



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

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

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.

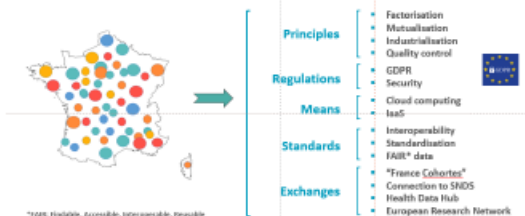
Results

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; Therisque: Drugs database

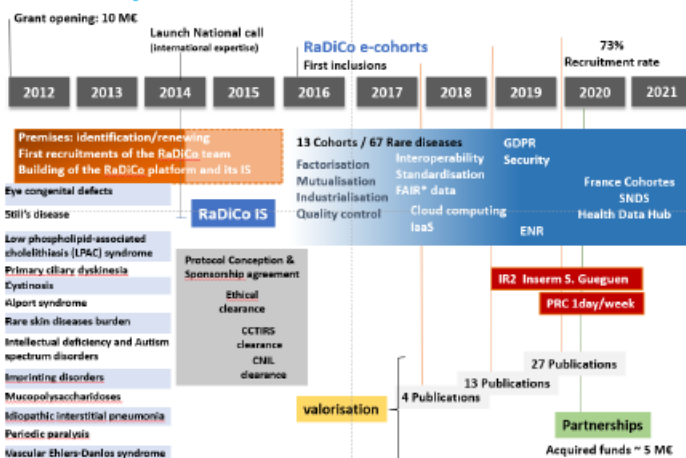
The RaDiCo platform in brief: How did we proceed?



13 ongoing RaDiCo e-cohorts involving 67 RDs

Diseases	Cohorts	PI	RDHN	ERN
Eye congenital defects	AC-CEIL	N. Chaussoning P. Chavet	SENEGENSE ANDI-Rares	ERN-Eye
Still's disease	ACOSell	S. Saccoccia-Lucetelle B. Faurell	FAURZ	ERN-Rhe
LPAC syndrome	COLPAC	C. Corpechot	FILPOE	RARE-LIVER
Primary ciliary dyskinesia	DCP	E. Escudier B. Maitre	RESPIFIL	ERN-Lung
Cystinosis	ECYSO	A. Sereais	ORKID	ERKnet
Alport syndrome	EURISIO-Alport	L. Heidst B. Knöchelmann	ORKID	ERKnet
Rare skin diseases burden	FAIRD	C. Bodemer	FIMARAD	ERN Skin
Intellectual deficiency and Autism spectrum disorders	GenData	J.L. Maréchal	DARScience	ANDI-Rares ERN ITHACA
Imprinting disorders	IDMet	A. Lingard I. Nethline	FRENDO OSCAR DARScience	ENDO-ERN
Mucopolysaccharidoses	MPS	B. Héron	G2M	MetabERN
Idiopathic interstitial pneumonia	PID	A. Clement	RESPIFIL	ERN-Lung
Periodic paralysis	PP	S. Vioand	FILNUMBUS	ERN euro-NMD
Vascular Ehlers-Danlos syndrome	SEdVasc	X. Jeanneutra	AWA-MMO	VASCERN

RaDiCo key milestones



Conclusion

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