



RECAP

“Research on European Children and Adults born Preterm”

Grant Agreement number: 733280

Deliverable 2.1

The establishment of the EAHL-IAB interest group on governance of research

<i>Workpackage:</i>	WP X
<i>Task:</i>	T X.Z
<i>Due Date:</i>	30 th September 2018 (M21)
<i>Actual Submission Date:</i>	30 th September 2018 (M21)
<i>Last Amendment deliverable:</i>	30 th September 2018
<i>Project Dates:</i>	Project Start Date: January 01, 2017 Project Duration: 51 months
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Project funded by the European Commission within H2020-SC1-2016-2017/H2020-SC1-2016-RTD

Dissemination Level

Dissemination Level		
PU	Public	x
PP	Restricted to other programme participants (including the Commission Services)	
RE	Restricted to a group specified by the consortium (including the Commission Services)	
CO	Confidential, only for members of the consortium (including the Commission Services)	

Document History:

Version	Date	Changes	From	Review
V1.0	30-09-2018	First version	Evert-Ben van Veen	TNO

SUMMARY

This deliverable describes the actions taken to align with others who work on governance of research to share developments and work in progress. WP2 organised a seminar on this topic at the bi-annual conference of the EAHL in Bergen and the WP2 lead became member of the Code of Conduct drafting group.

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1 INTRODUCTION

1.1 Purpose and Scope

The purpose of task 2.3 is to align with others who work on governance of research in other projects or associations to share developments and work in progress.

1.2 References to other RECAP Documents

- RECAP Research and Innovation action

1.3 Definitions, Abbreviations and Acronyms

Table 1 List of Abbreviations and Acronyms

Abbreviation/ Acronym	DEFINITION
EAHL	European Association of Health Law
IAB	International Association of Bioethics
BBMRI-ERIC	Biobanking and BioMolecular resources Research Infrastructure – European Research Infrastructure Consortium

2 EAHL, BBMRI-ERIC AND CODE OF CONDUCT

This Deliverable calls for setting up a special interest group on the governance of research with health data in the European Association of Health Law (EAHL) and the International Association of Bioethics (IAB).

WP2 organised a seminar on this topic at the bi-annual conference of the EAHL in Bergen. The workshop was well attended but there proved to be no substantial interest in setting up a special interest group. The IAB does not know the concept of an interest group and hence could not participate either.

At the same time BBMRI-ERIC (Biobanking and BioMolecular resources Research Infrastructure – European Research Infrastructure Consortium) launched the initiative for a Code of Conduct on health research with data. This Code of Conduct aims to be much broader than data for biobanks which is the remit of BBMRI-ERIC.

The Code of Conduct will be drafted by a core group of writers of mixed composition of ethicists and lawyers and then reach out to a larger audience. See:

<https://code-of-conduct-for-health-research.eu/>

Instead of trying to set up another interest group, WP2 decided to liaise with this initiative. That would prevent duplication of efforts. The WP2 lead became member of the Code of Conduct drafting group and hence can immediately interact with stakeholders involved in the Code of Conduct and bring that knowledge to RECAP .