

Genomics Update

4 June 2019

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Agenda Item No: 8.4

Trust Board Report

Meeting Date:	4 th June 2019
Title:	Genomics Update
Executive Summary:	<ol style="list-style-type: none"> 1) Update regarding feedback of results and reports from the 100K Genomes Project. 2) Details about the existing Genomic Tumour Advisory Boards and the planned Genomic Rare Disease Advisory Boards 3) Information regarding proposals to embed genomics into clinical practice
Action Requested:	Received and noted
For the attention of the Board	
Assure	
Advise	To note the national and regional Genomics progress.
Alert	
Author + Contact Details:	Tel 01902 447146 Email c.hitchcock@nhs.net
Links to Trust Strategic Objectives	<ol style="list-style-type: none"> 1. Create a culture of compassion, safety and quality 2. Proactively seek opportunities to develop our services 3. To have an effective and well integrated local health and care system that operates efficiently 4. Attract, retain and develop our staff, and improve employee engagement 5. Maintain financial health – Appropriate investment to patient services 6. Be in the top 25% of all key performance indicators
Resource Implications:	<p>Revenue:</p> <p>Capital: There may be implications for funding of staff to fulfil training needs and implementation of future genetic and genomic referrals and consenting.</p> <p>Workforce: The genomic team has been disbanded as the 100,000 genomes project has come to an end and there is currently not enough work to require a band 7 administration post. However, there will be a need for future staff (potentially an admin post and a clinical post band 7) Genomic Ambassador continues to be funded through the WMAHSN</p> <p>Funding Source: There may be some funding coming through NHS England but this is not definite at present.</p>
Report Data Caveats	

CQC Domains	<p>Safe: patients, staff and the public are protected from abuse and avoidable harm.</p> <p>Effective: care, treatment and support achieves good outcomes, helping people maintain quality of life and is based on the best available evidence.</p> <p>Caring: staff involve and treat everyone with compassion, kindness, dignity and respect.</p> <p>Responsive: services are organised so that they meet people's needs.</p> <p>Well-led: the leadership, management and governance of the organisation make sure it's providing high-quality care that's based around individual needs, that it encourages learning and innovation, and that it promotes an open and fair culture</p>
Equality and Diversity Impact	Carried out at national level
Risks: BAF/ TRR	
Risk: Appetite	
Public or Private:	Public
Other formal bodies involved:	NHS England
References	LTP
NHS Constitution:	<p>In determining this matter, the Board should have regard to the Core principles contained in the Constitution of:</p> <ul style="list-style-type: none"> • Equality of treatment and access to services • High standards of excellence and professionalism • Service user preferences • Cross community working • Best Value • Accountability through local influence and scrutiny

Report Details	
1	<p>Feedback of Results and reports from the 100,000 Genomes Project Reports are beginning to come through from the West Midlands, Oxfordshire and Wessex Genomic Laboratory Hub (Women's Regional Genetics Laboratory). Clinicians are beginning to receive reports for 100K genomes cancer patients. Actionable reports may contain a link to a relevant clinical trial.</p> <p>90 Reports have been sent to clinicians since the implementation of the Genomic Tumour Advisory Boards. Of these 90, 6 have had actions recommended. These have been linked to clinical trials but of these clinical trials, only 1 is currently open and recruiting.</p> <p>The process for saving these reports to portal needs to be agreed upon and needs to be in such a way that they are easily recognised as being a Genomic Report. For the cancer Genomic Reports it would be of significant benefit if an alert can be put on to Portal to advise the patient has a Genomic Report should the patient have a recurrence or present with a different cancer diagnosis. At this point, the Genomic Laboratory Hub could be contacted to request further investigation of the genomic data. A suggestion has been made that the cancer reports should be sent to the pathologists and saved to the pathology section of portal. However, further discussion must be held as this will not be appropriate for the reports which will be received for Rare Disease patients.</p> <p>Rare Disease reports are taking a longer time to be returned and many of these have gone straight back to the clinical geneticists in the first instance. The genomic ambassador has requested that these reports be copied and forwarded to the Trust to be uploaded onto the portal record.</p>

