Agenda Items

1. Apologies
2. Review last meeting notes
3. DataSHIELD Journal Submissions
4. Governance Workshop
5. Evaluations of DataSHIELD
6. ConcePTION project
7. Other Sustainability Issues
8. Next meeting date
9. AOB

In Attendance

Present: Andrei S. Morgan (ASM), Becca Wilson, Angela Pinot de Moira (APM), Kim Cajachagua Torres, Simon Parker, Stuart Wheater, Yannick Marcon, Artur Rocha, Juan Ramón González, Rosa Gini, Elaine Smith. Guest: Gonçalo C. Gonçalves - INESC TEC

Apologies: None

Review

None to review.

DataSHIELD Articles (journal submissions)

On the DataSHIELD website, we started to collate all publications which cited using DataSHIELD in their analysis, however no formal process exists for reporting these. In addition, there is no core paper for researchers to cite. However, we can refer people to this page of publications on Google Scholar, which helps track the impact of the project. Periodically we message in the Forum for people to update papers. Any good ideas to track publications?

- Could include a blurb reminding authors to include us in their social media (dual benefit - we can promote their papers on social media too)
- DataSHIELD@newcastle.ac.uk email address for people to advise on publications
- Create a standard form for people to submit DOI?
- PhD and Masters theses - AR will send a list from INESC TEC
- Repository on Website.
- Should there be authors from the DataSHIELD team included on all papers? Depends on who is funded on the grant. National consortia in Germany doesn't have any links – they are completely independent, and we wouldn't be expected to be on their papers.
- Chasing up users isn't scalable as staff move institutions.
- Standardised citation is the most widely used method and makes much more sense.
- Include this in the Governance documents – as part of the Social Contract for users to feed back into the community.

Community Governance (workshop)

Feedback from Governance planning meeting
- ASM's new Framapad documents were amended from a combination of previous DataSHIELD documentation and a Debian (Open Source Software) model.
- The Forum post contains links to all of the documents: DataSHIELD Community Governance Workshop - News - DataSHIELD and a summary of the workshop agenda.
- Headings:
  - Code of Conduct
  - Diversity
  - Constitution
  - Social Contract

- Feedback on the Framapads was discussed and DAB members were encouraged to continue to add comments.
- The Governance documents were seen as a useful asset and tool for the community. Once posted on the website, they will give potential collaborators ready access to essential information.
- Any grants going forward will be costed through the University of Liverpool, in line with Paul's retirement and staff contracts moving from Newcastle from October 2022.
- **Legal association**
- DataSHIELD currently doesn't have a legal/formal association; these Governance documents will help to address this issue, in formalising what DataSHIELD is as a community. However, if DataSHIELD were bound by formal legal constraints, this may hinder open source global collaborations, bound by legal jurisdictions.
- In Debian they have a small separate legal firm who acts on their behalf.
- There may need to be multiple partners in different jurisdictions who take on a similar role, as Newcastle University have been doing, and now University of Liverpool. Also, ISGlobal could take on this role in their country/EU.
- RG's example. Rosa is employed in the private research sector by public institutions in Italy – and has recently been part of the birth of two similar legal entities.
  - vac4eu.org (an association formalised in Belgian law).
  - Sigma consortium is another example. Institutions have contracts with each other, with small fees and have a small pot of functional money. Governance: 3 leaders and 1 person per institution (20 total). Secretariat (which is funded) offer support to groups applying for funding. Not only academic institutions, also private. Governance is light. They linked existing international institutions and signed a joint contract – with a statute and bylaws. This is similar to Maelstrom, which is a non-profit organisation – any income generated goes to Maelstrom research (not McGill University).
  - Is this a good model for DataSHIELD? Perhaps in the longer term, this would be appropriate. Small foundation registered in a country with small paid secretariat - ESPR is a good example: fee to join per year with 2/3 people are employed by them. Toyed with this idea in the Recap consortium as a model for sustainability – some institutions could find €500/year, others couldn't.
  - We need a quick framework to operate in – flexibility needed. The above solutions could be more medium term. This couldn't be established quickly, and may take 1-2 years, with the complication of where to set this up.
  - A formalised structure would be good. In UK, could create a community interest company (non-profit group).
  - Need to separate the "product" of DataSHIELD from the team (in terms of ownership). As Paul steps back, who has the legitimacy to say what DataSHIELD is? If moving between institutions, we don't want arguments about this.
  - What happens if one institution in one country has a disagreement with another? Without an owner of the assets of DataSHIELD (IP owner), there is a risk that groups could start to

splinter and claim ownership, so we need to plan for this. One paid body could have legal mechanism to preserve DataSHIELD.

