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Marketing and publicity strategies for launching the pilot phase of the Hong Kong Genome Project

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Abstract

Aim: Public trust and confidence determine the acceptance of any population-based genome project. The Hong Kong Genome Institute (HKGI) was established in May 2020 by the Food and Health Bureau (Currently the Health Bureau) to spearhead the integration of genomic medicine into mainstream healthcare. One of HKGI's goals is to enhance public genomic literacy and engagement by launching the Hong Kong Genome Project (HKGP).

Methods: Three focus groups (undiagnosed and rare disease patients and their families, hereditary cancer patients and their families, and clinical geneticists and other medical subspecialists) involving 20 patients, family members, and healthcare professionals were completed in mid-2021 by an independent party. The aim was to harness insights into stakeholders' views, concerns, and aspirations on issues related to genomic studies and the HKGP: (1) the decision to undergo genetic testing; (2) concerns; (3) campaign format; and (4) other strategic suggestions for the Pilot Phase. These issues are complex and multifactorial and have not been documented in Chinese populations. The qualitative approach facilitates such exploration.

Results: Four themes emerged from the thematic analysis: (1) decisional considerations of undertaking genetic testing: perceived benefits and motivators; (2) concerns and worries: personal, familial, and societal concerns; (3) a quest for a patient-oriented, transparent, and decommercialized whole-genome sequencing campaign; and (4) communicating genomics efficaciously: the importance of informational support and literacy enhancement.

Conclusion: Our results shaped the strategies for publicizing the Pilot Phase of HKGP and laid a patient-oriented foundation for HKGP's Main Phase.

Keywords: Hong Kong Genome Project, genomic medicine, whole-genome sequencing, public awareness, genomic literacy

INTRODUCTION

Public distrust as a common obstacle to genomics advancement

With the advancement of genomic technologies and discoveries, scientists and researchers can perform accurate variant interpretation to solve clinical mysteries and inform medical diagnoses and treatment in actionable and precise ways. These interpretations can only be realized if DNA and supplementary medical data are provided for substantial numbers of patients and the public for research and clinical initiatives. The support and trust of patients and the public in collecting and using genomic data are central to the successful implementation and sustainability of any large-scale genomic research project[1]. Despite the contributions of genomic testing to precision medicine, public distrust remains a significant obstacle for health policymakers globally[2-4].

With reference to the collaborative efforts in global genome project initiatives, the substantial volume of data from China contributes to understanding human genomes and genomic diversity. The future of precision genomic medicine in the Chinese population relies on the ability of researchers and clinicians to access substantial quantities of genomic and health data. The Hong Kong Genome Institute (HKGI) was established in May 2020 by the Food and Health Bureau (currently the Health Bureau) to spearhead the integration of genomic medicine into mainstream healthcare. As mentioned in our previous publication, the Government of the Hong Kong Special Administrative Region established the Steering Committee on Genomic Medicine in 2017 to formulate strategies for the development of genomic medicine in Hong Kong; one of its objectives is to enhance public engagement in genomic medicine by launching the Hong Kong Genome Project (HKGP)[5].

The HKGP is the first large-scale genome sequencing project in Hong Kong that aims to (i) utilize whole-genome sequencing (WGS) to identify disease-causing mutation(s) in patients with undiagnosed disorders and cancers with a possible hereditary component; and (ii) enhance the application of genomic medicine to benefit patients and their families with precise diagnosis and personalized medicine. The goal is to facilitate public awareness and understanding, the foundation of building public trust in genomic medicine. HKGP spearheads the first "See the Unseen" campaign involving the efforts of genomic-science professionals in HKGI and other medical fields in Hong Kong.

HKGP - a participant-oriented project for the Hong Kong population

Since its incorporation in May 2020, the HKGI has been recruiting talent in the field, establishing the necessary hardware and software for implementing the HKGP. It is governed by six committees, overseen by the Board of Directors. Among the six committees, the Communications and Education Committee (CEC) is critical for (1) harnessing advice on the strategy and value proposition of HKGP in publicity and education matters; and (2) reviewing and overseeing HKGI's branding, communications, publicity activities, and critical messages delivered to the public.

