NHS
South West
NHS Genomic Medicine Centre

# 100,000 GENOMES PROJECT

Winter 2016

## South West NHS GMC Team


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**Website**
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## Our Partners

Northern Devon Healthcare NHS Trust

Plymouth Hospitals NHS Trust

Royal Cornwall Hospitals NHS Trust

Royal Devon & Exeter NHS Foundation Trust

Torbay and South Devon NHS Foundation Trust

Taunton and Somerset NHS Foundation Trust

Yeovil District Hospital NHS Foundation Trust

## Successful SWGMC Cancer Launch


SW delegates learn about Educational Opportunities for NHS Staff

The South West GMC with the support of NHS England was delighted to bring together Cancer specialists across the South West and beyond to learn more about the 100,000 Genomes Project. The event, held at Sandy Park on 29th November to officially launch the SWGMC 100,000 Genomes Project, (Cancer) was attended by over 60 delegates, eager to hear more about the project and how it's impact will change the way we deliver health care in the future.

Plenary lectures and workshops aimed at project teams including pathologists, clinical teams, specialist nurses and trainees were delivered by Professor Sian Ellard, programme lead, Dr Tom Fowler, Deputy Chief Scientific Officer, James Fisher, 100,000 Genomes Programme Director, Prof Dion Morton, Clinical Director, West Midlands GMC, Prof. Louise Jones, Clinical Lead Pathology, Genomics England, Mr Douglas Ferguson, Consultant Breast Surgeon, Exeter, Mr Adrian Harris, Medical Director, RD&E, and Mr John McGrath, SW GMC Clinical Lead.

## Cancer Launch (Cont'd)

The day included background to the project and discussions regarding pathway design, eligible patients and consent training. Representation from all Local Delivery Partners across the SW enabled delegates to network and share ideas.

Prof Sian Ellard welcomes LDPs to the Launch

Dr Tom Fowler, Deputy Chief Scientist, chatting to delegates.

John McGrath – Clinical Lead - Cancer

### Rare Disease Update

Participants are now able to link their 100,000 Genomes project appointment to appointments where routine bloods are to be taken. As a result of these changes to managing appointments which allows patients more flexibility, the number of DNAs has significantly reduced. Consenting takes place with trained staff before the participant visits the phlebotomist or GP practice as part of their routine care.

Thank you to all the recruiting staff and their departments for supporting a variety of clinic slots and even where necessary, home visits.

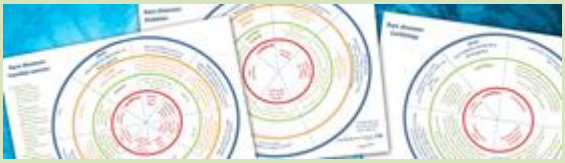
Thank you to all the staff attending the recruitment and consenting training day at the Dartmoor Lodge Hotel in November. This provided an opportunity to discuss and address any issues arising from the consenting process including the importance of highlighting what constitutes additional (looked for) findings from incidental (not looked for) findings. A list of current additional findings can be found at ;

https://www.genomicsengland.co.uk/taking-part/results/

As a result of feedback already received from participants, a workshop was held to discuss difficulties found with the method used to capture a family history at recruitment appointments. The outcome will translate into a new and hopefully improved data capture form.

We have seen a rapid increase in recruitment at Truro since the site went live. Participants are seen at the Knowledge Spa by staff from the R&D department and the paediatric team. We would like to acknowledge the support of the Royal Cornwall Hospital Trust R&D department and the NIHR Clinical Research Network for embedding genome recruitment into life at the Spa.

## 100,000 Genomes Project Eligibility Wheels



New reference guides to identify patients / participants eligible to take part in the 100,000 Genomes Project. The GEP, in collaboration with University Hospitals Leicester, have developed a series of easy reference tools to identify patients/participants eligible to take part in the 100,000 Genomes Project. Aimed at any staff recruiting patients within GMCs or local delivery partners, the wheels have been developed in-line with the most recent changes to the Project's eligibility criteria (July 2016).

The eligibility wheels have brought together conditions that would be seen by specific physicians in a clinical setting.

The first series of wheels to be delivered feature:

- Cardiovascular disorders
- Ciliopathies
- Rheumatological disorders
- Skeletal disorders

Additional sets of wheels, covering a variety of conditions, will be delivered monthly until March 2017. You can view the first ten wheels on the website https://www.genomicseducation.hee.nhs.uk/taught-courses/eligibility-wheels-library/

## New Patient Information Line Opens


If you have questions about taking part in the 100,000 Genomes Project you can talk to our trained advisers on:

Freephone 0800 389 8221

The information line is open from:

Monday – Friday

9am – 5pm

Provided by South West NHS Genomic Medicine Centre

## Meet our new SW Genomic Champion

**Martina Muggenthaler**
Cardiology Genomics Champion
Plymouth

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# Explore Whole Genome Sequencing from 23rd January

**Join our Futurelearn course to explore behind the scenes of this emerging healthcare technology**

Whole genome sequencing is a relatively new technology that allows us to 'read' a person's or organism's entire genetic code. But how does it work and what does it mean for all of us?

The GEP will be running its online course 'Whole Genome Sequencing: Decoding the Language of Life and Health', on 23rd January. The course explores the ins and outs of whole genome sequencing and features interviews with leading scientists and medics working at the forefront of this new technology.

Led by Dr Anneke Seller, the GEP's incoming Scientific Director, the course has been developed to give learners an insight into how whole genome sequencing works as well as its varied uses within healthcare – from personalised treatment of cancer to cutting edge 'walking labs' tackling Ebola and Zika.

Feedback from those who completed the course when it ran for the first time in September has been very positive, with many recommending it to others:

"A wonderful course - something that every patient and clinician should find time to do."

"The course has provided me a much better understanding of the possibilities that WGS offers in terms of improving healthcare provision and in particular the ability to offer/provide more targeted treatments to individuals."

With a recap on the fundamentals of genetics and real life case studies, the course is ideal for non-experts.

Please sign up and share here.

**Check out our website for more information about the SW 100,000 Genomes Project and contact details at www.swgmc.org**

Follow us on Twitter @SW_GMC