

“An exploration of genetic health professionals’ experience with direct to consumer genetic testing in their clinical practice.”

Thankyou for choosing to participate in this study.

Our aim is to investigate the experiences of genetic health professionals with direct to consumer genetic testing (DTC-GT). This survey will ask you general questions regarding your experiences and to identify if you have had client(s) referred to you as a result of having undertaken DTC-GT. If appropriate, you will then be asked to answer questions regarding the nature of the consult.

The survey is completely anonymous and no personal details will be collected about yourself or your client(s). We will remove any references to personal information that might allow someone to guess your identity. However you should note that as the number of genetic health professionals who report consulting with relevant client(s) may be small, it is possible that someone may still be able to identify you.

Please begin the survey below, completion of which will be considered your consent to participate. Your participation in this study is completely voluntary. Should you wish to withdraw at any stage, or to withdraw any unprocessed data you have supplied, you are free to do so without prejudice.

1. Are you a qualified:

- | | |
|---|---|
| <input type="checkbox"/> Genetic Counsellor | <input type="checkbox"/> Clinical Genetics Trainee |
| <input type="checkbox"/> Associate Genetic Counsellor | <input type="checkbox"/> None of the above → <i>Exit Survey**</i> |
| <input type="checkbox"/> Clinical Geneticist | |

****If you are not qualified in one of the listed professions, we thank you for participating in this survey as your time is greatly appreciated, however due to the limited nature of this study we require no further responses from you. Please still return the survey. If you would like to receive feedback regarding the results of this study, in the form of a short summary, please provide your contact details by email.**

2. In which country/countries are you a qualified [Q1]? _____

3. Are you currently practising as a [Q1]?

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

8. For each client who consulted with you after undertaking DTC-GT, please indicate where you were practising at the time, approximately when the consultation took place and by which means the client was referred to you:

		Client									
		1	2	3	4	5	6	7	8	9	10
Location	ACT, Australia										
	NSW, Australia										
	NT, Australia										
	QLD, Australia										
	SA, Australia										
	TAS, Australia										
	VIC, Australia										
	WA, Australia										
	Other										
When	2011										
	2010										
	2009										
	2008										
	Pre-2008										
Referral	Self*										
	General Practitioner										
	Medical Specialist										
	Other										
	Unknown										

* If self referred, please list (by client) any other medical professionals the client(s) consulted with regarding their DTC-GT: _____

9. Which DTC-GT companies had the client(s) utilised?

	Client									
	1	2	3	4	5	6	7	8	9	10
23andMe (www.23andme.com)										
Counsyl (www.counsyl.com)										
deCODEme (www.decodeme.com)										
DNAdirect (www.dnadirect.com)										
easyGENETICS (www.easygeneticstest.com)										
Genetic Technologies (www.gtglabs.com)										
Illumina (www.illumina.com)										
Knome (www.knome.com)										
Lumigenix (www.lumigenix.com)										
MyGeneProfile (www.mygeneprofile.com)										
Navigenics (www.navigenics.com)										
Pathway Genomics (www.pathway.com)										
Unknown										

Please list any other companies used and by which client: _____

10. Did the client(s) seek your services specifically as a result of their DTC-GT? (ie. Not referred for other reasons)

	Client									
	1	2	3	4	5	6	7	8	9	10
Yes										
No										
Don't know										

Comments: _____

11. What type of DTC-GT was ordered by the client(s)?

	Client									
	1	2	3	4	5	6	7	8	9	10
Testing of one or more SNPs or CNVs in a single gene										
Full sequencing of a single gene										
Testing of multiple SNPs or CNVs in multiple genes										
Full sequencing of two or more genes										
Whole exome sequencing (next generation sequencing)										
Whole genome sequencing (next generation sequencing)										
Unknown										

Please list any other tests ordered and by which client: _____

12. If you know how much your client(s) paid for DTC-GT and feel comfortable disclosing the amount, please select the appropriate price range in US\$ for each client:

	Client									
	1	2	3	4	5	6	7	8	9	10
\$0-500										
\$500-1000										
\$1000-1500										
\$1500-2000										
\$2000 +										
Don't know										

Comments: _____

13. We are also trying to get an indication of the reasons individuals choose to undertake DTC-GT. Please tick the boxes corresponding to factors identified by the client(s) as motivating their choice:

	Client									
	1	2	3	4	5	6	7	8	9	10
Wanting to identify monogenic conditions, including carrier testing										
Wanting to know their susceptibility/predisposition for complex conditions										
For pharmacogenetic uses										
Wanting to assess their sporting ability										
For academic purposes (eg. interest or curiosity)										
For other non health related applications (eg ancestry, nutrigenetics, paternity testing)										

Please list any other reasons given and by which client: _____

14. Did the client(s) appear satisfied with their chosen DTC-GT service(s)?

	Client									
	1	2	3	4	5	6	7	8	9	10
Very satisfied										
Somewhat satisfied										
Not satisfied										
Don't know										

Comments: _____

15. Did the client(s) regret having the test?

	Client									
	1	2	3	4	5	6	7	8	9	10
Yes										
No										
Don't know										

Comments: _____

16. For each client, do you think that the DTC-GT process was:

	Client									
	1	2	3	4	5	6	7	8	9	10
A waste of client time										
A waste of clinic time										
Was beneficial for the client										
Was beneficial for you										
Created anxiety for the client										
Created anxiety for yourself										
Easy to manage										
Difficult to counsel										

Comments: _____

17. What reason(s) were given by the client(s) seeking your professional services in regard to their DTC-GT?

	Client									
	1	2	3	4	5	6	7	8	9	10
Needed help interpreting the results										
Concerned for own health										
Concerned for health of family members										
Seeking reproductive risk information										
Questioning validity of DTC-GT results										
Seeking further genetic testing										
Seeking information on specific conditions										

Please list any other reasons given and by which client: _____

18. What was the outcome of the consultation?

	Client									
	1	2	3	4	5	6	7	8	9	10
Extensive counselling/multiple consults										
Genetic tests ordered to confirm DTC-GT results										
Genetic tests ordered in addition to DTC-GT tests										
Client(s) referred to specialist health professional(s)										
Family member(s) referred for genetic consultation/counselling										
No further action										

Please list any other outcomes and for which client: _____

19. In your opinion, was the client(s) DTC-GT clinically useful?

	Client									
	1	2	3	4	5	6	7	8	9	10
Very useful										
Somewhat useful										
Not useful										
No opinion										

Comments: _____

20. Do you have any further comments regarding your experience with clients who had undertaken DTC-GT? _____

Thankyou for participating in this survey, your time is greatly appreciated.

If you would like to receive feedback regarding the results of this study, in the form of a short summary, please provide your contact details by email.

Additionally, if you are interested in participating in an interview regarding your experiences with DTC-GT in your clinical practise, please specify this in your email.