A strategic focus of the three-year Strategic Plan (2022-2025) of HKGI spelled out the specific strategies for improving awareness and knowledge of genomic medicine in the general population[6]. The primary directive is to engage potential patients, targeted stakeholders, and the public to enhance their

understanding of genomic medicine by developing authoritative and user-friendly information and publications. It also sought to formulate strategic engagement plans for targeted stakeholders, including academic sectors, patient groups, and professional bodies, to promote awareness of genomic medicine and its benefits.

Since its formulation in 2021, the Clinical Operations unit of the Scientific Team and the Corporate Communications Unit of HKGI have been working tirelessly with the CEC to ensure that the Pilot Phase of HKGP synchronizes with the will of the potential participants. The way this large-scale genomic project is presented to the public is critical as the preliminary step in enhancing public genomic awareness. One important preparatory task was to review the focus group results with the HKGI team to map out the marketing and launching strategies for the first public HKGP campaign, "See the Unseen". These issues are complex and multifactorial and have not been documented in Chinese populations. Therefore, this qualitative study was designed to collate insights by exploring the themes integrating participants' views, concerns, and aspirations on issues related to genomic studies and the HKGP.

METHODS

To harness unbiased information directly from stakeholders, an independent agency specializing in social service marketing research was engaged to conduct three focus group sessions involving (1) undiagnosed and rare disease patients and their family members; (2) hereditary cancer patients and their family members; and (3) clinical geneticists and other medical subspecialists. Patients and family members of undiagnosed and rare diseases and hereditary cancers, and healthcare professionals experienced in working with these patients were eligible to participate in the focus group meetings. All eligible participants were prospectively recruited at the three Partnering Centers of HKGI, Hong Kong Children's Hospital, the Prince of Wales Hospital, and the Queen Mary Hospital. All eligible participants were informed of the study's objectives and data confidentiality standards and were invited to participate in the focus group interviews conducted by the independent agency. The Pilot and Main Phases of the HKGP and all related studies in the HKGP were covered by ethics approvals granted by the Central Institutional Review Board, the University of Hong Kong/Hospital Authority Hong Kong West Cluster, the Joint Chinese University of Hong Kong/New Territories East Cluster, and the Department of Health (HKGP-2021-001, HKGP-2022-001, UW 21-413, 2021.423, LM 257/2021). All focus group participants provided written informed consent to participate and be audio-recorded for publication.

An experienced facilitator conducted all focus groups from an independent agency that was not involved in the planning and execution of the HKGP. Each focus group consisted of a two-hour session, including a five-minute break. The discussion was conversational, guided by a semi-structured Focus Group Discussion Guide with a theme list. A set of carefully determined questions were included in the Focus Group Discussion Guide to assist the facilitator in leading the discussion, which included nine sections: introduction, participant's diagnostic odyssey, understanding of and perspectives toward WGS, HKGI, and HKGP, participant's views toward the Project's campaign, marketing and launching strategies for the HKGP, campaign ambassadors, promotional materials and sources, and public engagement. PowerPoint prompts facilitated focus group discussion to inform the participants on the purpose of the discussion, the HKGP, and the project campaign. Participation was anonymized to preserve confidentiality.

Data capture, coding process, and thematic analysis of qualitative data

The focus groups were conducted in Cantonese Chinese, audio-recorded after obtaining written informed consent, and transcribed verbatim by a technical assistant at the HKGI. Another research assistant reviewed and validated the audio recordings and transcripts independently. Data collected from the focus group

meetings were analyzed following the principles of qualitative analysis by Clarke *et al.* and were in alignment with the six phases of thematic analysis by Nowell *et al.*[7,8].

Initially, the familiarization step was achieved by reviewing the transcripts to form the initial coding framework, which was structured according to the Semi-Guided Question List. Coding was guided by inductive reasoning. Additional themes and subcodes were identified and added to the initial coding framework. Inductive reasoning relies on assessing the allocation of coded words, phrases, and paragraphs to the top-level codes and subcodes. The data within each theme were then continuously analyzed to identify variations and stop until thematic patterns saturated. ATWC and CCYC performed coding. Discrepancies were discussed between ATWC, CCYC, and BHYC, and disagreements were resolved by consensus.

