



Health & Social Care  
Information Centre

# **Data Provision Notice: Genetic Testing Rates**

## **For NHS Trusts in England – UKGTN Member laboratories**

**Notified 11/05/2016**



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This data provision notice is of specific relevance to laboratories that provide NHS genetic testing services across the UK. It will also be of interest to NHS Trusts; Clinical Commissioning Groups and Health and Wellbeing Boards in England (or their equivalents in the Devolved Authorities).

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## Contents

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<b>Background</b>	<b>4</b>
<b>Purpose of the collection</b>	<b>4</b>
<b>Benefits of the collection</b>	<b>5</b>
<b>Legal basis for the collection, handling, publication and dissemination</b>	<b>5</b>
<b>Persons consulted</b>	<b>6</b>
<b>Scope of the collection</b>	<b>6</b>
<b>Form of the collection</b>	<b>6</b>
<b>Manner of the collection</b>	<b>6</b>
<b>Period of the collection</b>	<b>6</b>
<b>Further information and support</b>	<b>7</b>
<b>Burden of the collection</b>	<b>7</b>
Steps taken by HSCIC to minimise the burden of collection	7
Detailed burden assessment findings	8
Assessed costs	8
<b>Help us to identify inappropriate collections</b>	<b>9</b>

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## Background

The Health and Social Care Act 2012 (the Act) gives the Health and Social Care Information Centre (HSCIC) statutory powers, under section 259(1), to require data from health or social care bodies or organisations that provide health or adult social care in England.

The Department of Health (DH) (on behalf of the Secretary of State) or NHS England may direct the HSCIC to establish a data collection.

When the HSCIC receives such a direction we issue a **Data Provision Notice** to the appropriate providers of the required data.

The data, as specified by the HSCIC in this published Data Provision Notice, is required to support a direction from NHS England to the HSCIC. Therefore, organisations that are in scope of the notice are legally required, under section 259(5) of the Act, to provide the data in the form and manner specified below.

## Purpose of the collection

The purpose of the data collection is to gather information on access to and provision of genetic testing provided for NHS patients in the UK. This will be done by collecting data from UK Genetic Testing Network (UKGTN) member laboratories that provide NHS services and calculating genetic testing rates for different healthcare populations (e.g. by NHS Clinical Commissioning Groups (CCG) in England and their equivalents in Scotland, Northern Ireland and Wales) from across the United Kingdom.

Genetic Testing services are commissioned by the Department of Health in England for the whole of the UK. The UKGTN provides commissioning advice to NHS England and the devolved authorities in the UK; submission of the data from labs is part of the membership requirements of the UKGTN.

The outputs of the data analysis will aim to promote equity of access to genetic testing for rare conditions while seeking to ensure that the highest possible quality standards in genetic testing are delivered. This information will be used to support commissioners in reviewing variation in access to services and take action to improve access where required. Individual laboratories and their supporting clinical genetics services will receive outputs including their own specific summary report. This will allow benchmarking of activity within and between healthcare populations. Individual providers and commissioners will be able to use the outputs to review their local genetic test provision. The report of testing rates is also freely available on the UKGTN public website ([www.ukgt.nhs.uk](http://www.ukgt.nhs.uk)) and therefore accessible to other laboratories and front line clinicians.

The reports are reviewed by the UKGTN Clinical and Scientific Advisory Group which has representatives from the Clinical Genetics Society, the Association for Clinical Genetic Science, the Departments of Health, the Royal College of Pathologists and Genetic Alliance UK.

## Benefits of the collection

UKGTN aims to promote equity of access to genetic testing for rare conditions while seeking to ensure that the highest possible quality standards in genetic testing are delivered. UKGTN promotes clinically appropriate gene testing and has been fundamental in facilitating change in the NHS.

UKGTN reviews testing activity on a UK-wide basis to review access to genetic testing by population and supports the UK Strategy for Rare Diseases published by the Department of Health in November 2013. The UKGTN reports are the only source of this type of population based healthcare data within the UK. The work is part of the UKGTN annual work programme agreed by the Department of Health, Health Science & Bioethics Division.

Previous collections of data on genetic testing rates have contributed to the diagnostic themed e-atlas which is used as evidence to support clinicians, commissioners and managers to release resources to reinvest in higher value healthcare for local patients and populations. This data collection may also be used to support updates to that e-atlas.

Future publications will be made available on the HSCIC website. Once the data is available, requests for access to the data can be made via the [HSCIC data access process](#).

## Legal basis for the collection, handling, publication and dissemination

The HSCIC has been directed by NHS England under section 254 of the [Health and Social Care Act 2012](#); to establish and operate a system for the collection and analysis of the information specified for this service to be known as “the Genetic Testing Rates Information System”. The Directions was considered by the HSCIC board on July 15, 2015 and subsequently issue by NHS England on 12 October 2015.

