

## Summary of ICODA Scientific & Strategic Advisory Council Meeting – December 2022

Date: 5 December 2022

Chair: Agnes Binagwaho and Martin J Murphy

Attendees: Trudie Lang  
Nicky Mulder  
Frank Rockhold  
Andrew Morris (HDR UK)

1	<h3>Welcome &amp; Introductions</h3>
	<p>AB opened the sixth and final meeting of the SSAC, thanking the ICODA team and the SSAC members for their continued support of the initiative. She provided an overview of the agenda for the Council’s consideration.</p>
2	<h3>Session 1: ICODA initiative: achievements, learnings and legacy</h3>
	<p>AM briefly reiterated the mission and vision of ICODA, and Anne Wozencraft (AW) and Neil Postlethwaite (NP) shared lessons across the four pillars of ICODA’s work.</p> <p><b>Pillar #1: Building a collaborative global alliance</b>, involving partners from academia, industry and health systems, with a particular focus on researchers in low- and middle-income countries.</p> <p><i>Lessons learned</i> included:</p> <ul style="list-style-type: none"> <li>• The importance of working collaboratively with a wide range of partners to increase the reach and impact of the initiative</li> <li>• Engaging with a wide range of partners from the outset, to ensure all perspectives are taken into account</li> </ul>

- Leveraging the varied strengths and skills of different partners – funders, alliance partners and technology and data science experts – to create a successful initiative.

**Pillar #2: Strengthening a trustworthy data ecosystem** through public, patient and community involvement and engagement, and robust and trustworthy governance

ICODA's Ethics and Governance Framework played a key role in this area. It was developed in close consultation with ICODA's Ethics Advisory Council and focused on five perspectives: bringing patient benefit; fostering equity; respecting patients and research participants who contribute data; protecting privacy; and providing responsible stewardship. The Framework also informed the development of governance policies and processes for ICODA, which have been made available for future use to avoid duplication and enable new initiatives to start with a set of proven policies and processes.

*Lessons learned* on data sharing included:

- Data sharing challenges for international health data research include lack of global governance models and variations in ethics requirements
- Ongoing challenges also include questions about data sovereignty, differences between international legal regimes, cultural reluctance to share data and data wrangling.

To address these challenges, ICODA focused on the following, guided by its core principles and governance and advisory bodies:

- Successfully used the "five safes" concept on a global scale –Safe Projects, Safe Settings, Safe People, Safe Data, Safe Outputs
- Used mostly summary level/aggregate or openly available data for ICODA projects
- Worked to ensure alignment with HDR UK and relevant national government policy
- Incorporated data sharing agreements into each of the grants that were awarded to the ICODA driver projects
- Worked with industry experts to alleviate technical challenges and create a simplified workstream and health data cycle for researchers.

**Pillar #3: Enabling scale and longevity** through taking a sustainable approach to making data FAIR and providing a Workbench/ trusted research environment for analysis

ICODA, in partnership with PA Consulting, re-purposed HDR UK's existing [Innovation Gateway](#) to support the initiative. The ICODA Gateway provided meta

data services, researcher accreditation and data access request functionality. This approach allowed ICODA to codify the five safes concept, save cost and time, prevent duplication of efforts, facilitate sharing of meta data, and pilot this mechanism for meta data federation. Furthermore, the COVID-19 digital work bench provided researchers with a secure space to perform collaborative research, with controlled access, analysis tooling, data storage & provisioning, hosting and support.

*Lessons learned* included:

- Difficulty of data curation and variation in the needs of the different research groups
- Simplified, project-specific data dictionaries provided the best approach for driver projects across the initiative
- Having specialist technical partnerships and advice available from the outset facilitated the progress of the driver projects. (ICODA partnered with Aridhia Informatics, Cytel, and MMS Holdings)
- Natural language processing (NLP) provides an insightful way to parse and curate medical text fields
- It is important to ensure that resources and outputs of the initiative have sustained impact and usefulness. Data sets will be available for future research on HDR's Innovation Gateway and established technical partnerships will continue to endure. In addition, digital object identifiers (DOIs) with a standard template will be used for tracking the re-use of resources.