RESULTS

Twenty participants were recruited to participate in the three focus group meetings, including eight undiagnosed and rare disease patients or their family members (40%), five hereditary cancer patients or their family members (25%), and seven healthcare professionals (35%). A range of rare and undiagnosed diseases and hereditary cancers were covered, including Costello syndrome, Alstrom syndrome, Angelman syndrome, Rett syndrome, undiagnosed disease, hereditary breast and ovarian cancer, and rare brain cancer. Gender and age were reasonably well balanced among the groups, with eight male (40%) and 12 female (60%) participants. Among the 15 participants who reported age at recruitment, the mean age was 41.2 years, ranging from 18 to 56.

Four major themes were derived from thematic analysis: "decisional considerations of undertaking genetic testing: perceived benefits and motivators", "concerns and worries: personal, familial, and societal concerns", "a quest for a patient-oriented, transparent, and decommercialized WGS campaign", and "communicating genomics efficaciously: the importance of informational support and literacy enhancement". Selected quotes based on these four themes are summarized in Supplementary Table 1.

Decisional considerations of undertaking genetic testing: perceived benefits and motivators

Integration of genomics into medicine raises ethical and psychosocial challenges. These include public acceptance and decisional considerations. Several qualitative studies from Western countries have shed light on the perspectives and attitudes of parents and patients with rare diseases toward genomic sequencing, highlighting common motivational factors; these include the desire for a diagnosis and potential treatment implications[9-12]. Resembling their Caucasian counterparts, the possibility of genetic testing in confirming personal diagnoses and informing clinical management is also a significant motivator introduced by Hong Kong Chinese patients and families with undiagnosed and rare diseases and hereditary cancer.

Focus group participants (patients and their family members) felt that their decision to undertake genetic testing was affected mainly by "*whether the genetic diagnosis would impact clinical management*" (son of hereditary cancer patient P11). According to their personal and family experiences in going through genetic counseling and testing process, such attempts made them feel relieved after receiving the genetic diagnosis, as it has allowed them to "*explore about the disease prognosis and plan for the next steps in life*" (father of rare disease patient P2).

Long diagnostic journeys often plague patients with rare diseases and hereditary cancers[13]. WGS is often offered as a last resort to obtain a diagnosis; this process has substantial potential to impact clinical management, although benefits are often challenging to achieve in the short term. Nevertheless, patients

and families are willing to participate in genomic research for "the greater good" despite a lack of immediate direct personal benefit; this sentiment was a common theme from the present thematic analysis.

"*Perhaps there is not much help for my son, but I believe eventually one day, it will benefit many children, I mean our next, next, next generations*". (mother of rare disease patient P5)

"*I think since my kid is affected already, why don't we contribute to the society or the world? I believe it* (WGS testing) *has its purpose. Well, let me tell you frankly, at this moment, even if a pharmaceutical company could identify a drug for my daughter, it must go through phase 1, phase 2, phase 3 trials, you can foresee that. My daughter is a grown-up now, the reason for us to advocate that much is obviously not simply for my daughter. I hope that there is something we can do to contribute to the world*". (father of rare disease patient P3)

"*Well, if I contribute my DNA for* (WGS) *sequence, or my body tissues* (samples)*, I hope that I will be able to help other people in the future, and I believe all patients are willing to do so*". (hereditary cancer patient P10)

Echoing the "greater good" narrative, the emphasis on participants' contributions to research in the local setting supports previous research evidence in this area, highlighting participants' altruistic motivations[9,11,12,14]. Our focus group participants emphasized the importance of establishing a local clinical genomic database for personalized medicine and disease risk prevention. By establishing a flexible platform with a rich database for genomic technologies and multi-omics studies, and promoting disease-focused research networks in local and international settings, genomic sequencing is anticipated to facilitate genomic science and discoveries.

