

Health Education England supporting a national network of Genetic Diabetes Nurses

The training strategy

A national training programme, co-ordinated through a National Centre of Excellence on Diabetes based in Exeter, has developed a highly skilled national workforce of Genetic Diabetes Nurses (GDNs). The programme utilises the model of 'training the trainers'.

Training a specialist workforce:

- Attendance at a foundation training programme on genetics and Maturity-Onset Diabetes of the Young (MODY) in Exeter (2 days).
- Continuous professional development through attendance at three development programmes per year (1.5 days every four months).



Clinical competence:

- Nurses are assessed by the lead trainer and the specialist team in Exeter to ensure they have met the training competency standards for this programme.



Cascading information:

- Trained GDNs cascade information about MODY to other healthcare professionals across their region through presentations and case discussions.



Improving patient care:

- An informed workforce increases the recognition of patients with MODY, ensuring access to genetic testing and appropriate treatment and clinical management.
- GDNs liaise with local healthcare teams involved to facilitate access to information and appropriate treatment for people with MODY and help co-ordinate genetic testing for family members.



What is MODY?

Maturity-Onset Diabetes of the Young – or MODY – affects 1%-2% of people with diabetes, although about 80% of patients are either undiagnosed or misdiagnosed as having Type 1 or Type 2 diabetes. It is known as monogenic diabetes, as the condition is caused by a change in one gene. To date, six different genes have been identified, accounting for 87% cases of MODY in the UK.

The three key features of MODY are diabetes that:

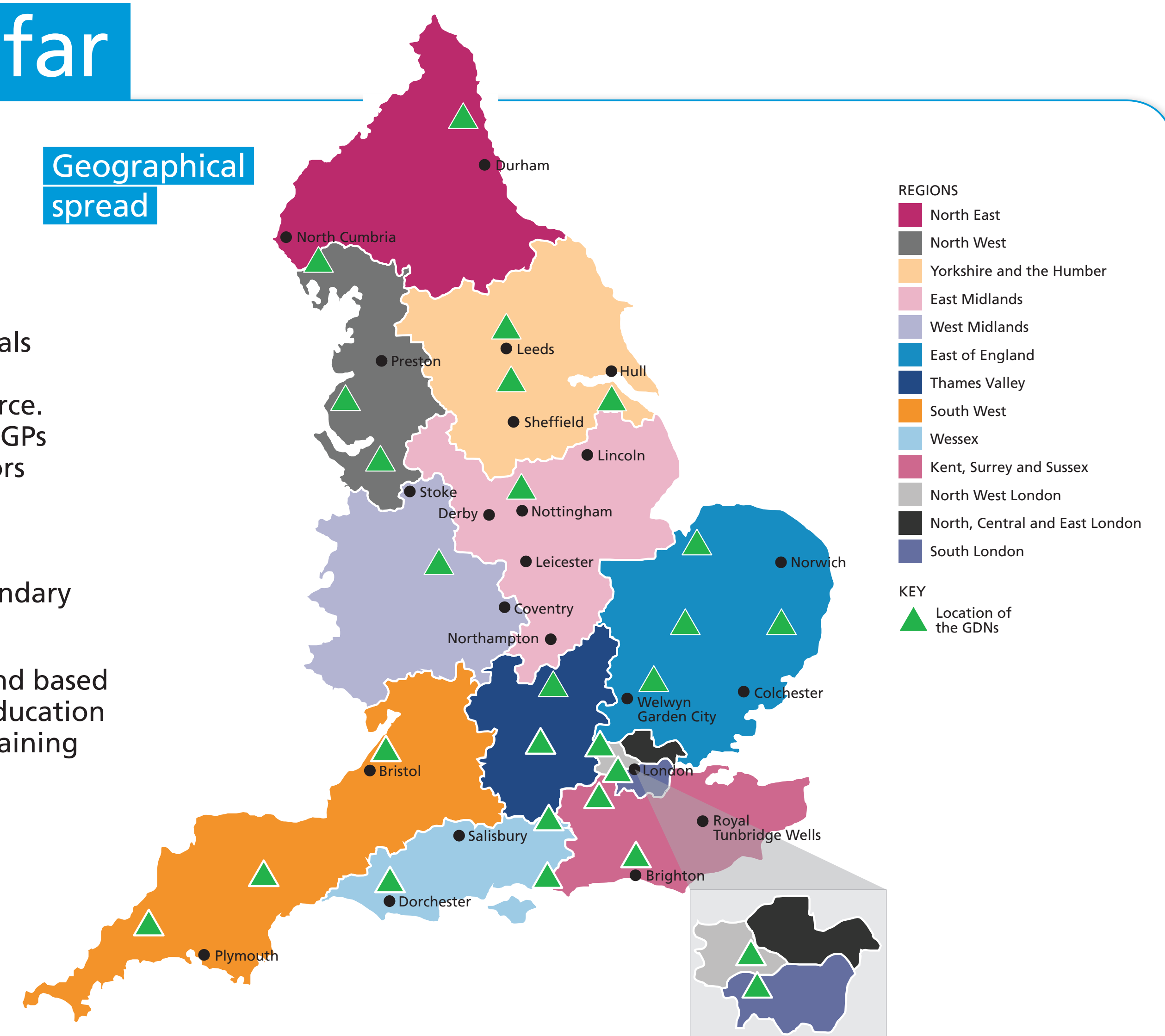
- develops before the age of 25;
- runs in families from one generation to the next (autosomal dominant inheritance); and
- may be treated by diet or sulfonylurea tablets and does not always need insulin treatment.

Progress so far

Since 2002, with initial funding from the Department of Health, 52 Genetic Diabetes Nurses have been trained. They have provided training in monogenic diabetes to more than 7,500 healthcare professionals across the UK spanning a broad section of the healthcare workforce. This includes practice nurses and GPs in primary care; nurses and doctors working in paediatrics, obstetrics and renal teams; and diabetes specialist nurses, dietitians and doctors working in diabetes secondary care teams.

There are now 25 GDNs in England based in areas that align with Health Education England's Local Education and Training Boards (LETBs). These GDNs have established 10 regional specialist monogenic diabetes clinics across the UK in collaboration with diabetologists, improving the care offered for patients with MODY and their families.

Geographical spread



Outcomes of the GDM programme

This project has had a number of successful outputs impacting directly on patient care, as well as saving costs.

Improved rates of diagnosis of MODY²

Since the start of the GDN network in 2002:

- There has been an increase in the annual referral rates for genetic testing (111 in 2001 to 635 in 2012).
- More patients have a confirmed diagnosis of MODY (483 in 2001 to 2,092 in 2012).

GDNs have a higher positive pick-up rate of a MODY diagnosis than patients who are referred from other sources (36% vs 23% (p<0.0001)).

GDNs have referred 939 individuals with suspected MODY and 625 family members for genetic testing, with these results:

- 710** The number of patients with a confirmed genetic diabetes diagnosis
- 187** Patients initially diagnosed as having type 1 diabetes and able to stop insulin injections and transfer to sulfonylurea tablets

Reduced treatment costs

£466 per year Savings made per individual after transferring from insulin to sulphonylureas

£23,000 per lifetime

£160,000 Estimated lifetime cost-savings for patients identified by the GDNs since HEE began funding the programme in March 2014

The successful development of a GDN network has increased awareness of MODY across the UK which has led to increased diagnosis of this condition ensuring appropriate treatment and family follow-up for these patients.

Acknowledgements

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Genomics Education Programme

Health Education England

References

¹Shields BM et al (2010). Maturity-onset diabetes of the young (MODY): how many cases are we missing? Diabetologia 53(12):2504-8

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