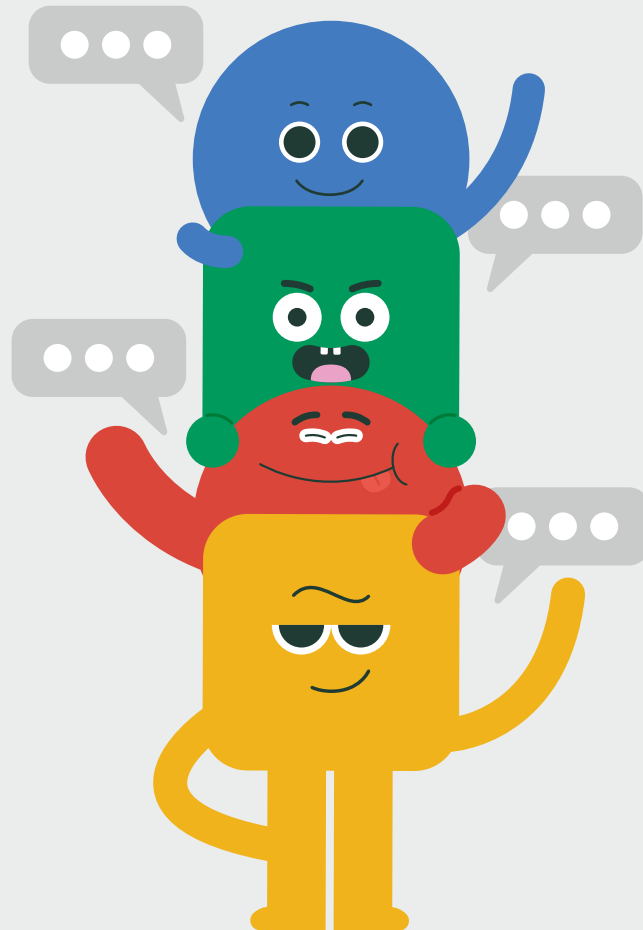
If you leave the Project, you will still be able to get the quality of medical services you normally receive.

11 What will happen when I become an adult?

When you reach the age of 18, according to law, you will be able to decide for yourself whether to stay in the HKGP. At that time, we will contact you to ask if you consent to remain in the HKGP.



Chapter 4: Others



12 Monitoring of the Project

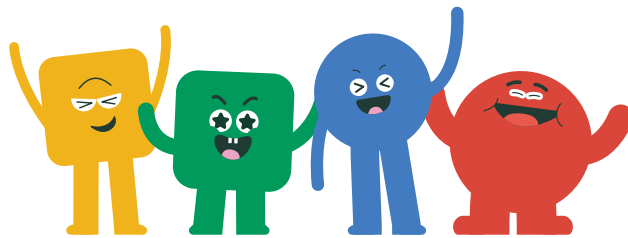
The HKGP is approved by various research ethics committees, and must abide by the laws in Hong Kong.

13 Compensation and treatment for injuries

Joining the HKGP comes with minimal risks to your health and safety. We do not offer any compensation or additional medical treatment at this time.

14 Contact information

If you have any questions, you may wish to discuss further with your parent(s) / legal guardian(s). You are also welcome to find more information about the Project on our website: **www.hkgp.org**



Thank you for supporting the Hong Kong Genome Project

Please visit our website for further details:

