

## UKGTN External Enquiries – April 2009 to March 2010

### Context

In August 2005 the UK Genetic Testing Network (UKGTN) website was launched to inform all stakeholders, from clinical geneticists to members of the public, of the work of the UKGTN. Various methods were advertised for the public to be able to contact the UKGTN project team with any queries or requests for specific information.

The UKGTN administrative team relocated from Bexley Care Trust to the National Specialised Commissioning Team (NSC Team) at NHS London on July 1<sup>st</sup> 2009.

There are three types of access that were available during this period:

- Email directly to the UKGTN at [ukgtn@bexley.nhs.uk](mailto:ukgtn@bexley.nhs.uk) and [ukgtn.enquiries@london.nhs.uk](mailto:ukgtn.enquiries@london.nhs.uk) (from 1<sup>st</sup> July 2009)
- Hotline telephone number 020 8298 6111 and 0207 9323969 (from 1<sup>st</sup> July 2009)
- Postal contact to the Project Team based at NSC Team (NHS London)

The enquiries detailed in this report do not include the internal enquiries made by heads of member laboratories, members of the UKGTN Steering Group and of the UKGTN working groups or by the lead genetic commissioners associated with the member laboratories. For example the enquiries listed in this report concerning submission of Gene Dossiers only refers to queries from outside of the laboratory network.

### April 2009 to March 2010

From April 2009 to end of March 2010 the UKGTN Project Team received **159 enquiries**. This is an increase from 88 for the previous period from April 2008 to end of March 2009.

These requests were made by clinical professionals, charities, members of the public, media, private companies and NHS commissioners based primarily in the UK but some enquiries were also made from professionals and members of the public from overseas.

Figure one: Number of enquiries by type of enquirer

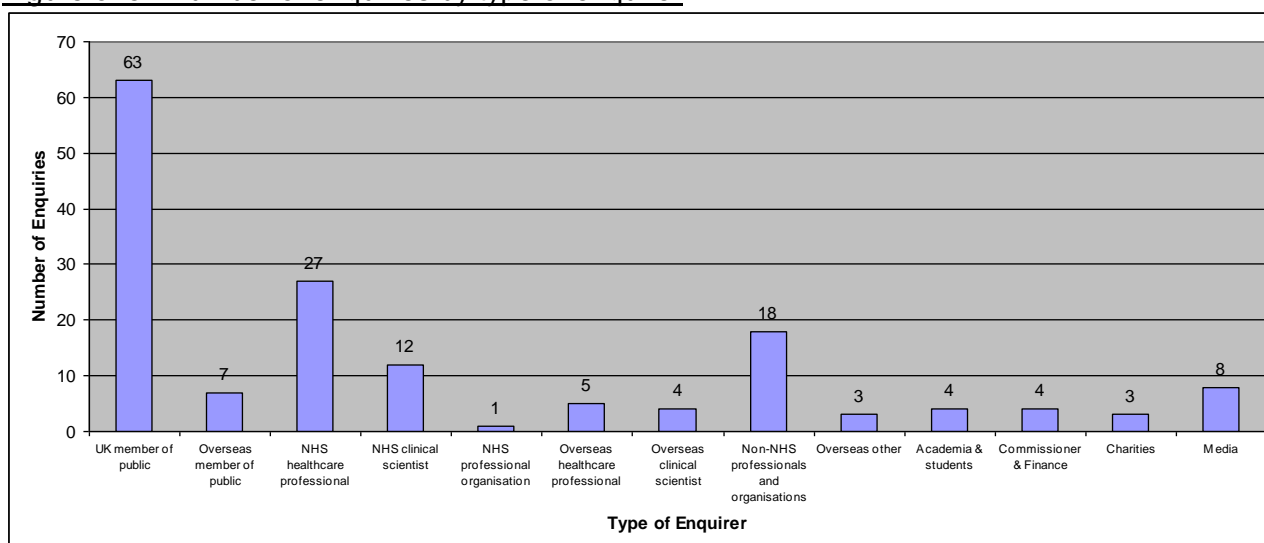
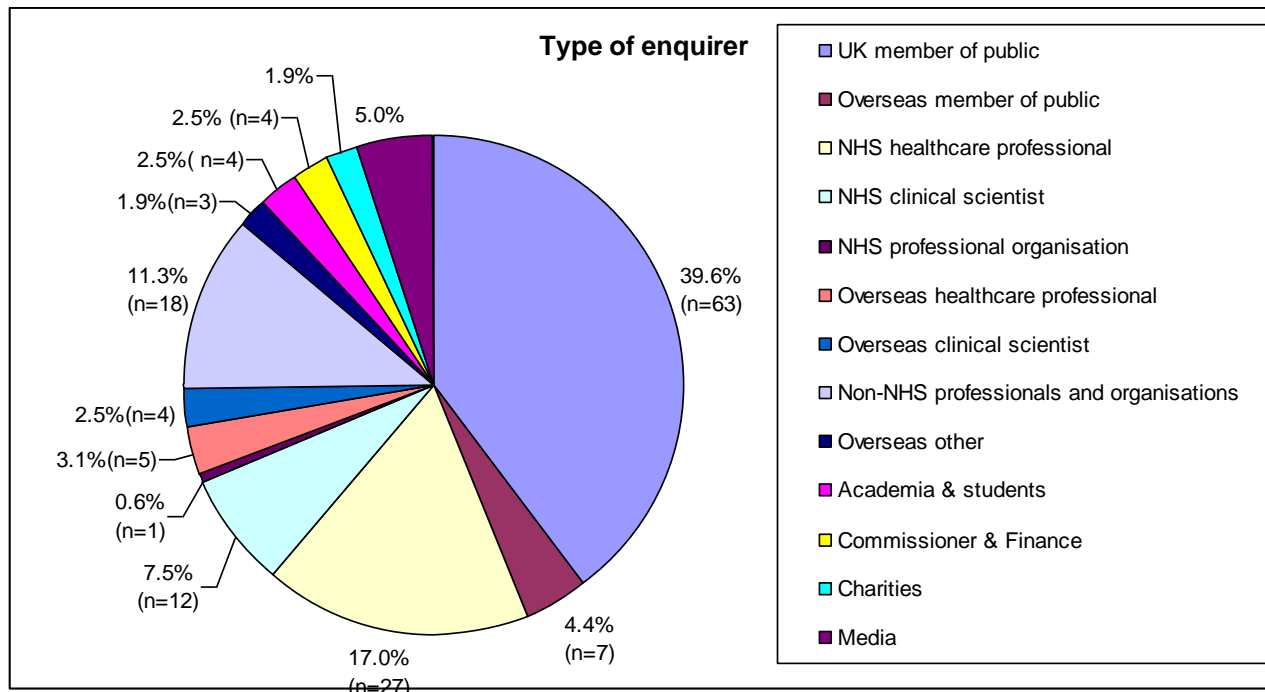


