## Agenda Items

1. Apologies
2. Review last meeting notes (including action points)
3. DataSHIELD Conference
4. Terms of Reference
5. DataSHIELD Governance/organisation
6. Quality Assurance
7. Other Sustainability Issues
8. Next meeting date
9. Any other business

## In Attendance

**Present:** Andrei S. Morgan (ASM), Artur Rocha, Becca Wilson, Juan Ramón González, Simon Parker, Stuart Wheater, Kim Cajachagua Torres. (*Initially 6 board members were present, which allowed the meeting to be quorate*).

**Apologies:** Paul Burton, Rosa Gini, Angela Pinot de Moira (APM), Yannick Marcon, Elaine Smith.

## Review of Last Minutes

Minutes were reviewed and agreed.

## Previous Actions

1. RG – await report on Quality Assurance in May (carried over from last Minutes)
2. ToR – ASM posted on Forum
3. Website governance image on website needs to marry ASM's new diagram (ASM/ES)
4. ASM will write short description explaining updated governance diagram (for DS futures paper) and circulate to DAB
5. Conference: BW and ES met to begin organising online tools and discuss website updates
6. Website – DAB Minutes from March were uploaded (ES)
7. APM shared legal paper application for circulation with DAB (**not for external sharing**) and will report back on the bid at the next meeting.

## DataSHIELD Conference

ASM created a new Framapad document entitled "datashield-conference-2021"- https://semestriel.framapad.org/p/datashield-conference-2021

- o With funding from Athlete via IS Global, registration will be free (thanks expressed to JRG)
- o Registration via Eventbrite (rather than Newcastle University)

- Livestreaming via Eventbrite and YouTube will be used for sessions, to allow for broad access (NHS have access issues with Zoom)
- Need to purchase several months' subscription to Eventbrite ~$20-30 month to cover:
  - Increase amount of recordings
  - Participant capacity to increase to 300
  - Additional online rooms
  - Simultaneous meetings
- Recording consent required from speakers before the event
- Need to consider sensitivity of sessions prior to recording
- New abstract deadline: 30 September 2021
- Invitees:
  - a specific invitation to Harald Binder (PI of MIRACUM) to give a 'highlight talk' on how DS is being used in Germany, their unique experience and the science being generated (which is quite a different perspective from many of the H2020 research projects)
  - Liverpool University – group in LifeCycle using DS, but not in contact with the DS team?
  - Key note talks?
  - Any interesting projects/new groups using DS who haven't presented before? Good to learn what users want and need developing
  - We don't need to include any competitors e.g. Personal Health Train
- Advertising – to share amongst the DAB networks & consortia newsletters: BW will draft invitations and share with the DAB to distribute
- Conference organising committee – BW will arrange a meeting for October

## Terms of Reference (ToR)

https://datashield.discourse.group/t/datashield-advisory-board-terms-of-reference-tor/402

ASM posted in the Forum in order to gather community feedback – only one comment was received by Tom Bishop, who questioned whether the DAB should be responsible for highlighting funding opportunities. This proposal was refuted because the DAB is a group of volunteers who do not have time to actively monitor for potential funding possibilities, but the Board would continue to act as a conduit for funding ideas. As no alterations were needed to the ToR document, it was agreed that this could be published on the website.

## Governance/organisation

There had been a DataSHIELD meeting planned last month to discuss updates on paper writing, where Andrei was hoping to share his diagram and discuss its structure further with the team. However, as this meeting did not take place, Andrei will now send a brief summary of the governance structure to DAB members.

Community organisation based on the suggested governance structure will be carried out in conjunction with plans from other members of the community, e.g. EUCAN-Connect who have proposed a system of "trios" to ensure good communication between users, developers and statisticians.

Having now finalised the ToR, the governance of the project will now be the next focus of attention for the DAB. The current section on the website will form a good basis from which to work: https://www.datashield.org/about/governance-policy

- ASM will create a new Framapad consisting of 2 pages with the old policy and a new blank page and begin to draft ideas – he will ask for feedback from the DAB in September

<u>Reporting Disclosure Risks</u>

Should these be reported through Issue Tracker on GitHub or should we create a public area on the Forum for this? Should these breaches be emailed to the DS team directly or open to the community?

