Hospital Pulau Pinang

# PUBLIC AWARENESS AND PERCEPTIONS OF GENETIC COUNSELLING AND DIRECT-TO-CONSUMER GENETIC TESTING (DTC-GT) : A CROSS SECTIONAL SURVEY

EP042



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## Introduction

Genetic counselling plays a crucial role in guiding individuals to make informed healthcare choices through provision of non-judgemental support and understanding of genetic risks.

However, public awareness remains limited, particularly amid the increasing availability of direct-to-consumer genetic testing (DTC-GT).

## Objectives

This study evaluated public awareness, attitudes, and perceived barriers related to genetic counselling and DTC-GT in a public health carnival.

## Methodology

A cross-sectional survey was conducted using a structured questionnaire distributed and facilitated by genetic counselling students during a two-day public health carnival in Penang.

The questionnaire collected demographic data and assessed awareness of genetic counselling services, understanding of genetic counsellors' roles, and awareness and perceptions of DTC-GT.

A counter for genetic consultation and a variety of interactive games, such as "Design Your Face" and "Myth versus Fact" were offered to engage public participation and to raise awareness about genetics.

## Discussion and Conclusion

Findings showed that nearly two-thirds of respondents had limited awareness of genetic counselling, DTC-GT, or how to access a genetic counsellor.

More than half recognized genetic counsellor's role in genetic risk assessment and testing, but only a third associated it with providing psychosocial support.

This study highlighted the barriers and motivators for seeking genetic counselling.

Educational initiatives and policy strategies are needed to enhance access and support informed genomic healthcare decisions.

A simple yet strategic approach to raising awareness and engaging the community, while providing genetic counselling students with practical and valuable experience to refine their communication skills and strengthen their role as advocates.

## References

1. Chris MRS et al. A Systematic Review of the Impact of Genetic Counseling on Risk Perception Accuracy. J Genet Couns. 2009 Jun 1;18(3):217
2. Melissa M et al. Awareness of Genetic Counseling and Perceptions of its purpose: a survey of the Canadian public. J Genet Couns. 2013 Aug 21;22(6):762–770

## Acknowledgement

We thank One Hope Charity for the invitation to set up a booth.

## Results

A total of 308 respondents participated, predominantly, female [n=207, 67.2%], and with secondary or higher education. Ethnic distribution included Chinese (49.0%), Malay (40.3%), and Indian/others(10.7%).

| Demographic data | n | % |
|---|---|---|
| Age (years) | | |
| < 18 | 27 | 8.8 |
| 18-34 | 112 | 36.4 |
| 35-54 | 147 | 47.7 |
| ≥ 55 | 22 | 7.1 |
| Educational level | | |
| Primary school | 17 | 5.5 |
| Secondary school | 98 | 31.8 |
| Diploma/certificate | 76 | 24.7 |
| Bachelor and above | 117 | 3.0 |

**Q1: "Have you heard of genetic counselling ?" NO [n=211, 68.5%]**
**Q2: "Do you know where to find a genetic counsellor in your area ?" NO [n=237, 76.9%]**
**Q3: "Have you heard of Direct-to-Consumer (DTC) genetic testing ?" NO [n=217, 70.5%]**

| What do you think genetic counsellors do? | % |
|---|---|
| Explain genetic test results | 55.8 |
| Assess risk of genetic diseases in the family | 59.1 |
| **Provide emotional support** | **35.7** |
| Provide guidance to assist making informed decisions about genetic testing | 55.8 |
| **Not sure** | **22.4** |

| What are the challenges or barriers of accessing genetic counselling services? | % |
|---|---|
| **Lack of awareness about the service** | **75.3** |
| Limited availability of genetic counsellors | 47.7 |
| High cost of services | 51.9 |
| Fear of results implications | 38.6 |
| Fear of insurance implications | 28.6 |

| What factors would influence you to see a genetic counsellor? | % |
|---|---|
| **Doctor's recommendation** | **56.8** |
| **Family history of a genetic condition** | **57.8** |
| **Personal health concerns** | **54.5** |
| Availability of nearby services | 29.5 |
| Cost of the genetic test | 31.2 |

| What do you think DTC-GT is used for? | % |
|---|---|
| Assessing carrier status for inherited diseases | 59.7 |
| Finding out ancestry or family origins | 42.5 |
| Predicting health risks (eg. cancer, diabetes) | 53.2 |
| Determining physical and behavioural traits | 36.7 |
| Fun or entertainment purposes | 9.7 |
| Wellness, nutrition and fitness | 36.4 |
| I don't know | 23.7 |