Figure two: Percentage of enquiries by type of enquirer



Contact was made through accessing two out of the three types of media as shown in table 1.

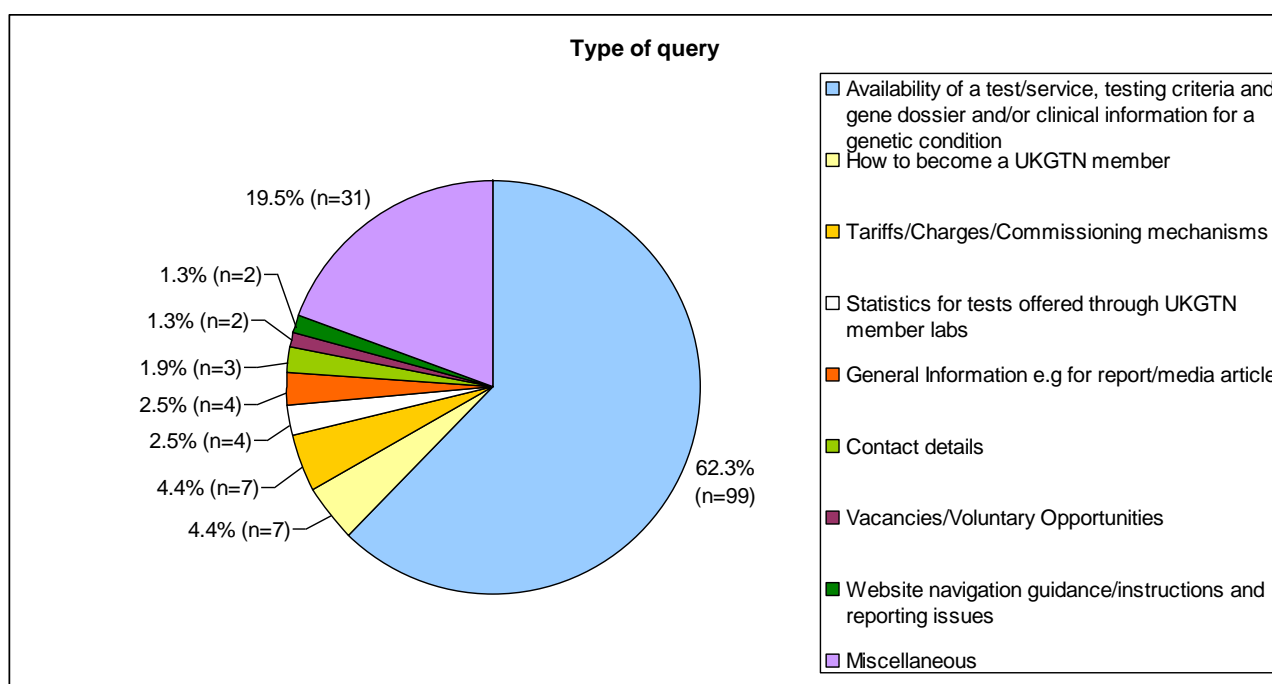
Table one: Media used to submit enquiries by type of enquirer.

