

The logo consists of the text "Re CoD ID" in white, sans-serif font, centered within a dark blue rectangular background.

Hybrid Stakeholder Meeting

October 17-19th 2022, Hinxton, United Kingdom

EMBL's European Bioinformatics Institute
United Kingdom & Online *via Zoom*



To join the meeting remotely via Zoom
please register using the following link:

<https://embl-org.zoom.us/meeting/register/tJ0lcOmsqjkrHda6Wm4bq8Nwi6TKVC5aUxMp>

RECODID project has received funding from the European Union's Horizon 2020 research and innovation programme under Grant Agreement N. 825746 and from CIHR Institute of Genetics Grant Agreement N. 01886-000

PROGRAMME

17 th MONDAY		
TIME (BST)	SUBJECT	PRESENTER
9:00-9:15	--Welcome Coffee--	
9:15-9:30	WELCOME	THOMAS JAENISCH (Heidelberg Univ. Hosp.) and GUY COCHRANE (EMBL-EBI)
9:30-9:45	EUROPEAN COVID-19 DATA PORTAL: UPDATE ON COHORT DATA SHARING & NEXT STEPS	GABRIELE RINCK (EMBL-EBI)
9:45-10:10	OVERVIEW OF LEGAL ASPECTS AND CHALLENGES OF DATA SHARING AND HOW THE PANELS WILL WORK OVERVIEW OF LEGAL ASPECTS, DAC, AND GDPR ROLES (PRESENTATION)	FRUZZINA MOLNÁR-GÁBOR (UHEI)
10:10-10:25	--Coffee Break--	
10:25-10:45	CONNECTING DATA AND KNOWLEDGE GOVERNANCE IN RECODID: ADDRESSING PEARL ISSUES (PRESENTATION)	PRISCILLA CESAR (McMaster- IEPI)
10:45-11:05	LOCAL GOVERNANCE MODEL: COLOMBIAN EXPERIENCE (PRESENTATION)	ROSA MARGARITA GÉLVEZ RAMÍREZ (Centro de Atención y Diagnóstico de Enfermedades Infecciosas-CDI, Colombia) & ANYELA LOZANO (Universidad Industrial de Santander, Colombia)
11:05-11:50	Q&A (Fruzsina, Priscilla, Anyela, and Margarita)	Moderator: LAUREN MAXWELL (Heidelberg Univ. Hosp., Germany)
11:50-1:00	--Lunch Break--	

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1:00-1:30	INTRODUCTION TO STANDARDS	Moderator: HEATHER HUFSTEDLER (Heidelberg Univ. Hosp., Germany) & YANNIK ROELL (Univ. Colorado Denver) I2B2, CDISC, LOINC
1:30-1:45	Q&A	
1:45-2:45	COHORT CONSORTIA EXPERIENCES IMPLEMENTING DATA CAPTURE OR EXCHANGE STANDARDS WHAT WORKED AND WHAT DIDN'T	Moderator: HEATHER HUFSTEDLER (Heidelberg Univ. Hosp., Germany.) Panel: EUGENIA RINALDI AND CAROLINE STELLMACH on behalf of ORCHESTRA (SNOMED, LOINC; FHIR); LAUREN MAXWELL on behalf of ECRAID (CDASH, SDTM) GEMMA CASTAÑO (END-VOC)
2:45-3:00	Q&A	
3:00-3:30	Round Table Discussion White Paper	Moderator: HEATHER HUFSTEDLER (Heidelberg Univ. Hosp., Germany.) & YANNIK ROELL (Univ. Colorado Denver)
3:30-3:45	--Coffee Break--	
3:45-4:15	Round Table Discussion White Paper	Moderator: HEATHER HUFSTEDLER (Heidelberg Univ. Hosp., Germany.) & YANNIK ROELL (Univ. Colorado Denver)
4:15-4:45	KEYNOTE: BENEFIT-SHARING / GLOBAL SOUTH AND NORTH DIALOGUES	Moderator: CLAUDIA EMERSON (McMaster-IEPI) CARLA SAENZ (PAHO)
4:45-5:00	Q&A	
5:00	BUS TO CAMBRIDGE LEAVES FOR CITY TOUR & DINNER	
7:00-11:00	Group Dinner at Trinity Hall, Cambridge 7:00-7:30 Drinks Reception 7:30-11:00 Dinner at the Graham Storey Room https://conferences.trinhall.cam.ac.uk/dining/graham-storey-room/	

