Points for discussion of NEY Regional LS Expert Network

The Association of Medical Royal Colleges (AoMRC) Genomics Professional Partnership Group (GPPG) have recommended adopting a 3-tier approach to genomic disease management in order to develop services where genomic testing has become an increasing part of day-to-day patient management.

The NHSE Genomics Unit have supported GMSAs with a 2-year project to embed improvements in patient pathways for testing for Lynch Syndrome where colorectal and endometrial cancers have been diagnosed. One recommendation coming from this project is to develop regional and national expert networks to support that process in line with the AoMRC recommendation (see appendix 1 below). We would like to discuss how to set up regional LS expert network across the NEY region at the forthcoming webinar on 7.12.22.

1. What elements should a NEY Regional LS Expert Network include?

The national LS project has suggested elements which could include:

- Multi-disciplinary and multi-specialty representation (affiliated to clinical genetics services, but including a broad range of multidisciplinary expertise from gastroenterology, gynaecology, nursing, pathology and others)
- Provide support to secondary care teams providing 'mainstreamed' genetic testing
    - Review results and advise on complex cases
    - Ensure that mainstreamed diagnoses of LS are linked to regional genetic service referral pathways, and ascertained for national screening
- Provide an electronic platform so that communication is possible between clinicians within the geography and the specialist network
- Accessible MDT meetings for discussion of genetic test interpretation, clinical queries, complex case discussion etc.
- A dedicated Network Pathway Coordinator funded by NHSE. This coordinator would liaise between mainstreaming services in cancer MDTs and specialist services to ensure that all mainstreamed LS diagnoses are managed consistently.
- Participate in internal audit and research
- Have clear governance arrangements (twice yearly review with GMSA board)

Question: which of these elements would be a priority for your MDT?

2. Who will co-ordinate and run the network?

As described in Appendix 1, the national centre and regional networks have been endorsed by the NHSE, to which they will report. Funding routes at present are less clear and could include commissioning a single NHS Trust or ICB to lead on each network. It would be useful to understand if there are any similar LS networks in place across NEY already and who might be interested to join initial discussions of an expanded NEY network.
Question: what LS networks are in place already across NEY? If you would like to be part of the discussions to take this forward, please leave your names in the chat.

Appendix 1: National description of Lynch syndrome Expert Networks

Population Needs

Lynch syndrome affects approximately 1 in 400 adults and predisposes to multiple cancers including colorectal, endometrial, ovarian, and a range of other cancers. There is consistent evidence of the cost-effectiveness and clinical benefit of a structured diagnostic pathway in patients with LS following a diagnosis of cancer linked to cascade testing in families.

Although a common condition, only 5% of patients with Lynch Syndrome (LS) are known in the UK. The GMSA Lynch syndrome project aims to deliver more effective diagnosis by cancer teams who offer genetic testing to their own patents, rather than referring them elsewhere along more complex diagnostic pathways.

Subsequent routine clinical management may be delivered in primary and secondary care guided by clinical genetics services. Many patients will have complex needs that benefit from a multi-specialty and multi-disciplinary coordinated approach that is best delivered through a centre of regional expertise. However there is extensive evidence that access to this care for people with LS is currently highly variable across England.

Principles of Regional Expert Networks

- Ensure and monitor equity of access for patients with Lynch syndrome
- Support mainstreaming pathways
- Ensure consistency by mainstreaming service providers
- Manage lifelong care of people with Lynch syndrome

Structure

The Association of Medical Royal Colleges (AoMRC) Genomics Professional Partnership Group (GPPG) recommend a 3-tier approach to genomic disease management.

1: A National Centre

2: Regional Expert Networks

3: Local leadership within cancer teams (champions / genomic advisors)

A national centre would provide oversight of regional centres, develop strategy and address variation between regional expert networks on behalf of NHSE.

We propose that in England, 7x Regional Lynch Syndrome Networks are established, aligning to the existing geography of the Genomic Medicine Service and Cancer Alliances.
The national and regional centres will be endorsed by NHSE, to which they will report.

Overview of Regional Expert Network Activity

The network should be responsive to local / regional needs but is likely to include the following elements:

1. Multi-disciplinary and multi-specialty representation (affiliated to clinical genetics services, but including a broad range of multidisciplinary expertise from gastroenterology, gynaecology, nursing, pathology and others)
2. Provide support to secondary care teams providing ‘mainstreamed’ genetic testing
    1. Review results and advise on complex cases

    2. Ensure that mainstreamed diagnoses of LS are linked to regional genetic service referral pathways, and ascertained for national screening
3. Provide an electronic platform so that communication is possible between clinicians within the geography and the specialist network
4. Accessible MDT meetings for discussion of genetic test interpretation, clinical queries, complex case discussion etc.
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6. Participate in internal audit and research
7. Have clear governance arrangements (twice yearly review with GMSA board)

Who they should support

- Local cancer MDTs via Lynch champions within MDTs
- Mainstreaming pathways
- Family history services
- Primary care clinicians

Virtual MDT meetings

Expert centres and regional networks can offer 'virtual review' of patients from other centres who will receive management locally but for whom support may be given in management decisions and/or specific treatments, e.g. segmental of extended resection in LS, resection of CRC in FAP patients, advise about the appropriateness of potential referrals to expert centres.

Supporting Documents

Principles for the implementation of genomic medicine from AoMRC

Delivery of a comprehensive service for the detection of Lynch syndrome - The British Society of Gastroenterology (bsg.org.uk)