"*Well, if you ask me, we should have done this much earlier… as WGS helps society a lot, this is a very effective tool… currently if you send the patient to a hospital to look for the underlying reason, many of the times the doctors will not be able to give you an answer, because they have no tools. But if you set up this genomic database, the doctors will have the platform, then at least he will be able to investigate what is going on with the patient. This also saves a lot of societal resources*". (father of rare disease patient P3)

"*I think that it is always good to have one more set of data, if everyone refuses to join, if you are not willing to accept it, then we will never be able to contribute to scientific advancement*". (patient with undiagnosed disease P1)

"*I support my mother to undergo testing as it didn't only give her an answer* (why cancer was running in her family)*, but it could also help the Chinese population and the world to understand this syndrome better*". (son of a female patient with hereditary breast and ovarian cancer syndrome P11)

On the other hand, local healthcare professionals in Hong Kong underscored the clinical benefits of genomic sequencing for patients, especially the importance of a genetic diagnosis for ending the long diagnostic journey. Above all, clinical geneticists accentuated the importance of big data through genome projects to "discover treasure" for medical development in the long run, reducing uncertainties during the diagnostic process.

"*Our initial intention as doctors is to diagnose.* (…) *At least most of the patients and families feel relieved when there is a genetic diagnosis* (…) *I guess most of them would like to know what condition they are suffering from because some of them lived with it for over 30 years without knowing what it is*". (clinical geneticist P18)

"*Even when there is no cure, it is important to have a diagnosis.* (…) *in many of our adult patients, the diagnosis actually helped to avoid unnecessary investigations and follow-ups, which is beneficial, I believe, to both the general public and health system in terms of saving resources*". (medical specialist P16)

Concerns and worries: personal, familial, and societal concerns

Despite having positive attitudes toward genomic sequencing, participants also expressed ambivalence about genome projects and the translation of genomics into routine clinical practice. Resembling studies conducted in the United Kingdom (UK), the United States, and Canada, patients and families in Hong Kong are concerned about potential psychological distress in themselves and their family members[9,10,12,14].

"*If I went to test when I was 18 and found out that I've got a disease that will present when I am in my 40s, what am I going to do in the upcoming 30 years?*" (son of hereditary cancer patient P11)

"*To be honest, I think it doesn't really matter if it is just for myself because you agreed and gave consent, and you wanted to know the answer. But at the end, my family did the test too. So what did the test bring them into? Well… my mum was very worried. As in, she might have been okay initially, but what if you found something wrong? What should we do? No one could answer us this question*". (undiagnosed disease patient P8)

"*Let's say if I did WGS at 20 years old and found out that I have many problems, so in my future life, I may need to make decisions such as whether to get married and have kids. It feels like I am carrying bombs around. How can I get through it? This is something I am very worried about*". (hereditary cancer patient P10)

Concerns and skepticism regarding data privacy and data-sharing related to genomic research and genome projects were introduced by focus group participants[2,9,10,12,14-16].

"*How would I know who is in charge of this genomic research project? And I would think whether that person would collect our genetic data for personal use or to conduct another research study? Like, I don't know. Is there a way I will be notified when someone accesses my data? Such as having an alert on my phone?*" (mother of rare disease patient P6)

"*When I first heard about this* (project)*, that we are building a genomic database, a genomic database for the Hong Kong population, my first thought was about data privacy issues*". (hereditary cancer patient P10)

All the clinicians interviewed emphasized the importance of making the process as "transparent" and "fully informed" as possible to tackle concerns regarding data privacy and enhance public trust. Importantly, clinical geneticists shared their experiences and thoughts on highlighting patients' rights in the informed consent process, especially regarding data confidentiality and project withdrawal.

"*You have to be transparent; otherwise, people will not understand what you are trying to do in your project. If you hide the data, and if the participants are not able to find answers from the project's website, then people will start to make guesses*". (clinical geneticist P15)

"*I think the biggest concern among patients and families is how are they protected. That's their genomic data; of course, they would like to know how they are protected. So if that paragraph* (paragraph on patients' rights in the information booklet) *includes more information in this area, with the details clearly written, then they will have less things to be worried about*". (clinical geneticist P14)

A quest for a patient-oriented, transparent, and decommercialized WGS campaign

A previous meta-analysis indicated that broad audiences observe and emulate celebrities' actions and decisions. Their endorsements can remarkably impact knowledge, attitudes, and behaviors and affect the community sentiments on health-related projects and services[17]. Celebrity endorsers include "digital influencers" who can achieve recognition through various communication channels[18]. In the social media era, social media influencers can broadcast images and messages that are accessed and reposted instantly.

