

# Direct to Consumer Genetic Testing Fact Sheet

This document has been created by Genetic Health Queensland for **clinicians referring patients who have had direct to consumer (DTC) genetic testing.**

## Background

- Direct-to-consumer (DTC) genetic tests are purchased by individuals without involvement of a medical doctor. They are typically requested over the internet with reports issued directly to the individual.
- An individual may undertake DTC testing for several reasons, including clarification of biological parents, understanding one's ancestry or for interest or entertainment. Some DTCs also claim to report on health implications, including risk of developing certain diseases.
- In recent years, there has been a significant increase in the number of DTC genetic tests available, with the potential for results to place an increased load on public health systems.

## DTC and Genetic Health Queensland

Genetic Health Queensland (GHQ) is the statewide public clinical genetics service, providing assessment and counselling for patients and families with a known or suspected genetic condition. Many conditions are multifactorial or do not have a known genetic cause at this time. Importantly, GHQ does not currently provide genetic testing in healthy individuals without an established family history of a relevant condition.

### **Please note that we are unable to accept referrals regarding:**

- Interpretation of or counselling regarding DTC test results
- Individuals who have had or are requesting genetic testing relating to maternity or paternity

These indications are beyond the scope of a public health service.

If your patient has a possible or likely genetic condition, based on their personal and/or family history, a referral to a genetics service is recommended for clinical assessment, counselling, and consideration of a clinical genetic test. If this is the case, please send an updated referral with the relevant clinical information.

Please refer to the clinical prioritisation criteria and referral guidelines for general and cancer genetic services at: [https://metronorth.health.qld.gov.au/specialist\\_service/refer-your-patient/genetic-health](https://metronorth.health.qld.gov.au/specialist_service/refer-your-patient/genetic-health)

## Clinical testing vs. DTC testing

As individuals, we all have differences in our genetic makeup. Not all of these differences are associated with a health condition. It is important to distinguish between clinical (diagnostic) testing and DTC genetic testing.

### Clinical testing

- Requested by a medical doctor to answer a clinical question. This is typically due to health issues in the individual or a known genetic condition in the family.
- Performed by professionals in a clinical laboratory. In Australia, clinical laboratories must adhere to strict quality control standards and are accredited by the Australian Government's National Association of Testing Authorities (NATA).
- Results are reported in consideration of strong evidence and per international guidelines on reporting of genetic variants.

## DTC testing

- Requested directly by an individual, usually through an online service.
- Performed by private organisations who are not subject to national and international laboratory standards and may not adhere to quality control regulations.
- Results may be reported without a clear basis in scientific evidence, may be speculative or may reflect normal genetic variation. Genetic differences are typically not reported against international guidelines on reporting of genetic variants.

Patients should be encouraged to read the terms and conditions regarding their DTC test (both on the product information documentation and report issued). DTC reports will typically highlight that the report should be used for information or entertainment only and should not be viewed as medical advice.

## Resources

The following resources may help guide discussion with your patient regarding their DTC test:

- Direct-to-Consumer genetic testing (Statement)  
<https://www.nhmrc.gov.au/about-us/publications/direct-consumer-genetic-testing-statement>
- Discussing Direct-to-Consumer Genetic DNA testing with patients: A short guide for Health Professionals  
<https://www.nhmrc.gov.au/about-us/resources/discussing-direct-consumer-genetic-dna-testing-patients>
- Understanding Direct-to-Consumer genetic DNA testing  
<https://www.nhmrc.gov.au/about-us/publications/understanding-direct-consumer-genetic-dna-testing>
- The Provision of Direct-to-Consumer Genetic Tests: Guiding Principles for Providers  
<http://www.health.gov.au/internet/main/publishing.nsf/Content/health-npaac-path-bestpractice>