

15<sup>th</sup> March 2021

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## Agenda Items

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1. Apologies
2. Review last meeting notes
3. Draft of Terms of Reference
4. Other governance issues
5. Academic/Tech issues (papers/direction of travel)
6. Community Issues (conference/workshop)
7. Financial considerations
8. Next meeting date
9. Any other business

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## In Attendance

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**Present:** Andrei S. Morgan (ASM), Angela Pinot de Moira (APM), Artur Rocha, Becca Wilson, Juan Ramon Gonzalez, Kim Cajachagua Torres, Paul Burton, Simon Parker, Stuart Wheater, Yannick Marcon.

**Apologies:** Rosa Gini, Elaine Smith.

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## Review of Last Minutes

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Minutes were reviewed and agreed.

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## Previous Actions

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1. Website amendments made re PB status on DAB
2. Terms of Reference (ToR) was circulated on framapad and contributions made
3. EDI statements – only one found from Newcastle University and added to the shared document. On the DataSHIELD Forum, it was noted that there had been an anti-harassment statement, but no formal EDI statement. EUCAN-Connect have no EDI statement themselves, as each Institution would have their own.
4. (RG will report back on Quality Assurance in May).

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## Draft Terms of Reference (ToR)

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<https://mensuel.framapad.org/p/datashield-advisory-board-9lad?lang=en>

Thanks were given to KCT for leading with the draft. The document is still active and members will continue to work on the ToR, with APM and BW reorganising sections. The document was amended in real time during the meeting, so all discussion points were noted.

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## **Other Governance issues**

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The mode of operation of the DAB was discussed (for example, if the Chair was to be absent).

Question was raised whether we need supporting documents (e.g. and Equality, Diversity and Inclusion statement) for the DAB or for the community as a whole. There should be consistency in documents across the DataSHIELD community, e.g. code of conduct should be on the website and this would be the standard for all DataSHIELD related work (e.g. forum, wiki, conferences, etc)

It was felt we should focus on the ToR and that the DAB should advise regarding other documents.

We could also make reference to following policies of supporting institutions, e.g. following the governance (GDPR) policy of the host institution (currently University of Newcastle).

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## **Academic/Tech issues (papers/direction of travel)**

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- The DataSHIELD team are currently writing papers with collaborators. PB is leading on a new DataSHIELD paper for the IJE (International Journal of Epidemiology), where ASM is writing a section on Governance; each section is limited to 300 words, so presents a challenge. There will be an opportunity for other members of the DAB to input and review.
- We will develop an organogram (organisational chart) of DataSHIELD to include the DAB and its relationship to the rest of the community. This would also need to be displayed on the website.

## **GDPR compliance**

- There are currently no papers which focus on GDPR compliance and DataSHIELD. Useful for the following:
  - No certification for GDPR
  - Due Diligence reporting
  - Medical Device Regulations
  - Post Brexit, good for EUCAN-Connect to analyse this from a European perspective
  - For potential adapters, this would massively increase confidence
  - USA market
- Next steps:
  - If a legal researcher and/or someone from EUCAN-Connect consortia were to write this, this would be apposite. APM will raise at next EUCAN-Connect Meeting/contact Eleanor Hyde – better to come from a ‘user’.
  - The previous paper written by Susan Wallace at Leicester University could be updated. [Protecting\\_personal\\_data\\_in\\_epidemiological\\_research\\_DataSHIELD\\_and\\_UK\\_Law](#)
  - Would be better to have official certification – no tool/certification is known. ISO 27,001 might have applicable section, as technology within organisations has been certified.
- Useful contacts:
  - Evert Ben Van Veen - RECAP Preterm
  - Artur Rocha (AR)
  - Susan Wallace - Leicester University
  - John Hodgson – Data Protection Team, CRUK

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## Community Issues (conference/workshops)

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### Conference

- Raison d'être:
  - Overdue – it will be 2 years since the last conference
  - If virtual, no need to align with EUCAN-Connect conference, and good to reach whole DataSHIELD community, not just consortia members
  - Present ToR for ratification
  - Showcase the ~10 year history of DataSHIELD
  - No training sessions needed as these have been ongoing and available online
- Suggested schedule:
  - 1.5 days of science; 0.5 days governance/admin.
  - An example of good practice: RECAP conference was held from 10am-3pm with adequate breaks
  - Hybrid event? – Difficult due to transport/financial/border issues
  - Who will organise this? ASM happy to do this – with support; he will open a new framapad document.
- Abstracts
  - Free to submit
  - NU online submission software previously used
  - Call for abstracts is focal point – “what can I showcase/finish in time?”
  - Would be great to see real use-case examples: “These are the results we got using this tool” as we’ve yet to focus on people using DataSHIELD and the outputs generated.
  - Tying together talks from developers and researchers work well

Agreed we definitely need a meeting and that it should be virtual to allow equity of access (groups can meet in their own institutions of course). The DataSHIELD Advisory Board will take on the organising role with the support of Newcastle University.

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## Financial considerations

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### General Funding Overview

- Horizon EU project has started
  - Comprises individuals not consortia
  - Exciting things from them to come, hopefully...
- North West Regional Datasets are implementing DataSHIELD
  - Geospatial and health research data bid submitted
- Pan European (European Research Association Network) pre-proposal with AR and ASM

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## Actions

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1. ToR
  - 1. APM volunteered to edit the General Responsibilities section
  - 2. BW volunteered to amend the Mode of Operation section
  - 3. Everyone will continue to add their suggestions
2. Website governance image on website needs to marry ASM's new diagram (ASM/ES)
3. Website – DAB Minutes to be uploaded once agreed (ES)
4. APM will raise GDPR legal paper for DataSHIELD at next EUCAN-Connect Meeting/contact Eleanor Hyde
5. ASM will send Evert-Ben's paper to APM
6. ASM will circulate a new notepad re DataSHIELD conference 2021; all to think about potential dates and overall structure
7. Agenda points for next meeting: conference and abstracts; sign-off ToR; report back from RG about QA

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## Next Meeting

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Monday 17<sup>th</sup> May 2021 13:00 BST (14.00 CEST), Zoom  
(Zoom link sent in calendar invite)