

UNDERSTANDING AND PERCEPTION OF DIRECT-TO-CONSUMER GENETIC TESTING IN HONG KONG

VCC Hui¹^, HC Li¹^, JHK Chow¹^, CSC Ng¹, CYW Lui², JLF Fung³, CCY Mak³, BHY Chung^{3*}, KK Lau^{4*}

¹Bachelor of Medicine and Bachelor of Surgery Programme, Li Ka Shing Faculty of Medicine, The University of Hong Kong; ²Bachelor of Nursing programme, Li Ka Shing Faculty of Medicine, The University of Hong Kong; ³Department of Paediatrics and Adolescent Medicine, Li Ka Shing Faculty of Medicine, The University of Hong Kong; ⁴Division of Neurology, Department of Medicine, Queen Mary Hospital, Hong Kong

^co-first authors

*co-corresponding authors

Introduction

Direct-to-consumer genetic testing (DTCGT) is gaining popularity in Hong Kong (HK). As DTCGT forgoes specialist medical involvement, healthcare professionals have raised concerns regarding its validity, utility, and the public's ability to interpret DTCGT results. Thus, genetic counselling (GC) is recommended to facilitate understanding of DTCGT. This study aimed to investigate HK public's perception towards DTCGT and the importance of GC in DTCGT.

Methods

This is a multidisciplinary health research project within the curriculum of Faculty of Medicine, The University of Hong Kong. 304 HK adults were invited to complete a 37-item survey online. Participants' genomic literacy, understanding and attitude towards DTCGT and GC, and responses to a mock DTCGT scenario were assessed.

Results

The majority of participants were young (aged 18-30, 72%) and tertiary-educated (90%). 48% of the participants were aware of DTCGT while 82% indicated an interest. 30% of participants were aware of GC services in HK; 49% were interested in GC services for understanding DTCGT results. Participants scored on average 7.6/11 in the genomic sequencing knowledge scale and were weak in limitations of genomic testing. In the mock DTCGT scenario, 73% of participants expressed concern with the positive results initially. After being explained limitations of DTCGT, 40% of participants reported decreased concern. Reduced perceived helpfulness in medical management and lifestyle modification were also reported by 35% and 27% respectively.

Conclusions

This HK population demonstrated a high level of awareness and interest in DTCGT. As potential DTCGT users, they might experience excess concern and overestimate the usefulness of positive DTCGT results particularly in medical management. The importance of GC to educate and guide interpretation of DTCGT results is supported; yet awareness and access of GC services is inadequate in HK.