	Email	Hotline	Email and phone	Total
UK member of public	30	33	0	63
Overseas member of public	7	0	0	7
NHS healthcare professional	11	15	1	27
Overseas healthcare professional	4	1	0	5
NHS clinical scientist	8	3	1	12
Overseas clinical scientist	3	1	0	4
NHS professional organisation	1	0	0	1
Non-NHS professionals and organisations	3	14	1	18
Overseas other	2	0	1	3
Academia & students	2	2	0	4
Commissioner & Finance	3	1	0	4
Charities	0	3	0	3
Media	1	7	0	8
<b>Total</b>	<b>75</b>	<b>80</b>	<b>4</b>	<b>159</b>

The information that was requested was summarised into 9 categories.

The total number of enquiries in each category is shown in figure 3.

**Figure 3. Total number of enquiries in each category**



The enquiries made by each type of enquirer have been categorised and this is illustrated in table 2. Enquiries submitted by clinical scientists, health-care professionals and members of public were split according to location within the UK or overseas. The non-NHS professionals and organisation category is comprised of private companies/laboratories, consultancy firms and organisations such as the Royal Colleges.

From figure 3 and table 2, it can be seen that the majority of requests were categorised as queries on “availability of a test/service, testing criteria and gene dossier and/or clinical information for a genetic condition”. The majority of these requests were from UK members of the public. Where clinical information was requested, the UKGTN responded by advising that we are unable to provide clinical advice and suggested that the enquirer either contact their GP to discuss the possibility of being referred to a genetics clinic or contact their local regional genetics centre directly. In response to questions concerning access to genetic testing, the UKGTN advised that this was through GP referral to their local regional genetics centre or other appropriate specialty.

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Table 2: Category of enquiry made by each group of enquirer

Enquiry	Enquirer												Total	
	UK member of public	Overseas member of public	NHS healthcare professional	Overseas healthcare professional	NHS clinical scientist	Overseas clinical scientist	NHS professional organisation	Non-NHS professionals and organisations	Overseas other	Academia & students	Commissioner & Finance	Charities		Media
Availability of a test/service, testing criteria and gene dossier and/or clinical information for a genetic condition	56	6	19	3	4	3		3		2	1	2		99
How to become a UKGTN member			3		4									7
Tariffs/Charges/Commissioning mechanisms			2	2		1					2			7
Statistics for tests offered through UKGTN member labs			1		1			1		1				4
General Information e.g for report/media article	1							1		1	1			4
Contact details								2				1		3
Vacancies/Voluntary Opportunities	2													2
Website navigation guidance/instructions and reporting issues			1		1									2
Miscellaneous	4	1	1		2		1	11	3				8	31
<b>TOTAL</b>	<b>63</b>	<b>7</b>	<b>27</b>	<b>5</b>	<b>12</b>	<b>4</b>	<b>1</b>	<b>18</b>	<b>3</b>	<b>4</b>	<b>4</b>	<b>3</b>	<b>8</b>	<b>159</b>

For enquiries regarding availability of genetic tests listed on the on-line database, guidance in navigating the website was offered to the enquirer either verbally (phone) or by e-mail. This involved providing details on how to use the online UKGTN database of laboratories and tests in order that they may be able to find this information again in the future.

Several enquiries were from overseas from members of the public asking for advice on getting a test done in the UK that is unavailable in their home country. The UKGTN responded that some UKGTN member laboratories may accept private referrals from overseas and that a clinical professional that has assessed the patient in their country could make enquires about costs and arrange for a sample to be sent to the laboratory.

