



## **ETHICS ADVISORY COUNCIL**

2 November 2020, 1pm -2.30pm (GMT)

### **Note of first meeting**

#### **Attendees**

- Effy Vayena (EV) [Chair]
- Pamela Andanda
- Claudia Emerson
- Sharon Kaur
- Graeme Laurie,
- Elettra Ronchi

ICODA team: Andrew Morris (AM), Julia Levy, Nicola Perrin

Apologies: Katherine Littler

#### **1. Welcome and introductions**

EV welcomed members to the first meeting of the Ethics Advisory Council (EAC). Members introduced themselves, and the breadth of international representation and experience in ethical, legal and governance issues relating to data sharing was highlighted.

#### **2. Introduction to the International Alliance**

AM provided a high-level overview of the International COVID-19 Data Alliance (ICODA) and its aims. He emphasised ICODA's commitment to building a trustworthy ecosystem and the Alliance principles.

#### **3. Role of the EAC and Terms of Reference**

The EAC provided feedback on the draft Terms of Reference that had been circulated prior to the meeting. It was agreed that the EAC's role should be to provide advice and act as a critical friend. The role of EAC should be to give guidance to help ICODA take different cultural contexts into account, work towards fairness between researchers in different countries, and demonstrate a trustworthy approach, but EAC could not be expected 'to ensure' these things.

There was also discussion about the independence of the Committee, and the flow of information between ICODA and the group. It was agreed that the Committee's role might best be described as "to assist in identifying ethical issues". The ICODA team will bring key issues to the Committee, and EAC can probe and ask questions to explore ICODA's

proposals in more detail. The Chair of the EAC will be a member of the ICODA Board, which will be helpful to improve shared understanding and communication.

The Terms of Reference for the EAC will be updated accordingly.

It was confirmed that EAC would not be expected to design operational mechanisms, but would be asked to comment on whether ICODA was learning from best practice examples appropriately when establishing processes. Transparency would be essential, and the EAC would be able to publish its views on any ICODA activity.

Membership of the EAC was agreed to be representative, and it was noted that the Chair of the Public Involvement Expert Group would be invited to join once the group was established.

***Actions:***

***NP to update EAC Terms of Reference***

***Chair of Public involvement Expert Group to be invited to join EAC [once appointed]***

#### **4. ICODA Governance overview**

The discussion focused on proposals for an Ethics and Governance Framework. Given the rapidly changing context of COVID-19, it was agreed that it would be important to be explicit that the Framework is a responsive living document that is regularly reviewed. ICODA's commitment to openness should be explained in more detail, including being clear about the expectations of FAIR data. Other points raised included:

- How will we ensure that the data available through ICODA is ethically sourced? Thought should be given as to what ICODA might do to check the quality and trustworthiness of the data itself, and the way it was collected.
- How can we take social value into account? Community engagement should be fully inclusive, to involve people in agreeing research priorities together.
- The phrase 'data custodianship' might capture ICODA's relationship to the data most effectively. Stewardship suggests some element of gate keeping, while ownership would be an obstacle to responsible sharing.
- What are the incentives for data sharing? ICODA should look for novel and game-changing ways to encourage data sharing, with an emphasis on providing recognition for those who have collected the data, and being genuinely inclusive and equitable.
- To demonstrate transparency, it should be clear who is using the data, for what purpose and what the outcomes are.
- How can ICODA prevent harm when results are published? In addition to ensuring research is responsible, communicating the outcomes of research must also be responsible and culturally sensitive. For example, descriptions that border on reflections of ancestry or race for stereotypes can undermine public confidence.
- The emphasis should be on 'demonstrating' trustworthiness.

***Actions:***

***Paper on draft Ethics and Governance Framework to be discussed at next EAC meeting.***

## 5. Current data governance issues

The paper set out ICODA's approach to providing review processes, where data custodians choose to delegate to a central mechanism. These processes would cover both accreditation of researchers and review of project proposals. EAC was asked whether the proposals were appropriate.

Members stressed the importance of ensuring that any review was proportionate. In particular, the level of review would depend whether any assessment of risks and benefits had already been captured by another review process, whether ethical, scientific or by funders. A Data Access Committee would traditionally focus specifically on data related issues that had not been considered by other review committees, and so it might be more facilitative in nature. It would be important to get the right balance of expertise on any access committee or review panel. One suggestion was to consider the proposed criteria for privacy – what would be assessed, and how should this be described. The Committee was invited to provide any further thoughts about review criteria.

The Committee agreed that a triage approach for project review of Driver Project 1 was appropriate initially, as part of a pilot phase, but that an appeals process should be offered as part of the learning process.

### **Actions:**

***ICODA team to explore options for independent review panel / data access committee and to report back to EAC at next meeting.***

***Current review process to be adapted to include an appeal process.***

## 6. AOB

It was noted that ICODA is currently exploring the concept of working towards a Data Trust, or a legal entity of some form to provide trustworthy independent stewardship of data. This topic will be discussed in more detail at the next EAC meeting.

The next meeting will be held in February 2021.

### **Actions:**

***Paper on Data Trusts to be discussed at next EAC meeting.***

***Dates for 2021 meetings to be circulated.***