Summary of ICODA Ethics Advisory Council Meeting – November 2022

Date: 10 November 2022

Chair: Effy Vayena

Attendees: Claudia Emerson (CE)
               Elettra Ronchi (ER)
               Katherine Littler (KL)
               Andrew Morris (AM)

Apologies: Graeme Laurie (GL)
               Pamela Andana (PA)
               Sharon Kaur (SK)

ICODA team: Anne Wozencraft (AW)
               Edel McNamara (EM)
               Neil Postlethwaite (NP)
               Sally Boylan (SB)
               Sarah Fullegar (SF)

1	**Welcome & Introductions**
	The Chair of ICODA's Ethics Advisory Council (EAC) welcomed everyone and thanked them for joining the meeting. She explained that the meeting would focus on a review of how ICODA's Ethics and Governance Framework, developed under EAC's guidance, had shaped and supported effective and trustworthy delivery of the 10 Grand Challenges ICODA driver projects.
2	**Session 1: Update on ICODA initiative**
	AM added his thanks to all EAC members for joining, and particularly for the pro bono advice and support they have provided since the ICODA initiative was established in July 2020. He then gave an update on the overall initiative, particularly on progress made since the last meeting.

He also asked Council members to consider if there is an opportunity for the ethics and governance principles, tools and approaches that have been developed in partnership for the ICODA initiative to be used at scale for wider international initiatives. |

3	**Session 2: EAC's role and remit**
	Given the time period that had elapsed since the last meeting, AM provided a brief overview of the role and remit of EAC, highlighting their role in shaping ICODA's Ethics and Governance Framework and the critical role this Framework has played in informing design and delivery of the cohort of 10 Grand Challenges ICODA driver projects.
4	**Session 3: Use of the Ethics and Governance Framework for the cohort of 10 Grand Challenges ICODA driver projects**
	AW gave Council members a reminder of the ICODA principles that all researchers and partners had been asked to commit to, and which had informed the development of the Ethics and Governance Framework. These covered five main areas:

1. Delivering patient benefit
2. Fostering equity
3. Respecting the patients and research participants who have contributed data
4. Protecting privacy, using the 'five safes' approach
5. Providing responsible data stewardship

A summary was provided of the achievements, challenges and lessons learned in each of these five areas, detailed in an accompanying slide deck. Overall reflections on the Framework were shared with Council members: researchers and delivery partners had fed back that the principles and Framework developed by EAC were straightforward and easy to follow, providing clarity, transparency and excellent guidance.

A discussion followed on the key issues relating to ethics and governance of the ICODA initiative. Key points made included the following:

Strong **oversight and governance** have been critical for successful delivery of all 12 ICODA driver projects. This included weekly Executive Leadership Team meetings in the initial stages of the initiative, which provided both an external and internal gauge and advice to ensure the initiative was achieving its goals and allowed the initiative to progress effectively and at speed

Stakeholder engagement, particularly with communities and patients, was initially a weak area for ICODA driver projects. This was strengthened through the application and support process for the open funding call in 2021 that led to the identification of the 10 Grand Challenges ICODA driver projects. From the 400+

applications received, 22 longlisted teams were supported through a secondary application process, with workshops provided on engaging communities, patients and the public, as well as policy makers. This resulted in improved research study design, stronger applications and greater delivery of patient benefit, with final selection criteria including one that focused on stakeholder engagement
During the initiative, the ICODA team also ran a series of workshops on stakeholder engagement, and exemplar driver projects presented case studies in this area to other ICODA driver projects and the wider Gates Foundation's Grand Challenges Data Science Community

Individual institutions were responsible for **data controllership** for the projects, which proved difficult to both provide and demonstrate responsible data stewardship. The ICODA team therefore piloted how HDR UK could act data steward and sign data contributor agreements, enabling the transfer of data. This was done using one of the Grand Challenges ICODA driver projects, led by a Principal Investigator in Fiocruz, Brazil. The ICODA team created a suite of documentation; and Fiocruz reviewed these documents and processes, and provided feedback. This was a very helpful exercise for HDR UK and the ICODA team, and we will now genericise these documents and make them openly available on our website for re-use by other organisations and initiatives, as already completed for data governance agreements and other relevant policies and processes.

| 5 | **Session 4: Building on learnings and legacy of ICODA** |

EAC noted the phenomenal number of lessons learned through the ICODA initiative and a brief discussion followed on how these could be disseminated and shared widely to maximise impact and benefit.

The ICODA team thanked EAC for their comments and noted that ICODA's governance and advisory bodies have been exceptional throughout the initiative. The team proposed development of a co-authored paper with EAC members focused on the Ethics and Governance Framework, the approaches taken and lessons learned. This would be compiled in line with the four ICODA 'pillars' and provide an opportunity to share learnings with a wider range of international stakeholders.

KL also suggested the development of a detailed case study highlighting how embedding ethics and governance principles and approaches from the early stages of research studies works well and can bring benefits to communities and patients. All EAC members agreed with this approach.

6	**Session 5: Update on the HDR Global Programme**
	Building on strong connections with The Global Health Network (TGHN), HDR UK has convened a new programme, HDR Global, which will focus on enabling data science approaches to address a wide range of global health challenges. Foundational funding for this programme has been received from the Bill & Melinda Gates Foundation for a partnership initiative, led by three regional partners in Latin America Caribbean, Africa and Asia - Fiocruz, Africa CDC, and Icddr,b - together with TGHN. In addition, Prof Trudie Lang, Director of TGHN has joined HDR as the organisation's Global Research Director. HDR Global was formally launched in September 2022, and focuses on three main areas: 1.Developing data science capability and leadership 2. Enabling a strong health data infrastructure 3. Engaging stakeholders to ensure uptake of data science insights. Progress to date includes establishment of a Global Health Data Science digital hub to best meet the needs and requirements of this community of practice, with a working group helping the HDR Global team to develop and shape resources and tools on the hub.