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Some enquirers asked about access to tests offered by private companies (advertised on internet) and the UKGTN responded by emphasising that we are unable to offer advice on private genetic testing as we are an organisation involved in genetic testing through NHS service. One exception would be for UKGTN member laboratories that are technical providers (none currently) and in this circumstance UKGTN would advise that the referral process is identical to that for a member diagnostic laboratory: GP referral to local regional genetics centre. A technical provider is a UKGTN member where diagnostic laboratories send samples for testing. The UKGTN does not assign membership to a technical provider for direct to consumer testing.

Several enquiries regarding information on accessibility to tests for cancer, in particular breast cancer, were received and the UKGTN provided weblinks to charities and NICE for guidelines. A few enquiries were from individuals requesting the availability of pharmacogenetics tests on the NHS and the UKGTN responded that these tests are not currently within UKGTN remit but advised to access the PHG Foundation website for further information.

Media enquires were received from BBC (Panorama), The Economist, a reporter from Bristol Newspaper, ODK films, GMTV, Orion TV Company, BBC News and the Sunday Post.

There were 31 miscellaneous enquires and the detail of each of these is shown in table 3.

**Table 3: Miscellaneous Enquiries**

Type of enquirer	Miscellaneous enquiry
Non-NHS professionals and organisations	Was advised to liaise with/inform UKGTN about his project which is looking at over the counter DNA tests and regulation and understanding of risk by the general public. Developing guidelines for new mums.
Non-NHS professionals and organisations	Query whether process of referral for breast cancer gene testing is the same in Northern Ireland as in England
Non-NHS professionals and organisations	Request for us to write an overview of genetics for their publication.
Non-NHS professionals and organisations	Sales phone call to ask if we would be interested in their product which is access to a server specific to our needs containing parliamentary communications on genetic testing.
Non-NHS professionals and organisations	Sales phone call to offer web design services.
Non-NHS professionals	Request for information on the process of funding genetic collections and to ask for

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and organisations	consideration be given to alternative high quality DNA collection methods.
Non-NHS professionals and organisations	Is reviewing service delivery for clinical genetics in West Midlands and would like information on the outcome of UKGTN commissioners survey
Non-NHS professionals and organisations	Queried the regulation of direct to consumer genetic testing in the UK.
Non-NHS professionals and organisations	Sales phone call for testing kits.
Non-NHS professionals and organisations	Queried the relationship of SCOBEC to UKGTN
Non-NHS professionals and organisations	To sell advertising
UK member of public	Query regarding genetic testing for pet snakes
UK member of public	Queried the regulation of private companies which provide DNA testing, paternity testing in particular
UK member of public	Query on the reliability of paternity tests offered by commercial companies
UK member of public	Looking for Dr Kay from Harrow (no details left)
Overseas member of public	Query from a man suffering with DMD and is requesting information about the possibility of recruitment to a PTC124 research trial in the UK
NHS Healthcare Professional	Has left a message with ION about testing for maternal inherited diabetes but laboratory has not returned call
NHS Professional Organisation	Request to include Fanconi Anaemia (British spelling) in our search database rather than just Fanconi Anemia
Overseas Other	Looking for a training position in the UK in molecular genetics.
Overseas Other	Queried the evidence behind UKGTN gene dossiers, commissioning and prioritisation
Overseas Other	Request for advise on implementing the UKGTN model of the governance and structure for national genetic testing in Australia.
Media	Interested in finding out about the ethics around patenting gene sequences.
Media	Would like to find out information on direct-to-consumer selling of genetic tests and the impact on healthcare systems
Media	Queried the number of tests and people suffering with Pitt-Hopkins
Media	Would like to source an expert to interview for a film they are producing for NHS Choices, called "Having a genetic test"
Media	Requested information to do a piece on teenage pregnancies and paternity testing on the NHS
Media	Looking for a company to do ancestry testing for a TV documentary
Media	Called asking for Alistair Kent
Media	Asked for statistics for genetic tests carried out in Scotland over past few years, especially with reference to prenatal testing.
NHS Clinical Scientist	Query whether application for PMS2 gene should be submitted as a new test or an additional provider
NHS Clinical Scientist	To inform of change of address and ask for advise on how to change their test listings

### **Summary**

This document reports on external enquiries received between the period April 2009 and March 2010. It does not include internal enquiries made by member laboratories, members of the UKGTN Steering Group, members that sit on any of the UKGTN working groups and members of the UKGTN team and Department of Health. The enquiries made by organisations and people that are external to the UKGTN have increased as the UKGTN website is more widely publicised and used. The UKGTN will continue to monitor the number and type of enquiries it receives and will provide a summary for the period April 2010 to March 2011.