

The Restructure of Genetics Services in England



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Alström Syndrome UK
Strength for today, hope for the future

Genetic Laboratory Services Overview

- Current services
- New proposals

Existing services

1. 23 genetic laboratories across UK (working alongside clinical genetics services)
 - England 17
 - Scotland 4
 - Wales 1
 - Northern Ireland 1
2. UKGTN (UK genetic testing network):
 - Established in 2003
 - An advisory organisation promoting equity of access to genetic testing and providing commissioning support to the NHS in the UK.
 - 562 tests recommended
 - 95 NGS panels (with 231 subpanels)
 - 4800 genes can be tested within NHS genetic laboratories (rare disease and cancer)

100 000 Genomes Project

- NHS England (~ 54 million)
- Nationwide network of 13 NHS Genomic Medicine Centres (GMCs)
- Rare disease
- Cancer – develop strategies for personalised medicine

Genetic Laboratory Services: The vision

- NHS England
- To build on the legacy of the 100 000 Genomes Project
- Using most up-to-date genetic testing techniques
- Equity of access
- Setting standards of testing, improving quality, reducing variability
- Genetic testing to be mainstreamed: i.e. part of routine care and treatment
- (efficiency savings)

Genetic Laboratory Services: The vision

- 7 'Regional' Genomic Central Laboratory Hubs (GLH), supported by
- 'Local' laboratories
- National Genomic Test directory
 - To specify which genomic tests are commissioned by the NHS in England, the technology by which they are available, and the patients who will be eligible to access a test
 - For rare and inherited disease
 - For cancer
 - Core and specialist tests
- www.england.nhs.uk/publication/national-genomic-test-directories
- Available from October 2018, but still waiting

Restructuring of Clinical Genetics Services will swiftly follow