**Pillar #4: Using a driver project delivery model**, with a cohort of research studies that are research question-led, build collaborations and test the platform, policies, processes and tools

The ICODA initiative provided support for 12 driver projects, all of which used secondary data to address major research questions related to COVID-19. These projects involved 135 researchers from 19 countries and used a broad range of data types from 60+ countries. All projects were completed on 04 October 2022. Principal Investigators for each of the driver projects will share their findings and lessons learned during an on-line ICODA Showcase event scheduled for 16 December 2022.

*Lessons learned* included:

- The importance of having sufficient time to explore the data sets. Time was short, particularly for the 10 Grand Challenges ICODA driver projects, highlighting the need to focus on particular research questions with specific data

	<ul style="list-style-type: none"> <li>• The use of the driver project approach prevented over-engineering: the ICODA initiative focused on delivery of essential systems, processes and policies that were necessary for the completion of the individual research projects</li> <li>• importance of piloting an approach before expanding scale and reach. The 10 Grand Challenges ICODA driver projects that came after the two initial ones had a smoother experience, highlighting the importance of starting small, then expanding.</li> </ul> <p>Finally, AW highlighted that the legacy of ICODA will continue through the HDR Global programme, as well as through the resources and outputs it has generated. These include: 37 publications to date; datasets and dashboards; governance policies and processes; ongoing partnerships and collaborations; and the global health data science community of practice that has been developed through this initiative.</p> <p>This session was followed by Q&amp;A.</p>
<b>3</b>	<b>Session 2: ICODA Showcase Event</b>
	<p>AW provided an overview of the agenda for the on-line ICODA Showcase event on 16 December 2022, and invited all SSAC members to attend. The Co-Chairs accepted AW's invitation to provide brief reflections at the start of the event.</p>
<b>4</b>	<b>Session 3: HDR Global update and SSAC engagement moving forward</b>
	<p>TL reminded the Council that the HDR Global programme, in partnership with The Global Health Network and three regional partners, has been awarded a five-year foundational grant from the Bill and Melinda Gates Foundation, and additional funding from other sources will be coming in. TL set out the main objective and theory of change framework for the programme. In summary, the HDR Global programme seeks to address global inequity in health data research through:</p> <ul style="list-style-type: none"> <li>• developing data science capability and leadership</li> <li>• enabling a strong health data infrastructure; and</li> <li>• engaging stakeholders to enable uptake of data science insights.</li> </ul> <p>All of these areas will be supported through pathfinder projects that will seek to develop and share approaches and methodologies to both accelerate the health data cycle and strengthen the data research ecosystem. The ultimate goal is to have health data science research that is built on good practice and strong networks, and is regularly conducted by researchers in LMIC settings, and whose outputs shape policy and practice.</p>

TL provided some highlights on the work of HDR Global since it was announced on 27 September 2022. A Global Health Data Science digital hub has been developed, which is supporting the development of a community of practice. Over 2000 members have signed up across the global south, and a draft protocol has been developed for working with stakeholders to identify and reach consensus on essential health data science skills and identify appropriate health data infrastructure. HDR Global is also identifying potential global & regional pathfinder projects, working alongside its three regional partners: Africa CDC, icddr,b and Fiocruz.

TL indicated that, following a review of governance and advisory bodies required for the HDR Global programme, it has been agreed that a new Technical Advisory Group will be established to help address health data science challenges in specific regional and inter-regional contexts. The HDR Global team is currently drawing up the terms of reference for this new advisory group. AM thanked all SSAC members for the major contribution they have made to the ICODA initiative, and extended an invitation to members to express interest in providing advice and input on an individual basis to the HDR Global programme.