2	<p>Genomic Tumour Advisory Boards have been set up by the West Midlands Genomic Centre. There are currently 3 Advisory Boards to incorporate specific specialties. GTAB 1: Bladder, Renal, Breast and Lung, GTAB 2: Sarcoma, Neurological, haematological GTAB 3: Endometrial, Ovarian and Colorectal. These act as Genomic Regional MDTs. Based on the validated results which come back from sequencing, the decision is made prior to the GTAB being held, whether a patient should be discussed. This is determined by whether there have been any findings which are deemed pertinent for discussion beyond a local MDT. The GTAB has the patient's latest clinic letters, MDT reports, scans and pathology reports to look at alongside the sequenced data. Discussion is held with members of the GTAB which is made up of specialists from the surgical specialties, oncologists, pathologists & genetic scientists. The report is then written and sent to the referring clinician with the intention that these can be discussed at the local MDTs. We have two surgeons who attend one tumour advisory board and it is to be hoped that there will be other surgeons who will take part in the future to represent the other specialties. Consultant pathologists from RWT also sit on a couple of the GTABs. The GTABs are held in Birmingham and consultants are able to phone in. A proposal has been made that a couple of GTABs be held at the 3 hub sites (Wolverhampton, Stoke and Coventry) to allow local consultants to attend and get a clearer understanding of what is happening at these events.</p> <p>The intention of the Genomic Medicine Centre is to create a Genomic Rare Disease Advisory Board along the same lines as the GTABs. To this end, interviews for representatives to be on the Rare Disease Advisory Groups took place last week and these proved very successful. Of note, there was one applicant from RWT. Further interviews will take place in a couple of months. Because the feedback of rare disease results will be logistically different as local MDTs are not normally held, the initial remit of the members of the GRABs will be to discuss the best means of efficiently and effectively feeding back results.</p> <p>As emphasis is put upon the return of results, the roles of the Genomic Ambassadors will be amended for the next six months to facilitate this. The Genomic Ambassador based at RWT will be working with the newly formed GRABs to build upon this pathway and to work with clinicians to maintain a pathway for future genomic and genetic testing on a regional basis.</p> <p>The Genomic Ambassador who is currently based at Coventry will be taking the same role with the GTABs.</p>
3	<p>Embedding Genomics in Clinical Practice</p> <p>The Long Term Plan has included the importance of genomics. In October 2018 Matt Hancock, the Health and Social Care Secretary announced the intention to sequence 5 million genomes. The Topol Report also stressed the place of genomics in the future of healthcare.</p> <p>The Genomic Laboratory Hub in Birmingham will be arranging a meeting to discuss their plans for standardisation of genetic testing with the Head of the Pathology department to ensure a clear communication of intention and to provide logistical information.</p> <p>The Genomic Laboratory Hubs have been set up to facilitate the processing of samples and Genomic Medicine Services will be established to implement the focus of service improvement and embedding of genomics. The GMS and the GLH will be working together to move this forward and ensure that there is equity nationally.</p> <p>As the tenders for the Genomic Medicine Services have not been put out as yet, the existing 13 GMCs have had their contracts extended until April 2020 to ensure the return of results and the continuity of service.</p> <p>The national plan is for 7 Genomic Medicine Services to be established alongside the 7 GLHs to provide the operational and strategic support for the transition from project to a functioning genomic service within the NHS. Funding will be provided for all Whole Genome Sequencing and, from April 2020 for genetic tests which are on the NHS Test Directory (This is available on line at https://www.england.nhs.uk/publication/national-genomic-test-directories/)</p>

Nationally working groups have been set up (Patient Choice Groups) to discuss the 3 main components of moving toward whole genome sequencing in routine practice: 1) Patient information, genomic consent and research consent. 2) Implementation and 3) Workforce Education.

A draft version of the patient information and consent forms has been sent to some consultants for comment. The intention is that at the time of asking for a patient's consent to carry out genomic sequencing, they will also be asked to consent to their sample being used for research purposes. In the first instance only a small number of cancers have been opened to genomic sequencing: sarcoma, paediatric cancers and haematological cancers. It is thought that this will open up to colorectal and lung cancers early in 2020. To this end, the Trust needs to establish a process for consenting as well as ensuring that a fresh frozen pathway is provided from theatre to pathology to enable the collection of viable tissue for DNA extraction.

The Genomic Ambassador has been discussing ways to increase understanding of the genetic tests available via the test directory and the eligibility of patients for specific testing or genomic testing. In discussion with a genetic counsellor and in line with proposals put forward at the annual genetic counsellors conference, a suggestion has been made to introduce a genetic counsellor to the Trust's workforce (either by secondment or as a substantive post). This role would focus on educating clinical staff around identification of the appropriate tests at the time of initial consultation to improve the patient pathway; they would also run a genetic counselling clinic in house as opposed to the occasional outreach clinic. If this proposal were accepted, RWT would be the first Trust to implement this process as a pilot which could be replicated nationally.

The Nursing and Midwifery Council (NMC) standards of practice now include knowledge of Genomics putting the onus upon Trusts to encourage and to provide access to genomic skills, education and work for nursing staff. The NHS England Genomics Unit is working on a collaborative approach for embedding genomics into nursing practice and there will be an initial workshop for Directors of nursing and senior nursing staff in July to introduce the plans to implement this. The RWT Genomic Ambassador has been asked to present at this workshop. Health Education England is working alongside the Genomics unit and their focus will be upon provision of Genomic Education.

Appendices

1	GTAB links to clinical trials
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