In Hong Kong and Asian cultures, it is not uncommon to identify celebrities - often actors or actresses to act as "ambassadors" for government-spearheaded health initiatives or health-related campaigns. It is beyond the scope of this study to examine the complicated and interrelated economic, marketing, neuroscience, psychological, and sociological mechanisms of celebrity impact. However, deciding to use celebrity ambassadors and how to engage them has become a valid decisional consideration for many health-related campaigns. In the initial planning stage for the launching strategies for HKGP, there was a series of discussions within the CEC on adopting celebrity ambassadors in promotion strategies.

Concerning marketing strategies, a common theme shared by patients and family members of hereditary cancers and rare and undiagnosed diseases was that a health project like HKGP is legitimate and intends to benefit the community; it should speak for itself without the need to have excessive and dramatic marketing strategies. A common theme opposing using celebrities as ambassadors of the HKGP was unequivocal: Focus group participants preferred spokespeople who had shared the journey to speak on their behalf.

"*In this generation, do we still need celebrities, so-called celebrities, to be ambassadors? Doctors can be* (ambassadors). *And would it be possible to find someone, who are not necessarily famous, but someone who carries a meaning, a meaning that will stand out? Because I think this idea* (celebrities) *really does not work* (in promoting HKGP), *frankly speaking, I think it is a waste of money*". (hereditary cancer patient P10)

"*That is to say, I think there is no benefit to use an artist for this campaign. Things will look fake and commercialized. (…) Because artists give people an impression of commercialization, and when this becomes commercial… since this* (HKGP) *has an ambitious mission, as soon as you use an artist to speak about it, you just have a feeling of "wow, how much do you charge for this advertisement?*" (hereditary cancer patient P10)

"*We must find someone who is relevant* (to be the ambassador). *That is, he/she must have experienced it. Then, as an audience, when I see someone who has experienced this to talk about this matter, even if I don't know this person, I will trust him/her because of his/her experience*". (hereditary cancer patient P10)

"*In fact, I think if you need to find one* (ambassador) *if it is necessary… like if you want to target a certain issue, I think you need to find someone who is relevant. Because if the host or somebody* (i.e., patients and caregivers) *questions you* (at a seminar/talk), *and if you can't answer the question, it becomes rather embarrassing. As in, if you don't even know about it* (genetic diseases), *how do you understand me? Like, sorry, first of all, if I sit here to listen, I think I will be more willing to listen to you if you understand what I am going through*". (undiagnosed disease patient P8)

"*In fact, I think we should just be straightforward and find a patient* (to be the ambassador). *I would know that it was a genetic disease at a glance. It was simple, straightforward, and had an even more profound impression*". (father of rare disease patient P3)

"*I would think it would be much powerful if you use a real case*". (father of hereditary cancer patient P9)

"*This* (campaign) *needs to be very serious, so I guess public promotion cannot be too entertaining. That is, it is not a plan to entertain the public; it's just that you want to call for an iconic person* (…) *so that people will know about this. But this person must be politically neutral*". (clinical geneticist P14)

Communicating genomics efficaciously: the importance of informational support and literacy enhancement

In an ideal world, governments would embark on extensive "genomic literacy" campaigns, insisting that genetic information and related technologies be introduced in the formal curriculum as early as possible. In reality, promoting the subject is usually left to scientists.

It is expected that in science (like genomic medicine), the speed of innovation and service dramatically outstrips public awareness and capacity. Specific challenges in genomic education include tailoring complex topics to diverse audiences ranging from the public and patients of different ages to highly educated professionals.

All focus group participants (from clinical geneticists to patients and their family members) emphasized one crucial point that aligns with an imperative the Steering Committee highlighted. To successfully integrate genomic medicine into mainstream health services in Hong Kong, the genomic literacy of the general public and the medical field has to be substantially enhanced.

Hereditary cancer patients, rare and undiagnosed disease patients, family members, clinical geneticists, and medical subspecialists in Hong Kong agreed that genomic medicine is challenging for non-specialists to understand. A common theme identified from these focus groups is that most participants agree that the Hong Kong public is not well-equipped to understand the complexity of genomic science. They highlighted the importance of providing solid informational support by designing simple presentations of clinical information and genomic materials for various age groups.

