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## **RaDiCo (Rare Disease Cohorts): a platform for rare disease (RD) e-cohorts**

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### ► **To cite this version:**

Sonia Gueguen, Serge Amselem, Annick Clement, Paul Landais. RaDiCo (Rare Disease Cohorts): a platform for rare disease (RD) e-cohorts. World Conference on Rare Diseases (RARE2021), Feb 2021, Virtuel Event, France. inserm-04059748

**HAL Id: inserm-04059748**

**<https://inserm.hal.science/inserm-04059748>**

Submitted on 5 Apr 2023

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**Background** Implementing RD cohorts is a challenge: RDs are seldom, often underdiagnosed and spread over the national territories.

**Objective** To create a national platform for the development, within a research framework, of RD e-cohorts.

**Material and Methods** The platform, built on the "cloud computing" principle, oriented as an "Infrastructure as a Service"; Interoperable; In compliance with the GDPR; Within a Certified Health Data Host; Ensuring continuous monitoring of data quality and consistency; In line with the French Health Data Hub.

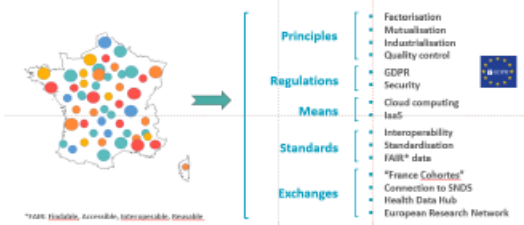
**Results**

**The RaDiCo Information System**



Cloud Microsoft AZURE; CHDI: Certified Health Data Host; CGM: ComputerGroup Medical; Portal: Users authentication & selected access to the cohorts; Back Office: Management of access rights; PIST: Patient Identification System Translator; REDCap: Research Electronic Data Capture; EGCS: Electronic data capture Gateway Controller Service; MedDRA: Medical Dictionary for Regulatory Activities; Therégex: Drugs databank

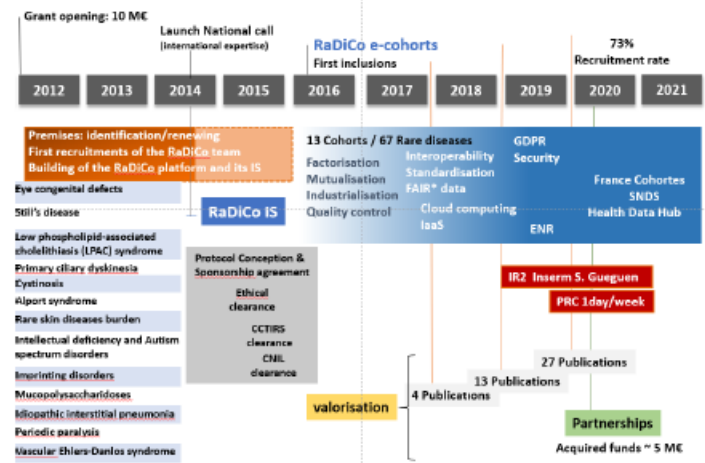
**The RaDiCo platform in brief: How did we proceed?**



**13 ongoing RaDiCo e-cohorts involving 67 RDs**

Diseases	Cohorts	PI	RDHN	ERN
Eye congenital defects	AC-CEIL	N. Chesneau	SENSEGENE	ERN-Eye
		P. Calvas	AnDDI-Rares	
Still's disease	ACOSStill	S. Georgin-Lavie	FA2R	ERN-Rita
Still's disease		B. Faourel		
LPAC syndrome	COLPAC	C. Corpechot	FILFOIE	RARE-LIVER
Primary ciliary dyskinesia	DCP	E. Escudier	RESPIFIL	ERN-Lung
Cystinosis	ECYSKO	D. Maïtre		
		A. Servalis	ORKID	ERKnet
Alport syndrome	EURBIO-Alport	L. Heidat		ORKID
		B. Knebelmann		ERKnet
Rare skin diseases burden	FARD	C. Bodemer	FIMARAD	ERN Skin
Intellectual deficiency and Autism spectrum disorders	GenIDA	J.L. Mandel	DeScience	AnDDI-Rares
Imprinting disorders	IDMet	A. Lingart	FISEND	ERN ETHACA
		I. Netchine	OSCAR	ENDO-ERN
Mucopolysaccharidoses	MPS	B. Héron	G2M	MetabERN
Idiopathic interstitial pneumonia	PIO	A. Clement	RESPIFIL	ERN-Lung
Periodic paralysis	PP	S. Vicard	FILNEMUS	ERN euro-NMD
Vascular Ehlers-Danlos syndrome	SEDVasc	X. Jaunaultre	FAVA-Multi	VASCERN

**RaDiCo key milestones**



**Conclusion**

RaDiCo provides a flexible & easily sharable platform for the creation & follow-up of national/international RD e-cohorts.