- o Funding bodies in the UK have restrictions on who they fund, similarly in the EU. This may lead to being precluded from funding if DataSHIELD is set up legally in one country.
- o The DAB was set up to help the project transition from its original model under Paul Burton.
- o Debian model – software and power of development is held by community. The assets are held by a legal firm.
- o DataSHIELD is a series of community packages – each developer is responsible for their packages. The core platform, including dsBase, and others like DSI sit in DataSHIELD repository. Longer term, it would be good to have a legal foundation/non-profit to oversee these.
- o With Paul's retirement, UoL to take over staff contracts and maintain dsBase repository. This could be an interim measure until the steering committee is set up. Who do we want to say is maintaining the core functionality of DS repository? This needs a whole technical sub-project to strategise this.
- o AR has been involved in similar processes before, where the legal process were difficult – even for a small non-profit. A foundation would be a more flexible approach, and a way to isolate institutions from liability. Our offer with DataSHIELD is free software, but there's an opportunity for further paid support. The caveat "Users use at own risk" is needed, however, users would prefer to be protected. We can't ensure 'bullet proof' protection, as this would be subject to huge liability.

Finalise planning for Governance Workshop

- Should we share documents in the Forum prior to next week's workshop?
    - o DAB to read and comment before publishing on the Forum by the end of this week.
    - o Publish an outline of the day on Eventbrite - ES to add draft agenda.
    - o BW to set up an email and reminders on Eventbrite to people who've signed up and include links to Framapad on Eventbrite.
    - o Are we presenting on the day as documents we're happy with, or as models we're happy to use? ASM hoped to offer documents we're 95% happy with, and could tinker with. But even though ASM has created this, he would appreciate others in DAB to amend.
    - o A few members from DAB could meet on Friday to go through any changes we want to make to it. Makes more sense for DAB to polish and send out before next Thursday – with comments we've dealt with, but still leave in comments for things we'd like people's opinion on.
        - ▪ 10am Friday (11am CET) 11th March (action)

Evaluations of DataSHIELD

University of Heidelberg - Fruzsina Molnár-Gábor
- Discussions were held with Heidelberg to carry out an independent review of DataSHIELD – re international transfers and legal issues. Fruzsina will contact BW re costing and scope by the end of March.

UKDS – Matthew Willard, Director– SP reported that they would be happy to look at results and how they would pass disclosure controls and integrate into a work flow.
- BW agreed that this was a good way forward, as there is a lack of accreditation in this software area. They were happy to experiment to integrate with their work. Need a follow up meeting with both groups to fund this. BW has a small pot of money – but person time from both sides needed.
- Quid pro quo for UKDS – could we set up an environment for them as an incentive?
- SP to give ES contact details of UKDS and have a scoping meeting. Should be funded from our respective budgets for each part of work.

- No formal framework in UK for sensitive data releases. SP has co-authored a book on this subject, but it focuses on particular scenarios (tables, graphs), whereas DataSHIELD doesn't use the same approach, so it's difficult to map across DataSHIELD and SP's model. DataSHIELD uses the same disclosure techniques across multiple data outputs; Simon's book looks at all the disclosure controls for one particular data output.

Data+ with Mette Hartlev, Copenhagen University. The January meeting confirmed that there was no crossover/duplication of work with our proposed reviews and their Data+ work; Mette was looking forward to seeing our results.

- There'll be a post doc in Copenhagen working on DataSHIELD.

Also, in EUCAN-Connect, there's no overlap on work in WP7 on ELSI/Data Governance.

- All harmonious work streams, so we aim to share across all 3 projects which can be used as evidence.

Quality Assurance

- RG shared her presentation on "Conceptual frameworks to represent Real World Data and their processing/analysis: where does DataSHIELD fit?" This was well received by the DAB and slides are available and will be shared.

Other Sustainability Issues

- None

AOB

- Reminder for DAB to register on Eventbrite
- Strapline on DataSHIELD logo – posted on Forum to change. DAB decision/community? Competition before next Conference.
- Dates and host for next conference to discuss in next meeting

Actions

1. AR to send details of PhD/Masters publications to datashield@newcastle.ac.uk
2. ES to add draft Governance agenda to the Eventbrite page
3. BW to set up reminders on Eventbrite
4. Send Zoom invite for another working meeting on Friday 11th March – ES
5. SP to send ES UKDS contacts to set up a scoping meeting
6. Send a recording of RG's presentation to JRG
7. RG is happy for her presentation slides with the DAB – ES
8. Agenda items for next meeting: Strapline and dates/host for next conference.

Next Meetings

Monday 9th May 2022 13:00-15:00 BST (14:00-16:00 CEST)