

Summary of ICODA Ethics Advisory Council Meeting – March 2021

Date: 11 March 2021
 Chair: Effy Vayena
 Attendees: Pamela Andanda
 Claudia Emerson
 Sharon Kaur
 Katherine Littler
 Elettra Ronchi
 Andrew Morris (HDR UK)
 Julia Levy (Director, ICODA)

1.	Welcome & Introductions
	EV welcomed members to the second meeting of the Ethics Advisory Council (EAC).
2.	ICODA update and progress
	<p>Andrew Morris presented an overview of the International Covid-19 Data Alliance (ICODA)'s recent activities and highlights, including an update on the first two Driver Projects and the Grand Challenges ICODA global funding call, which had attracted significant interest. Research studies selected for funding will join the cohort of ICODA Driver Projects.</p> <p>EAC discussed specific information governance issues, including data contributor agreements, partnership with SAIL databank, and preparations for the Grand Challenges ICODA projects.</p>
3.	Ethics and Governance Framework
	<p>The discussion focused on the first draft of an Ethics and Governance Framework for ICODA.</p> <p>The draft builds on guidance and best practice from existing documents, together with ICODA's founding principles, and takes a high-level approach, setting out principles and best practice.</p> <p>It was agreed that the next iteration of the Framework should include some additional detail about the specific practical actions that ICODA will take to deliver the principles.</p>

	The final principles, once agreed, should also be reflected in ICODA's founding principles.
4.	Data stewardship concept paper
	The paper set out a proposal to explore the possibility of creating a Data Institution(s) or legal structure to provide trustworthy stewardship of data, in the medium to long term. The aim would be to support data contributors from anywhere in the world to provide access to data, by reducing complexity and offering an independent entity to help give confidence in decisions about how data is processed and managed.
5.	Public and patient involvement and engagement
	<p>Julia Levy gave an update on the steps the ICODA team had taken to seek advice on developing a strategy for public and patient involvement and engagement, including a workshop in November 2020 and a breakout session at the ICODA Forum.</p> <p>The Committee welcomed the focus on community engagement and public and patient involvement, but recognised the difficulty of embedding engagement at a global scale, and particularly highlighted the diversity of approaches in different countries</p> <p>It was agreed that an initial focus on embedding public and patient involvement in the cohort of driver projects would help to make the work more tangible.</p>