How best to notify the community: Do people read emails or prefer posts on the Forum? Could there be pop up messages, when logging on i.e. "message of the day" with notification of bugs/ disclosure risks. Should this process be advised on the organogram?

This is the most important issue on the Governance Policy. This needs to be addressed before the DS Conference, where it will be presented to the community for approval.

To be discussed in more detail at the meeting in September.

<u>Community Advice</u>

Code of conduct for different members of the community – developer agreement needed, but not enforceable, as community driven.

Testing of statistical disclosive problems – we need to be evaluating code audits (as an end goal).

Software approaches to solving problems of code review – we can outline in Governance Policy – then look at this separately. Functions should be quality assured.
SW has updated the website to include DS community packages:
 https://www.datashield.org/help/community-packages
This was seen as an excellent start to documenting what's been developed. Additional information would be needed re. package testing etc.
RG's feedback would be good to hear, as her team have been involved in tackling similar questions.

## Quality Assurance

Ideas were proposed to help mitigate the continuing problem of GDPR:

- Collaborate across DAB to share funding for a GDPR analysis
- Write a paper, which would be peer-reviewed by experts in data ethics
  - Give examples from several countries, giving their interpretations and address how DataSHIELD mitigates restrictions.
- Produce an internal report on issues that the DataSHIELD community are having and address issues on point-by-point basis
  - Problem with this – why should this be trusted?

Following a meeting with Newcastle University's Data Security Officer, Wendy Craig, to discuss DS and GDPR, SW has begun to investigate the problems faced by groups further. There is no group of data owners in EUCAN-Connect, which means that identifying people to consult will be difficult. However, SW has initiated the process of asking for data steward support for GDPR.

SP advised that he would investigate GDPR with his legal contacts: how much it might cost and how much work would be involved.

This issue is complex and complicated further by each member state interpreting GDPR differently, as well as at Institutional level. In Germany, SP highlighted the fact that there are 17 different versions of GDPR in current use. Within Recap, Evert-Ben encountered innumerable problems in tackling this, without success.

As there has been no technical audit of DS or OBIBA, would a Risk Benefit Analysis be needed? This would be difficult as it needs to be **specific** for each study. As the DS platform is flexible (which is great) it is thereby unspecific, which prevents overhauling certification stating it's GDPR compliant! A key factor therefore, would be to define which aspect of GDPR we are aiming for e.g. article 89 (adequate security protection) article 45-50 (international transfers). This was seen as problematic and that ultimately the software host is responsible.

## Other Sustainability Issues / financial issues

- Several grant bids have been recently submitted
- New software grant (closing September) looks a good fit for DataSHIELD and SP happy to be included in the bid
- Andrei advised RECAP funding ends in September, but partners all working together to ensure ongoing sustainability of the project

## Actions

1. ToR – to be posted on the website (ES).
2. Website governance image on website needs to marry ASM's new diagram (ASM/ES).
3. ASM will circulate a short description explaining updated governance diagram (for DS futures paper) and circulate to DAB.
4. ASM to create new Framapads to start to update Governance Policy
5. Conference:
   - BW to organise meeting in October of those willing to help from Committee;
   - JRG to speak with Rodney Ortis (Athlete project manager) to discuss how to organise financial payments with Newcastle University
   - BW to write draft invitations for speakers and share with the DAB to disseminate
   - Website to be updated with further information: abstract submission; registration (ES)
6. Website – DAB Minutes from May to be uploaded (ES).
7. APM will report back on the legal paper application bid at the next meeting.
8. DataSHIELD Meetings for software grant application to include SP (ES to invite)
9. SP to investigate GDPR with his legal contacts
10. Agenda points for next meeting:
    - RG report back on QA in ConcePTION project
    - APM report back on legal paper
    - DS conference organising
    - DataSHIELD community governance / organisation.

## Next Meeting

Monday 20th September 2021 13:00 BST (14.00 CEST), Zoom
(Zoom link sent in calendar invite)