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/469262/Genetic\\_Testing\\_Directions\\_Oct\\_2015.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/469262/Genetic_Testing_Directions_Oct_2015.pdf)

In accordance with section 254(5) of the Health and Social Care Act 2012, the National Health Service Commissioning Board consulted the Health and Social Care Information Centre before giving these directions.

This Notice is issued in accordance with the [procedure](#) published as part of the HSCIC duty under section 259(8) of the Act.

## Persons consulted

Following receipt of a direction to establish the necessary system for collection of data relating to Data Provision Notice: Genetic Testing Rates the HSCIC has, as required under section 258 of the Health and Social Care Act 2012, consulted with the following organisations:

- NHS England
- UKGTN member laboratories

## Scope of the collection

This information is required by the HSCIC under section 259(1) of the Health and Social Care Act 2012. In line with section 259(5) of the Act, all UKGTN member laboratories in England must comply with the requirement and provide information to the HSCIC in the form, manner and period specified in this Data Provision Notice.

## Form of the collection

This collection is patient level data for molecular and cytogenetic activity (used to diagnose and monitor disease, detect risk, and decide which therapies will work best for individual patients) requiring postcode of residence and date of birth to allow Clinical Commissioning Group (CCG) and regional reporting and age standardisation of rates.

A Technical Specification and the collection templates are available on the HSCIC SCCI publication pages:

[www.hscic.gov.uk/isce/publication/scci2035](http://www.hscic.gov.uk/isce/publication/scci2035)

## Manner of the collection

The collection uses two submission templates, one for the molecular test activity and the other for cytogenetic test activity. These are to be submitted by uploading the completed templates to the HSCIC Secure Electronic File Transfer (SEFT) facility. Access to SEFT is granted to a named individual agreed with each lab by arrangement with the HSCIC SEFT team.

## Period of the collection

The first collection will cover 2014/15 and 2015/16. This will take place between 1<sup>st</sup> June and 30<sup>th</sup> August 2016. A specific deadline will be provided in the supporting communication materials which will be sent to each UKGTN member laboratory. Subsequent collections will take place on an annual basis within the same time period.

## Further information and support

This data collection has been accepted by the Standardisation Committee for Care Information (SCCI) which has the remit for the national governance of information standards and collections (including extractions). An Information Standards Notice (ISN) was published on 19 August, 2015

<http://www.hscic.gov.uk/media/18340/2035582015isn/pdf/2035582015isn.pdf>

If you have any queries in relation to SEFT or this collection, please contact the HSCIC Contact Centre via [enquiries@hscic.gov.uk](mailto:enquiries@hscic.gov.uk) with 'UK Genetic testing' in the subject line, or telephone 0300 303 5678.

## Burden of the collection

### Steps taken by HSCIC to minimise the burden of collection

In seeking to minimise the burden it imposes on others, in line with sections 253(2a) and 265(3) of the Health and Social Care Act 2012, the HSCIC has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

This assessment is carried out by the Burden Advice and Assessment Service (BAAS) who carry out a Detailed Burden Assessment (DBA) and report findings and recommendations, as part of the overarching SCCI process. The Committee oversees the development, assurance and acceptance of information standards, data collections and data extractions for the health and social care system in England.

The HSCIC has sought to minimise the burden on laboratories by providing an upload facility for the templates using the HSCIC Secure Electronic File Transfer (SEFT) facility, rather than requesting information in another format which may be more burdensome to process.

## Detailed burden assessment findings

This collection uses the HSCIC Secure Electronic File Transfer (SEFT) facility, rather than requesting information in another format which may be more burdensome to process and is only collected once a year.

### Assessed costs

The estimated associated burden of the data collection is:

Burden on providers	£29K	3 days per year for laboratories based in Acute Non Foundation Trusts = £8,310 and 5 days per year for laboratories based in Acute Foundation Trusts = £20,775
Set up costs for the data collection	£3.5K	Costs of developing and implementing the collection.
Other costs of the data collection	£15K	Costs of analysis and publication of the data.
Total costs	£47.5K	



## Help us to identify inappropriate collections

The HSCIC Burden Advice and Assessment Service (BAAS) offers a Collection Referral Service which is a simple and confidential way to allow data providers to refer data collections they feel would benefit from further scrutiny.

For more details and information on how to refer a collection, please visit:

<http://www.hscic.gov.uk/article/6183/Collection-Referral-Service>

More about the Burden Advice and Assessment Service can be found at: <http://www.hscic.gov.uk/baas>

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For further information

**[www.hscic.gov.uk](http://www.hscic.gov.uk)**

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