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

Sonia Gueguen, Serge Amselem, Annick Clement, Paul Landais

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Guéguen S, Amselem S, Clement A, Landais P for the RaDiCo team.

Background

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

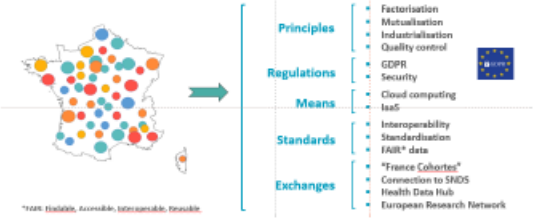
Objective

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

Material and Methods

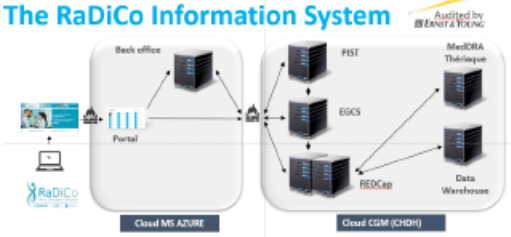
The platform, built on the "cloud computing" principle, oriented as an "Infrastructure as a Service"; Interoperable; In compliance with the GDPR; Within a Certified Health Data Host; Ensuring continuous monitoring of data quality and consistency; In line with the French Health Data Hub.

The RaDiCo platform in brief: How did we proceed?



Results

The RaDiCo Information System

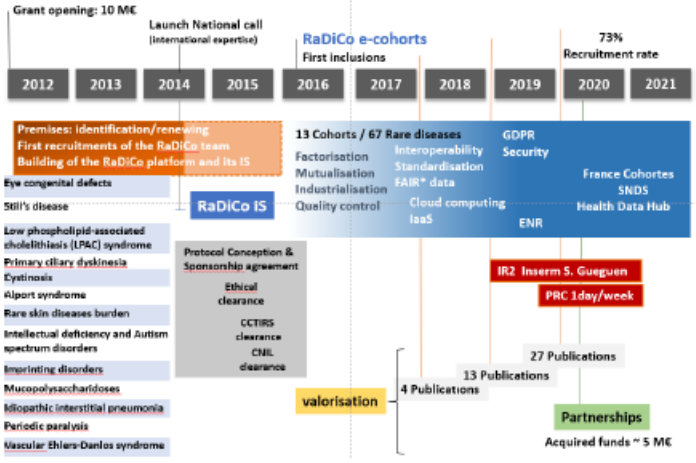


Cloud Microsoft AZURE; CHDH: Certified Health Data Host; CGM: CompuGroup Medical; Portal: Users authentication & selected access to the cohorts; Back Office: Management of access rights; PIST: Patient Identification System Translator; REDCap: Research Electronic Data Capture; EGCS: Electronic data capture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

13 ongoing RaDiCo e-cohorts involving 67 RDs

Diseases	Cohorts	PI	RDHN	ERN
Eye congenital defects	AC-CESL	N. Chassaing P. Calvas	SENSGENE AnDDI-Rares	ERN-Eye
Still's disease	ACOStill	S. Georgin-Lavialle B. Fautrel	FAI2R	ERN-Rita
LPAC syndrome	COLPAC	C. Corpechot	FILFOIE	RARE-LIVER
Primary ciliary dyskinesia	DCP	E. Escudier B. Maitre	RESPIFIL	ERN-Lung
Cystinosis	ECYSCO	A. Servais	ORKiD	ERKnet
Alport syndrome	EURBIO-Alport	L. Heidet B. Knebelmann	ORKiD	ERKnet
Rare skin diseases burden	FARD	C. Bodemer	FIMARAD	ERN Skin
Intellectual deficiency and Autism spectrum disorders	GenIDA	J.L. Mandel	DéfiScience	AnDDI-Rares ERN ITHACA
Imprinting disorders	IDMet	A. Linglart I. Netchine	FIRENDO OSCAR DéfiScience	ENDO-ERN
Mucopolysaccharidoses	MPS	B. Héron	G2M	MetabERN
Idiopathic interstitial pneumonia	PID	A. Clement	RESPIFIL	ERN-Lung
Periodic paralysis	PP	S. Vicard	FILNEMUS	ERN euro-NMD
Vascular Ehlers-Danlos syndrome	SEDVasc	X. Jeunemaître	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.