## Genomics England Limited - Board Meeting

## Minutes of Meeting held on 6 October 2016 at

## QMUL, Charterhouse Square, London, EC1M 6BQ

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| Present: | Sir John Chisholm (Chair) (JC) |
|  | Dame Sally Davies (SD) |
|  | Andrew Baigent (AB) |
|  | Prof Sir John Bell (JB) |
|  | Sir Malcolm Grant (MG) |
|  | Jon Symonds (JS) |
|  | Nick Maltby (Secretary) (NM) |
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| In attendance: | Graham Colbert (GC) |
|  | Peter Counter (PC) |
|  | Vivienne Parry (VP) |
|  | Augusto Rendon (AR) |
|  | Clare Turnbull (CT) |
|  | James Fisher (JF) |
|  | Simon Partridge (SP) |
|  | Katherine Bailey (KB) |
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| Apologies: | Prof Ewan Birney (EB) |
|  | Prof Mark Caulfield (MC) |
|  | Prof Dame Kay Davies (KD) |
|  | Prof Michael Parker (MP) |

**16-17/040 – Apologies:** See above.

**16-17/041 – Chair’s Introduction:** JC welcomed directors to the meeting and declared the meeting quorate.

**16-17/042 – Declarations of Conflicts of Interest:** JC reminded the Board that all conflicts needed to be declared.

**16-17/043 – Approval of the Minutes of the July Board Meeting and Actions Arising**

The minutes of the July Board Meeting were approved. The Company Secretary was authorised sign the minutes as a true record of the meeting. The status of Actions Arising was as follows:

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| **ACTION** | **OWNER** | **STATUS** |
| Ensure that: (i) the dashboard is provided fortnightly to Board members: (ii) a written explanation be sent out with the Board version; and (iii) the dashboard to be developed as noted. | GC | Done |
| GeL to provide a list of potential open research projects/in scope biobank collections to DH for sign off prior to activating recruitment and criteria for inclusion. | MC | Noted. |
| GeL to provide a note on how the DDD project might be brought into 100KGP. | MC | See Science Report. |
| GeL to work with NHSE to weave into the programme patient group involvement to boost recruitment. | VP/NHS England | In hand. |
| GeL to present the objectives in the light of the overarching GeL principles at September Board. | GC | Done |
| GeL to update the Board in due course on improvements that can be made to turnaround times. | GC | Noted. |

**16-17/044 – Executive Chair’s Report and Dashboard (JC):**

JC noted the following items from his report:

* *Reorganisation:* the reorganisation in September was designed to optimise pathways and to ensure that GeL and NHSE worked together more closely and that each organisation did not create issues for the other**.**
* *Pipeline:* There was a discussion as to where we were on the pipeline and what remained to be done. JC handed out 2 graphs illustrating the pipeline. We are ahead of Plan A for RD but it is too early to say where we are on cancer. There followed a discussion of pipeline informatics issues:
  + It was agreed that there was more to do around informatics. In particular, lessons needed to be learnt around the “Oxford Release”. GeL needs to have an informatics system that are sympathetic to the needs of GMCs.
  + There followed a discussion of how Open Clinica had been developed. **Action: PC to prepare a lessons learnt paper on the implementation of the Oxford Release for the November Board.**
  + It was confirmed that 10 GMCs are using Open Clinica and 3 are using Genie. Beyond Open Clinica there is a preference for xml uploads over file transfer systems. The challenge is to make Open Clinica user friendly. **Action: risk register to be updated to include informatics risk.**
* *Cancer*:
  + There was a discussion of what work remains to ensure that the cancer program is useful.

**16-17/045 – Risk (GC):** GC took the Board through the risk slide.

**16-17/046 NHS England Report (MG)**

* *Consent:* There was a discussion about the nature of the 100KGP consent process and whether this was sustainable for a future clinical service. It was noted that GeL and NHSE are now reviewing the patient literature as advised to the Board in July.

**16-17/047 Intellectual Property Policy (NM):**

* NM described the update to the IP Policy that was now proposed. The main changes to the policy that Board directors have previously seen is that we have now introduced a more subtle categorisation of the main situations in which IP might arise by introducing 3 additional scenarios where joint ownership or a strong licence may be the answer to reach an accommodation with the funders. The funders would now recognise the GeL approach when making awards. The next step was to publish the approved documentation on the GeL website and to write to HEIs to sign up.
* **The Board agreed the IP Policy as set out in the documentation sent to the Board.**

**16-17/048 Data Access (NM):**

* NM presented a paper recommending that GMCs have early access to data outside the GeL Data Centre and that suppliers (eg Illumina) be allowed to run their pipelines outside the GeL data centre. NM advised that both of the above were allowable and the question therefore followed whether they were desirable.
* NM noted further that the strong conclusion of NM’s paper was that research access outside Corsham was not acceptable for many reasons although it was the case that other UK organisations did not operate as a reading library.
* Concern was expressed about transferring data outside the UK, especially to the US (principally because of the Patriot Act) or China and this should be reviewed further. It was noted that UK subsidiaries of US companies were also subject to the Patriot Act.
* **The Board endorsed the direction of travel set out in the paper and looked forward to seeing detailed proposals based on the paper where data was to be shared outside the GeL infrastructure.**

**16-17/049 Operations Report (GC):**

* There was a discussion of current operational issues relating to the pipeline.
* *Q4***:** GC is confident that we should achieve the Q4 target smoothly.

**16-17/050 CIO Report (PC):**

* There was a discussion as to the progress with the participant system and the research environment.
* With regard to the Research environment the ideal approach would be to get the data straight out of hospital systems but there are significant issues with this.

**16-17/051 Science and GeCIP Report (CT):**

* **The Board approved the inclusion of epilepsy+ cohort.** It remains for GeL and NHSE to agree the logistics and contractual arrangements particularly around equity of access given the trial is based on North Thames alone.
* **The position on omics was confirmed: the moratorium on the requirement to collect omics will continue until lifted by the Board.** There is a meeting of the omics working group next week.

**16-17/052 Bioinformatics Report (AR):**

* A number of recruitments have been made, which brings the team up to full strength.
* BCIP should be in testing for cancer in December and for rare disease in March ’17.
* Congenica is now live and Wuxi NextCode should be live very shortly.
* It was noted that the data access discussion gives the executive team a helpful steer on GMC access.
* It was agreed that access to GMCs outside the embassy should only be given to those who have provided HPO terms. **Action: GeL to bring a paper to the Board in November regarding wider access to reporting datasets by GMCs.**
* The first cancer report has been issued and is with NHS England for checking.
* The first main program reports have been given back to GMCs.

**16-17/053 Communications Report and Participant Panel (VP)**

* VP has done stakeholder mapping of patient groups with regard to how they might assist in recruitment. This can deliver a motivated group of patients.
* The Participant Panel has developed a “Not the end of the road” leaflet to stress that if patients don’t get an initial diagnosis then this is not the final answer.
* It was agreed that this remains the single most successful part of the program.

**16-17/054 Genomic Enterprises (SP):**

* SP noted that a key area of investigation was how Gene might relate to academia and the NHS
* SP is exploring what is the next stage for the Gene consortium and will report back in due course.

**16-17/055 Board Committees**: No committee matters were raised.

**16-17/056 Any Other Business:** There was no other business.

**16-17/057** **Date, Time and Agenda for Next Meeting:**

**IT WAS NOTED that the next Board meeting would be held on 29 November 2016 between 14.00 – 17.00 at Genomics England in Charterhouse Square.**

**Close: The meeting closed at 17.05**.

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Signed Dated