## Genomics England Limited - Board Meeting

## Minutes of Meeting held on 29 November 2016 at

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

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| Present: | Sir John Chisholm (Chair) (JC) |
|  | Andrew Baigent (AB) |
|  | Prof Sir John Bell (JB) |
|  | Sir Malcolm Grant (MG) |
|  | Prof Ewan Birney (EB) |
|  | Prof Mark Caulfield (MC) |
|  | Prof Dame Kay Davies (KD) |
|  | Prof Michael Parker (MP) |
|  | Jon Symonds (JS) |
|  | Nick Maltby (NM) |
|  |  |
| In attendance: | Peter Counter (PC) |
|  | Vivienne Parry (VP) |
|  | Augusto Rendon (AR) |
|  | Graham Colbert (GC) |
|  | Simon Partridge (SP) |
|  | Sue Hill (SH) |
|  | Mark Bale (MB) |
|  | Patrick Wray (PW) |
|  |  |
| Apologies: | Dame Sally Davies (SD) |
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**16-17/058 – Apologies:** See above.

**16-17/059 – Chair’s Introduction:** JC welcomed directors to the meeting and declared the meeting quorate. .

**16-17/060 – Declarations of Conflicts of Interest:** JC reminded the Board that all conflicts needed to be declared. EB’s relationship with Oxford Nanopore was noted.

**16-17/061 – Approval of the Minutes of the October Board Meeting and Actions Arising**

The minutes of the October 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** |
| Prepare a lessons learnt paper on the implementation of the Oxford Release for the November Board. | PC | Outstanding |
| Risk register to be updated to include informatics risk. | GC | Done |
| Bring a paper to the Board in November regarding wider access to reporting datasets by GMCs | AR | See Board Pack. |

**16-17/062 – Executive Chair’s Report (JC):**

* JC noted the following items from his report:
  + GMCs: there was a discussion of the impending lab reprocurement.
  + Hinxton opening: the PM’s visit to Hinxton was successful. The PM is very focused on industrial strategy.
  + Participant panel: JC reminded the Board of previous Board discussions about the Participant Panel. GeL appreciates that the GMCs own the patient relationship and that our PP exists to support this. All the GMCs are represented on the panel and several of the PP members play a role in local PPPI.
  + Cancer: there was a discussion around the 4 week cancer genome. NHSE has selected 2 centres to focus on (S London and W Midlands) and see what can be achieved.

**16-17/063 Operations Report and Dashboard (GC):**

* Recruitment has increased to 500/week in the biorepository. We should achieve the Q4 target.
* It was noted that existing cohorts don’t appear to be a panacea in terms of recruitment and tend to under deliver.
* Progress on completing the data for the pilots is continuing.
* The Board would like to continue to receive th level of detail set out in the dashboard. .

**16-17/064 CIO Report (PC):**

* NHS Digital: there was a discussion regarding the move of the clinical environment to NHS Digital. We were going to move our PID environment to NHS Digital in February 2017 but are now reviewing.

**16-17/065 Participants Panel Presentation (ESP):**

* ESP was welcomed to the meeting.
* ESP described the work of the PP, which now comprises 20/25 people including from most GMCs. The objective of the PP was to put patients at the front of everything we do.
* The biggest issue for the PP currently is around the return of results. This has led to issues of expectation management. A portal might alleviate this if it allowed participants to track where their genome was.
* JC commented that the Board is very sympathetic to all these issues. A portal would be explored as there is a similar need for sample tracking in the GMCs.
* It was agreed that getting out the newsletter was a priority. **Action: GeL to get a newsletter out to participants.**

**16-17/066 Science and GeCIP Report (MC):**

* Omics: we now have a simpler omics strategy which the SAC has approved. This is set out in the Science Report. **The Board approved the revised Omics Strategy**.
* Biopsies: progress has been made. We will now agree a revised Protocol.
* It was noted that GeL is still viewed by the international science community as world leaders butmany other organisations are now gearing up.
* It was noted that EB is now chair of the Global Alliance for Genomics and Healthcare. EB wants to standardise data standards.

**16-17/067 Bioinformatics Report and Access to Genomes (AR):**

* It was noted that GeL would next week make certain functionality available to GMCs in the N3 environment. It was expected that this would satisfy many users.
* There followed a discussion as to whether GeL should also make VCFs (both Illumina VCFs and GeL VCFs) available and then whether generally or on an individual request basis and whether compliance with the GMC contract on the provision of data and validation should be a pre-condition.
* **The Board approved the recommendation that access to VCFs is provided to GMCs for a limited period on a trial basis and agreed that the ELT should determine how this should work operationally. The Board will review the position at the March ’17 Board.**
* **Action: AR to update the Board on access to genomes in March.**

**[MP left the meeting].**

**16-17/068 Communications Report and Genomics Conversation (VP)**

* The PM visit ran smoothly although was fairly low key media wise as planned. A joint press release from Sanger, Genomics England and Illumina was issued to specialist and regional press which included a quote from the PM. No.10 used the visit to promote a new £2bn annual fund for scientific research and development.
* VP highlighted the main conclusions of the Genomics Conversation Report to the Board. The public have concerns about the use of their data although they are generally pragmatic about its security. There are some red lines notably access by insurers. They don’t fully understand the distinction between individual data and aggregate data. They remain suspicious about industry access to data and the case needs to be made. CMO will have noted the section in the report on insurance.
* The Board welcomed the report and commented that is was a good addition to understanding the public’s views.

**16-17/069 NHS England Report (MG)**

* Rare disease recruitment is going well. We have now reached 30% of what is needed for the whole programme. NHSE expects to have 60k RD samples by September 2018. Of these 16% only will be singletons. We are recruiting to 164 of the 193 diseases. The number of samples within GMCs continues to fall.
* The story is very different for cancer. NHSE is now looking to put momentum and resources behind those centres who are performing.

**[GC, PC and SP left the meeting].**

**16-17/070 Confidential Item (JC)**

* JC thanked the Board for their input and concluded that there seemed to be general agreement on the importance of data flows in a future model and how these were supported and that the future should build on the present.

**16-17/071 2017 Draft Objectives (GC):**

* This was deferred to the January Board meeting.

**16-17/072 Genomic Enterprises (SP):**

* There was no discussion of this item at the Board.

**16-17/073 Board Committees**: No committee matters were raised.

**16-17/074 Any Other Business:** There was no other business.

**16-17/075** **Date, Time and Agenda for Next Meeting**

**IT WAS NOTED that the next Board meeting would be held on 17 January 2017 between 14.00 – 17.00 at Genomics England in Charterhouse Square.**

**Close: The meeting closed at 17.15**.

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Signed Dated