West of England Genomics Medical Partnership briefing

'Building future healthcare'

Edition 2 **August 2015**

Welcome

Welcome to the second newsletter for the West of England Genomics Partnership.
I was delighted to be asked to chair this partnership, as leading edge technology applied to greater patient benefits and treatment are issues close to my heart. The partnership of NHS Trusts, academic institutions and commissioners, among others, demonstrates a commitment not only to putting together a successful bid for a Genomics Medicine Centre in the West, but also the drive toward world class genomic medicine in the region; building upon the work and reputation for which the region is rightly proud. The 100,000 Genomes Project goes beyond research into delivering benefits and treatment from a transformational approach to the sequencing of genes. I look forward to the next phase of the tender process, confident of your continued input of time and expertise.

Tony Gallagher, Chair of the West of England Genomics Medical Partnership (WofEGMP).

This month's newsletter includes a number of columns: **Science**, presenting a case study showing how genomics medicine can transform lives; **People**, presenting a cameo of some of the key people involved in the partnership; and **Progress**, a quick snapshot of how things are developing.

Science

The most exciting part of the 100,000 Genomes Project is the opportunity to change lives by targeting healthcare to meet patient's needs much more effectively. The national Genomics England Limited website (http://www.genomicsengland.co.uk/) provides much more information and is well worth a visit.
A very good example that shows the transformative power of genomics is that of chronic myeloid leukaemia.

Chronic myeloid leukaemia (CML) is one of the the most common leukaemias in adults, accounting for 15-20% of all leukaemia cases. Its annual incidence has been estimated at between 1 and 1.5 cases per 100,000 and its prevalence at around 1 in 17,000. CML is characterised by the presence in the leukaemic cells of the Philadelphia chromosome, an abnormality resulting from a rearrangement involving chromosomes 9 and 22. This rearrangement creates a gene fusion that produces a protein that is permanently 'switched on' and causes the leukaemic cells to multiply.

Understanding this rearrangement at the DNA (genome) level allowed the development of a new drug, Imatinib mesylate, that targets this specific rearrangement and switches off the protein thereby halting the disease progression and dramatically changing the outlook for patients with this condition. Second and third generation treatments are now available for patients who fail to respond to imatinib because their disease has a slightly different change in their genetic material.

CML provides an excellent example of how improving our knowledge of the genome encourages the development of targeted therapies. Further advances in this area will be accelerated because of the 100,000 Genomes Project. By mapping the whole genome, treatments can be tailored to groups of patients with the same disease (as defined by the genomic changes). Moving away from the 'one size fits all' treatment offered by previous block buster drugs saves time and money and offers improved outcomes for patients.

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People

Another exciting aspect of the Genomics Medical Partnership is the enthusiasm and commitment of the people involved. This includes patients who know what it is like to live with a rare disease or cancer and who are committed to a project that can change the way medicine is practised in the future. In addition there are also many dedicated and experienced doctors, nurses, counsellors, scientists, managers, commissioners and academics working across the partnership in Bristol, Bath and Gloucester who are equally committed to realising the transformative possibilities of the genomics partnership.

This month we are pleased to introduce two key members of our partnership: **Professor Ruth Newbury-Ecob** and **Dr Martin Jones**. By bringing together clinicians involved with delivering services as well as those leading the commissioning of services the partnership is establishing itself as a vehicle for translating the learning from genomics into genuinely improved health services for the future.

Professor Ruth Newbury-Ecob is a leading member of the partnership. She works in the Clinical Genetics Service at University Hospitals Bristol. Ruth specialises in rare diseases including inherited cardiac conditions and has a research programme focussed on identifying new genes. She works closely with the regional genetic laboratory to develop new genetic testing, translating research findings into NHS service to patients in the UK and worldwide, and with colleagues at Bristol Royal Hospital for Children and the Bristol Heart Insititute to provide specialist multidisciplinary care. She is President of the UK Clinical Genetics Society and a Member of the Joint Genomics Committee of the Royal Colleges.

Ruth says: "Genomics has the potential to transform healthcare by developing a more tailored individualised approach to patient care and through better screening and targeting treatments to prevent development of diseases such as cancer and heart disease. The West of England partnership has brought together multiple interested parties for the first time to bring about this wonderful transformation in healthcare."

"Bristol CCG is excited at being closely involved in the Genomics project, the wide ranging potential applications and developments that this project will herald will be key to the advancement of modern medical science. Bristol has a strong track record in innovative research and development, this offers us the opportunity to further strengthen that position." **Dr Martin Jones, chair of the Bristol Clinical Commissioning Group**

Progress

We have been focused on getting all of the right people involved and committed to this project, but we still have more to do to get that right. **If you want to be involved and haven't had the chance to so far please give our project manager Rachel Ferris a call on 07765 345872.**

The partnership board and seven working groups have been scrutinising the services in place to ensure that they are of a very high quality to deliver a Genomics Medicine Centre. The partnership is now required to formally submit a bid to NHS England to secure Genomic Medicine Centre status. The timetable for this process is outlined opposite.

Date	Stage
30 Jul	PQQ issued
20 Aug	Face to face meetings with potential suppliers
21 Aug by 5pm	Deadline for any supplier questions/clarifications
28 Aug at 12pm	Deadline for submitting stage one PQQ applications
18 Sept	Results for stage one PQQ issued
18 Sept	Stage two ITT issued
22 Sept	Potential provider information day 2
20 Oct at 12pm	Deadline for submitting stage two ITT application
w/c 2 Nov	Site visits
4 Dec	Results for stage two ITT released
15 Dec	Contract award
1 Jan 2016	Contract begins - samples to be provided for analysis from this date
1 Jan 2016	Start of services