

Scientific & Strategic Advisory Council

First Meeting Minutes - Summary

9th December 2020

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	Decision/Action	Timeline	Lead	Involved
3.1	ICODA to share governance processes for SSAC review (<i>attached appendices 5 and 6</i>)	Complete	NP/AT	SSAC
3.2	TL to share with SSAC EDCTP data among LMIC researchers	15 Feb 2021	TL	-
3.3	ICODA to review EDCTP data to inform challenges of data sharing among LMIC researchers	28 Feb 2021	JLe/AT	TL
3.4	MM to introduce ICODA pro bono lawyer for Project Data Sphere	15 Feb 2021	AT	MM
3.5	Share ICODA Communications & Engagement Strategy	28 Feb 2021	JLe	-
4.1	ICODA Team to share Grand Challenge call with SSAC to share with diverse networks	Complete	JLe	SSAC

Participants	Affiliation	Role
Agnes Binagwaho	University of Global Health Equity Harvard Medical School	Co-Chair
Martin J. Murphy	Shanghai TuoXin Health Promotion Center	Co-Chair
Trudie Lang	University of Oxford Global Health Network	Member
Nicky Mulder	University of Cape Town H3ABioNet	Member
Frank Rockhold	Duke Clinical Research Institute	Member
Yu Wang	Shanghai TuoXin Health Promotion Center	Member
Steve Webb	Royal Perth Hospital Monash University	Member
Steve Kern	Bill & Melinda Gates Foundation	Funder
Jue Liu	Peking University	On behalf of WanNiang Liang
Kedest Mathewos	University of Global Health Equity	Observer
Brianna Ngarambe	University of Global Health Equity	Observer
Kevin Si	CEO Roundtable on Cancer - China	Observer
Julia Levy	ICODA	Executive Director
Andrew Morris	ICODA and Health Data Research UK (HDR UK)	Director of HDR UK Chair of the ICODA Executive Team
Nicola Perrin	ICODA	Governance Lead
Adrienne Testa	ICODA	Research Manager
Névine Zariffa	ICODA	Driver Project 1 Lead

Apologies	Affiliation	Role
John Danesh	University of Cambridge Health Data Research-Cambridge	Member
Jane Gunn	University of Melbourne	Member
WanNian Liang	Tsinghua University	Member

1. Welcome & Introductions

AB invited everyone to introduce themselves and express their motivation to join the SSAC. The data science experience of the members was extensive, with members drawn from a diverse geography. Strong commitment to support ICODA to succeed was expressed by members including:

- Commitment to evidence-based public health improvement;
- Opportunity to demonstrate trustworthy data sharing and an ethical consortium as a global solution to a global challenge;
- Opportunity to provide evidence-based resources to frontline researchers and communities.

We know if we have big data we can do good things. But if those data are not equitably and transparently shared, then it's all for nought.

Martin Murphy

2. Introduction to the International Alliance

Andrew Morris

Appendix 1 – Slides 1-6

AM introduced ICODA's vision to unite data in fair manner to enable discoveries globally in a trustworthy data ecosystem, for both this and future pandemics and health challenges. SSAC is one of two advisory councils and will provide collective wisdom to shape ICODA's direction.

3. Role of the SSAC and Terms of Reference

Agnes Binagwaho

Appendix 1 – Slides 7-10, Appendix 2 – Paper 1: SSAC Terms of Reference

AB introduced the Terms of Reference (TOR) and stated that SSAC members would be expected to identify opportunities to tackle COVID-19 pandemic through data science and the workbench, ensure the platform is trusted and delivers scientifically. The TOR was discussed and agreed with no amendments and a broad discussion followed – key points summarised below.

We are starting to ask the questions toward using data research for better health outcomes and better care for all. It's a long journey and we don't have the answers now, but ICODA is promising.

Agnes Binagwaho

1 Challenges of Data Sharing

There was agreement that data sharing and collaboration was necessary to address COVID-19 and future pandemics and health challenges. However, currently, there are a variety of views amongst data custodians including: unwillingness to share data; controlling how data are used; and wanting to share and enable high quality work.

3.1	ICODA to share governance processes for SSAC review (<i>attached appendices 5 and 6</i>)	Complete	NP/AT	SSAC
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While members were supportive of making data accessible, there was recognition that scientific rigour and governance processes need to be maintained to respect the objectives of the original study design. It is critical for ICODA to be trusted. The Workbench is flexible and data cannot be exported beyond an 'air lock', which can be used as one way to demonstrate trustworthiness. Future consideration needs to be given to how data will be curated before it can be used.

TL offered to share survey data from an EDCTP project with 7,000 researchers in Africa, Asia and Latin America giving information about challenges of data sharing; equity of data access; benefits of data sharing; use of data; and data uptake. Challenges among LMIC researchers not in large research centres include lack of access to data management systems, resulting in non-sharable data. In addition, open access to reporting software will end shortly, leaving a gap to ensure good quality data in LMICs.

3.2	TL to share with SSAC EDCTP data among LMIC researchers	15 Jan 2021	TL	-
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3.3	ICODA to review EDCTP data to inform challenges of data sharing among LMIC researchers	28 Feb 2021	JLe/AT	TL
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2 Information Governance & Legal Issues

There was support for ICODA drawing on existing governance best practice (e.g. CSDR, Vivli, ISARIC, IDDO). The aim of governance processes is to ensure gatekeeping while providing an enabling and facilitating review process, rather than creating a barrier. ICODA is currently working with the Open Data Institute to review the type of entity ICODA needs to be to demonstrate trustworthy stewardship. The Project Data Sphere experience of lawyers drafting agreements pro bono was highlighted in relation to ICODA engaging partners.