"*Well, I think the main reason why it* (the diagnosis) *was delayed, or* "*wrong*"*, was due to the lack of genomic education. Be it to the public or to us doctors, if we are more educated* (in genomic medicine), *then this will be improved*". (clinical geneticist P18)

"*Even if you ask people who are educated, there aren't many of them who can tell you what is* "*Human Genome Project*". (clinical geneticist P15)

"*Honestly speaking, whether it is in Hong Kong or in Mainland China, majority of the doctors have never seen and have never heard of it* (the specific hereditary disease). *Well, he/she can't help, and you can't blame him/her*". (rare disease patient P3)

"*I need to use a medical dictionary to identify the jargons. I need to spend a lot of time to read and to understand one journal* (one paper) *because I have to simultaneously read and look up for the definitions from the dictionary…*" (rare disease patient P5)

DISCUSSION

After months of collaborative and tireless efforts, the launch of the HKGP Pilot Phase adopted the findings of the present study, focusing on the entire participant's journey with an emphasis on (1) transparent and

secured data collection procedures; (2) ethical and patient-oriented informed consent; (3) decommercialized promotional methods; (4) stress-free withdrawal initiated by participants anytime; and (5) provision of accurate and colloquial genomic information.

The obstacles of any population-based health project's marketing and publicity campaigns consist of the uncertainties and contributions of sudden and outsider effects, such as drastic changes in the public atmosphere and sentiment due to unprecedented social events. Fortunately, the HKGP Pilot Phase was launched when Hong Kong was in a phase of political and societal calmness. Although it occurred during the COVID-19 pandemic, the community had been immersed in personal health and well-being priorities. As stated in our previous publication, a dedicated project website with user-friendly information, videos, and publications on genomic medicine (as participants' information and welcoming package) was developed to complement and promote the launch of HKGP and to attract the public's interest in genomics and enhance genomic literacy (Available from: https://hkgp.org/en/)[5,19]. Based on the findings from the current study, promotional materials for the "See the Unseen" campaign are patient-oriented, with the two promotional videos adopting the stories of two patients (one adult and one minor). The background of the HKGP is featured in educational videos by clinical geneticists and medical professionals. Cartoon videos ensure simple, colloquial, and fun explanations for children [Figure 1].

With the project focusing on the entire patient journey, along with a robust and ethical informed consent process, a highly secured and transparent data processing platform, and a colloquial and simple information package, the Pilot Phase of HKGP was implemented successfully. Clinician and patient feedback were positive, with a withdrawal rate of 0.08% in the first year (as of November 2022). All media coverage was, in general, positive and supportive.

The HKGP now provides a valuable opportunity to learn how patients and their families respond when offered WGS in a hybrid clinical and research context. Our local findings align with previous research findings, showing that decisional considerations to participate in large-scale genome study (e.g., the HKGP) is not based solely on a rational choice following a weighing the personal benefits and concerns but also on the complex interactions between personal, psychosocial, and economic considerations, and the institutional context where consent is sought. Transparency and openness are highly valued and recognized as crucial elements of the HKGP public engagement strategy to encourage involvement and recruitment.

The importance of developing long-term strategies for enhancing genomic literacy and raising public awareness for the general population is increasingly recognized by governmental, non-governmental, and international organizations. Compared to Western countries, Hong Kong delivers genomic education at a much later learning stage[20]. Focus group patients, family members, and healthcare professionals highlighted that the general population of Hong Kong is not well-equipped for the complexity of genomic science and that overall genomic literacy must be significantly enhanced. As such, HKGP must provide robust informational support by designing simple and colloquial presentations of clinical information and genomic materials for different age groups. More importantly, strategies to enhance genomic literacy (e.g., funding of educational institutions, incorporation of genomic topics into formal education, and establishment of training programs for healthcare professionals) should be implemented[21].

