

Telephone Conference: CoC Drafting Group 4 June 2018

Summary Report

Working groups provided updates with regards to their progress. A sub-group to work specifically on the CoC Glossary has been formed. A first draft has been shared within the sub-group, and a face-to-face meeting is due to take place in order to work further on the document. Once the necessary edits have been made, the glossary will be shared with the rest of the Drafting Group members. Other sub-groups have continued to meet and work on their respective texts, which will be sent as soon as they have been refined

Procedural matters for turning in Codes of Conduct were discussed. The internal Working Party 29 working group responsible for procedural matters and when to turn in Codes of Conduct have still given no indication with regards to a time frame or process. It has been communicated that the topic has been tabled for discussion from Autumn.

Further topics discussed included consideration of international perspectives in order to ensure that the Code is aligned. Whilst the primary focus should be on Europe, international collaborative research projects are prominent. The topic of the black market for health data was flagged, particularly with the need to consider the motivation of potential hackers. It was agreed that the Code should focus on proportionate and appropriate safeguards with regards to data breaches and any safety concerns. Furthermore, it was agreed that the Code should have added value, and that this should be explicitly stated in Code. The issue of oversight with regards to eventual adherence to the Code as also discussed.