

Pillar 2 _ 2020 Annual Retreat _ 04-06 May 2020

Online

Preliminary Program

Day 1 (04/05/2020)

Plenary Webinar	10:00 – 10:30 CET	General presentation: Pillar 2 aims – what is the Virtual Platform – interaction with other initiatives			
	Focus Sessions	10:30 – 11:10 CET	Integrating Registries and the Virtual Platform		
			Resources for Sharing & Analyzing Experimental Data		
			Molecular pathways & analysis workflows		
			Resources and the VP		
	11:10 – 11:20 CET	<i>Break</i>			
	11:20 – 11:50 CET	Rare Disease Researchers Survey results			
11:50 – 12:30 CET	Questions & Answers				
12:30 CET		<i>End of morning session</i>			
Parallel sessions [1] <i>To be adapted according to the RD researchers survey results</i>	14:00 – 15:30 CET <i>The following topics will be discussed at the same time in different rooms. You will be able to switch from one session to another</i>	1	Metadata Common Data Elements	5	Finding stuff ! Navigating RD resources
		2	Informed Consent and Data access issues	6	Counting patients with certain conditions
		3	FAIRification: decision support with Data-stewards	7	Patients Matchmaking - beyond MME (addressing ERN and researchers need)
		4	Data analysis & molecular pathways	8	Registry design & construction - existing and missing standards
Wrap-Up	15:30 – 16:10 CET	[Gathering all participants]: 5 minutes presentation for each topic discussed in the parallel sessions			
16:10 CET		<i>End of afternoon session</i>			
16:00 – 17:00 CET		"social event"			

Day 2 (05/05/2020)

Parallel sessions [2] <i>To be adapted according to the RD researchers survey results</i>	10:00 – 11:30 CET	1	Resources for finding and sharing biomaterials	5	Finding stuff ! Navigating RD resources (<i>repeated</i>)
	<i>The following topics will be discussed at the same time in different rooms. You will be able to switch from one session to another</i>	2	Tools and Data for Translational and Clinical research	6	Informed Consent and Data access issues (<i>repeated</i>)
		3	Resources for experimental data sharing and analysis	7	Data analysis & molecular pathways (<i>repeated</i>)
		4	Deep Dive in the RD Researchers Survey results	8	TBD
Wrap-Up	11:30 – 12:10 CET	[Gathering all participants]: 5 minutes presentation for each topic discussed in the parallel sessions			
		12:10 CET	<i>End of morning session</i>		
Pillar 2 wrap-up [1]	14:00 – 15:00 CET	Report on the needs of ERNs and Researchers [lessons learned from the parallel sessions] Mapping with Work Foci (WF) activities Interaction with other Projects (GA4GH; Solve-RD)			
	15:00 – 15:10 CET	<i>Break</i>			
	15:10 – 16:00 CET	Breakout sessions Planning next steps (according to the needs raised by the mapping with the WF activities & cross-WF interaction)			
		16:00 CET	<i>End of afternoon session</i>		

Day 3 (06/05/2020)

Pillar 2 wrap-up [2]	10:00 – 12:00 CET	Breakout sessions - continue Planning next steps (according to the needs raised by the mapping with the WF activities & cross-WF interaction)			
			12:10 CET	<i>End of morning session</i>	
Pillar 2 AWP writing	14:00 – 16:00 CET	Annual Work Plan: Master Plan writing			
			16:00 CET	<i>End of Annual Retreat</i>	