Recognizing the importance of enhancing genomic literacy, several national genome projects have included education as one of their significant objectives[21]. In particular, Canada, Finland, France, and the UK have begun integrating genomics into primary and secondary education by updating the education curricula, upgrading the textbook contents, offering online educational platforms, and providing teachers with

Figure 1. Selected information booklets and promotional videos for Hong Kong Genome Project. (A) Information booklets and leaflets; (B) Hong Kong Genome Project Details - Animated Stories; (C) "See the Unseen" campaign - The Unseen Stories by patients; (D) Educational videos by clinical geneticists and medical professionals.

specialized training[21]. Similarly, in Hong Kong, to promote public engagement and enhance genomic literacy, the CEC of the HKGI planned to conduct stakeholder-specific initiates following the Strategic Plan 2022-25 to reinforce awareness of genomic medicine, including (i) engagement with the general public by preparing thematic articles on genomic medicine media outlets and taking part in public and industry events to promote HKGI and HKGP; (ii) engagement with the media to cultivate support for HKGI; (iii) engagement with stakeholders to identify and connect with relevant patient groups and professional bodies, and collaborate with the Hong Kong Academy of Medicine to showcase HKGI's commitment in nurturing talents and fostering research in genomic medicine; and (iv) enhancement of online marketing by making

effective use of digital marketing and search engine optimization tools to promote the HKGI and genomic medicine. The allocation of resources toward genomic education and talent development in Hong Kong is a priority to facilitate the integration of genomic medicine into mainstream healthcare.

Most genome projects highlighted the importance of human capacity, i.e., aptitude, knowledge, perceptions, responsiveness, and commitment to genomic information and campaigns. For example, the UK (a leader in genomic medicine development) stated that none of its success could have been realized without the involvement and participation of the wider UK population. As they pursue their goal to be the most advanced genomic healthcare ecosystem in the world in the coming decade, the UK prioritizes public engagement and assurance that the patient's voice is embedded throughout decision-making, as stated in the Genome UK Implementation Plan 2021-2022[22]. Qatar Genome is also actively increasing its human capacity by initiating several education initiatives from early school to postgraduate levels[23]. Public engagement must be implemented in phases and multifactorial dimensions and platforms.

In conclusion, with the concerted efforts of all members of the HKGI and the support of various stakeholders, the HKGP Pilot Phase had a smooth and successful launch. It is a long road before genomic medicine can become commonplace in Hong Kong and Asia. Public engagement is an ongoing and dynamic process. With age-specific marketing and strategic promotional plans backed by multi-disciplinary health reforms and long-term public education campaigns (supported by tertiary education curriculum and genomic knowledge outcome studies, to name but a few), we hope that via the HKGP and the related initiatives that geared up by its momentum, genomic literacy in Hong Kong and other Chinese-speaking cultures can be significantly advanced in the coming decade. Our study findings shaped the publicizing strategies of the Pilot Phase of the HKGP and laid a patient-oriented foundation for its Main Phase.

DECLARATIONS

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Authors' contributions

Conceptualization; project administration: Chu ATW, Chung BHY
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Methodology; writing-original draft: Chu ATW;
Resources: Chu ATW, Hong Kong Genome Project, Lo SV, Chung BHY
Supervision: Lo SV, Chung BHY
Writing-review & editing: Chung CCY, Lo SV, Chung BHY

Availability of data and materials

Upon a reasonable request, Focus Group Discussion Guide, theme list, PowerPoint prompts, and focus group transcripts reported in this article, after de-identification, will be made available to investigators whose independent review committee has approved the proposed use of the data. Data will be available from the corresponding authors up to five years following publication.

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Conflicts of interest
All authors declared that there are no conflicts of interest.

Ethical approval and consent to participate
The Pilot and Main Phases of the HKGP and all related studies in the HKGP were covered by ethics approvals granted by the Central Institutional Review Board, the University of Hong Kong/Hospital Authority Hong Kong West Cluster, the Joint Chinese University of Hong Kong/New Territories East Cluster, and the Department of Health (HKGP-2021-001, HKGP-2022-001, UW 21-413, 2021.423, LM 257/2021). The study followed the principles set out in the Declaration of Helsinki. All participants were informed of the study's objectives and data confidentiality standards and provided written informed consent to participate in the focus group meetings.

Consent for publication
Written informed consent for publication was obtained from all participants.

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