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

Sonia GUEGUEN, Serge Amselem, Annick Clement, Paul Landais

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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.

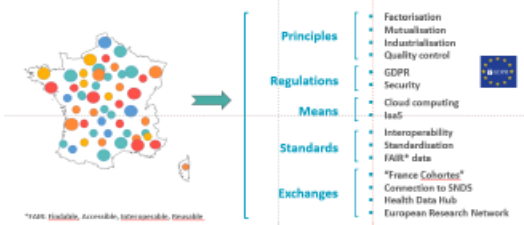
Results

The RaDiCo Information System



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

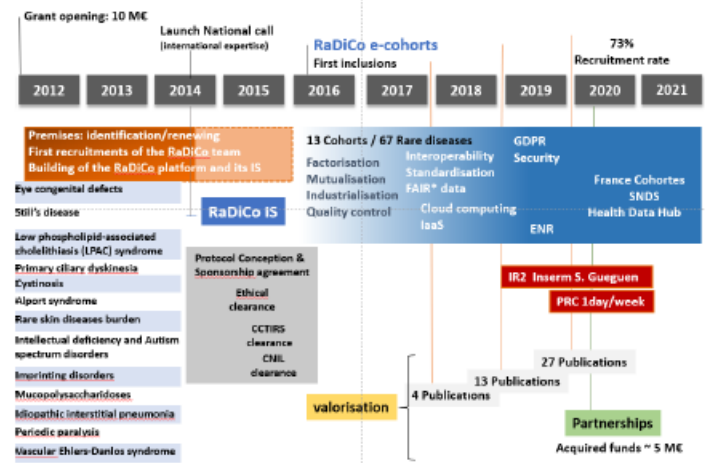
The RaDiCo platform in brief: How did we proceed?



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
LPAC syndrome	COLPAC	B. Faourel		
		C. Corpechot	FILFOIE	RARE-LIVER
Primary ciliary dyskinesia	DCP	E. Escudier	RESPIRE	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
		A. Clement	RESPIFIL	ERN-Lung
Idiopathic interstitial pneumonia	PID	S. Vicard	FILNEMUS	ERN euro-NMD
Periodic paralysis	PP			
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.