3.4	MM to introduce ICODA pro bono lawyer for Project Data Sphere	15 Jan 2021	AT	MM
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3 Communications & Engagement

There was agreement that communicating the vision, potential and utility of ICODA and the Workbench was critical, and a task SSAC members are well placed and committed to carry out among their networks.

3.5	Share ICODA Communications & Engagement Strategy	15 Feb 2021	JLe	-
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4. Responding to the COVID-19 Pandemic: Driver Projects

Appendix 1 – Slides 11-15, Appendix 3 – Paper 2: Driver Projects

Névine Zariffa & Julia Levy

NZ gave an overview of Driver Projects 1 and 2. Driver Projects are exemplar studies where ICODA is working in close partnership with data contributors and the research community. They will both address important research questions and serve to test our processes and tools as we build an approach for the long-term. Driver Projects allow us to bring together data, make it accessible and generate valuable insights. There are currently two Driver Projects:

- *DP1 – Holistic evaluation of efficacy and safety of drug treatments.*
- *DP2 - International Perinatal Outcomes in the Pandemic (iPOP) Study*

DP 1 is looking at COVID-19 treatments: It has been more complicated to access academic data – steering committee academics in addition to their institutional data sharing precedence make sharing data more complex.

ICODA is not just about data or technology. Ultimately, ICODA is a research community. On a good day any of us will have a good idea. All of us together will have even better ideas.

Névine Zariffa

4 Communicating Research Insights

ICODA has a drive to ensure meaningful and well-expressed research outputs, with a commitment for proposals and results to be accessible and understandable to lay audience, as well as researchers.

5 Patient Level Data Considerations

Original data at patient level is richest potential source of insights, but also the most difficult to access. DP1 is enabling access to enriched summary level data, defined to set standards. SSAC members raised questions around how to deal with patient level data in the future and whether ICODA should tackle this itself or through intermediaries. Gail Stevens recommended as point of contact if ICODA wishes to develop processes and systems to enable access to patient level data.

6 Regional Data Sharing Differences

Challenges of geographic differences in regulations and conditions of data transfer and sharing e.g. China vs. EU were flagged as an issue that could potentially be explored through a Driver Project. Discussion followed on strategies that can solve data sharing problems. In the longer term, federated analyses provide the opportunity to stop moving data to analysis and move analysis to data, however there was recognition that this needs a common language when collecting data.

Wang Yu and Liang are invested in sharing data from the world's most populous country (China), that has traditionally not been renowned for sharing data. They're finding ways to make it happen.

Martin Murphy

7 Next Set of Driver Projects – Appendix 1, slides 16-18

JLe outlined the process for the next set of Driver Projects. The Gates Foundation Grand Challenges model to facilitate innovative research is being applied to ICODA goals, with a call for grant applications up to USD100,000. SSAC will be involved in final selection of Driver Projects, with LMIC components for as many projects as possible. The Grand Challenge call will launch on 17th December 2020 and SSAC members were encouraged to share details of launch among their networks.

4.1	ICODA Team to share Grand Challenge call with SSAC to share with diverse networks	Complete	JLe	SSAC
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5. What do we need to do to have reach and longevity beyond the COVID-19 pandemic?

Appendix 4 - Paper 3: Data Ecosystems

Together we can accomplish something that individually none of us have been able to do on our own.

Steve Kern

1 Future Direction

Possibilities for ICODA's future evolution were discussed:

- Evidence Platform
 - As ecosystem of research should be looking beyond clinical trial data.
 - The Grand Challenge pilot aims to learn from research questions identified by researchers, the proposal process itself and the experience gained from delivering the winning initiatives. There is the hope in November 2021 to launch a larger call. If successful it could be an annual offering and an Alliance that goes beyond the pandemic.
 - It would be helpful for the SSAC to return to discussion about federated access in future meetings.
- Real World Data
 - How big data evidence informs decisions at patient's bedside. Clinical trials report average results, but doctors treat individuals. Potential to develop more precision for personalised medicine. Currently, ICODA and European Respiratory Society building bridges to translate from rigorous data and insights to clinical practice.
- Awareness, Engagement & Impact
 - Proactive reaching out to best journalists to cultivate relationships suggested to increase the impact ICODA generated evidence.

6. AOB - Closing Remarks

AB, MM and AM expressed gratitude to members for a promising start using data and research for better health outcomes and impact.

We have the chance now - the world is willing to share. Let's make the most of the novelty.

Agnes Binagwaho

7. Next meeting

Tuesday 16th March 2021

07.00-08.30 Seattle DST/ 14.00-15.30 London GMT / 16.00-17.30 Kigali CAT/ 22.00-23.30
Beijing CST/ 01.00-02.30 Melbourne AEDT

1 Appendix 1 – Presentation Slide Deck



SSAC 1st meeting
Dec 2020.pptx

2 Appendix 2 – SSAC Terms of Reference



Paper 1 SSAC Terms
of Reference.pdf

3 Appendix 3 – Driver Projects



Paper 2 Driver
Projects.pdf

4 Appendix 4 – Data Ecosystems



Paper 3 Data
ecosystem.pdf

5 Appendix 5 – Governance Overview



ICODA Governance
overview_20 October

6 Appendix 6 – Review Processes Overview



ICODA Review
processes overview - !

7 Appendix 7 – Paper by Ewers et al. Access to data from clinical trials in the COVID-19 crisis: open, flexible, and time-sensitive. Shared by Martin Murphy.



Access to data from
clinical trials in the CC

8 Appendix 8 – Paper by Bertagnolli et al. Advantages of a Truly Open-Access Data-Sharing Model. Shared by Martin Murphy.



Advantages of a Truly
Open-Access Data-Sh