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18 th TUESDAY		
TIME (BST)	SUBJECT	PRESENTER
9:00-9:20	EXPERIENCES FROM DIFFERENT DATA SHARING INITIATIVES (PRESENTATION)	FRUzsINA MOLNÁR-GÁBOR (UHEI)
9:20-10:30	DIFFERENT DATA SHARING INITIATIVES EXPERIENCES	Moderator: GABRIELE RINCK (EMBL-EBI) Presenters: FRUzsINA MOLNÁR-GÁBOR (UHEI) / (joining from previous talk) JULIA FOREMAN (DECIPHER database) / rare diseases experience / 10 min presentation CLARA AMID (Erasmus MC and the ReCoDID Pilot Project) 10 min presentation SARION BOWERS (Data Sharing at the Sanger Institute), 10 min presentation
10:30-11:00	--Coffee Break--	
11:00-12:00	OPERATIONALIZING FAIR DATA SHARING: LEGAL, ETHICAL, AND TECHNICAL ASPECTS (PANEL)	Moderator: PRISCILLA CESAR (McMaster-IEPI) LAUREN MAXWELL (Heidelberg Univ. Hosp., Germany) - FAIR DATA 10 min presentation MALLORY FREEBERG (EGA/EBI) 10 min presentation EVELYN DEPOORTERE (EC) 10 min presentation
12:00- 12:20	OPERATIONALIZING FAIR DATA SHARING: NEW FEATURES OF THE EGA WEBSITE SUPPORTING DAC / APPROVAL PROCESS	LAUREN FROMONT (EGA/CRG)
12:20-12:30	Q&A	Moderator: LAUREN MAXWELL (Heidelberg Univ. Hosp.), FRUzsINA MOLNAR-GÁBOR (UHEI)

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12:30-1:30	--Lunch Break--	
1:30-1:50	CRF BUILDER PRESENTATION AND DEMO	YANNIK ROELL (Univ. Colorado Denver), GUSTAVO GOMEZ (Industrial Univ. of Santander), FRANK TOBIAN (Heidelberg Univ. Hosp.)
1:50-2:10	Q&A	
2:10-2:30	TBD Presentation about harmonization models/ meta-catalogues (CINECA and EUCAN-Can)	THOMAS KEANE (CINECA), MORRIS SWERTZ (EUCAN-Can)
2:30-2:45	--Coffee Break--	
2:45-4:30	SEMANTIC & TECHNICAL INTEROPERABILITY OF COHORT CATALOGUES: CURRENT LANDSCAPE & NEXT STEPS 10 min intro from the panel members, followed by discussion	Moderator: LAUREN MAXWELL (Heidelberg Univ. Hosp.) Panel: CARLES GARCIA (IHCC) / 10min, ISABEL FORTIER (MAELSTROM) / 10min, GABRIELE RINCK (EMBL-EBI) (EUROPEAN COVID-19 DATA PORTAL) / 10min, RICARD MARTINEZ (Universitat de València) / 10min, PALLAVI BALTE (C4R) / 10min, THOMAS KEANE (CINECA) / (joining from previous talk), MORRIS SWERTZ (EUCAN-Can) / (joining from previous talk)
4:30-5:30	BREAKOUT ROOMS	STANDARDS AND COHORTS MEET
7:00	DINNER - Hinxton Hall Conference Center	

19th WEDNESDAY

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TIME (BST)	SUBJECT	PRESENTER
9:00-9:20	NLP BASED APPROACHES TO RETROSPECTIVE HARMONISATION: OPPORTUNITIES & LIMITATIONS	ALPHA TOM KODAMULLIL (Fraunhofer Institute, Darmstadt, Germany)
9:20-10:00	PANEL AND DISCUSSION	Moderator: YANNIK ROELL (Univ. Colorado Denver) & THOMAS JAENISCH (Heidelberg Univ. Hosp.) Panel: PAUL LUKOWICZ (DZKI), KIRILL VESELKOV (Imperial)
10:00-11:00	FINAL DISCUSSION AND WRAP UP - INPUT FROM BREAKOUT GROUPS	
11:00-11:15	--Coffee Break--	
11:15-12:30	INTERNAL DISCUSSIONS, CONCLUSIONS	CONSORTIA MEMBER DISCUSSION*
12:30-1:30	--Lunch Break--	

*For Consortium members only

Please [contact us](mailto:OLIVIA.PLUSS@CUANSCHUTZ.EDU) at: Olivia Pluss with any questions (OLIVIA.PLUSS@CUANSCHUTZ.EDU)

Zoom Connection Details:

Please register here to receive the Zoom connection details: <https://embl-org.zoom.us/join/registration/tJ0lcOmsqjkrHda6Wm4bq8Nwi6TKVC5aUxMp>

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