

# Workshop #2

# Interoperability

## Session 2

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### Facilitators

**Eric DURBIN** - Kentucky Cancer Registry

**Johanna GODERRE** - US National Cancer Institute

### Subthemes

- Are there existing crosswalks for varying formats/models?
- Are those crosswalks applicable for this proposed project?

## Discussants



**Marie CASTETS**  
France  
**INSERM – Share4kids**  
Co-director



**Paul RINAUDO**  
France  
**ADLIN Science**  
CEO



**Jacqueline CLAVEL**  
France  
**INSERM**  
Epidemiologist and  
Research professor

# Interoperability :

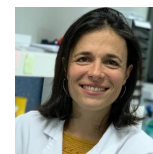
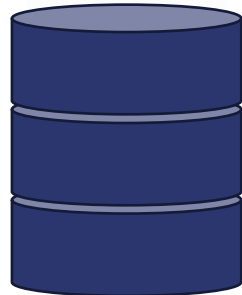
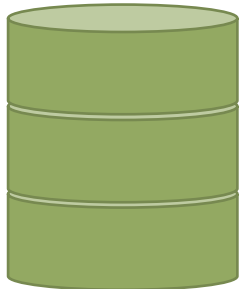
## How different institutions can collaborate by building an interoperable network ?

*The exemple of Share4Kids x CCOP x ADLIN science*

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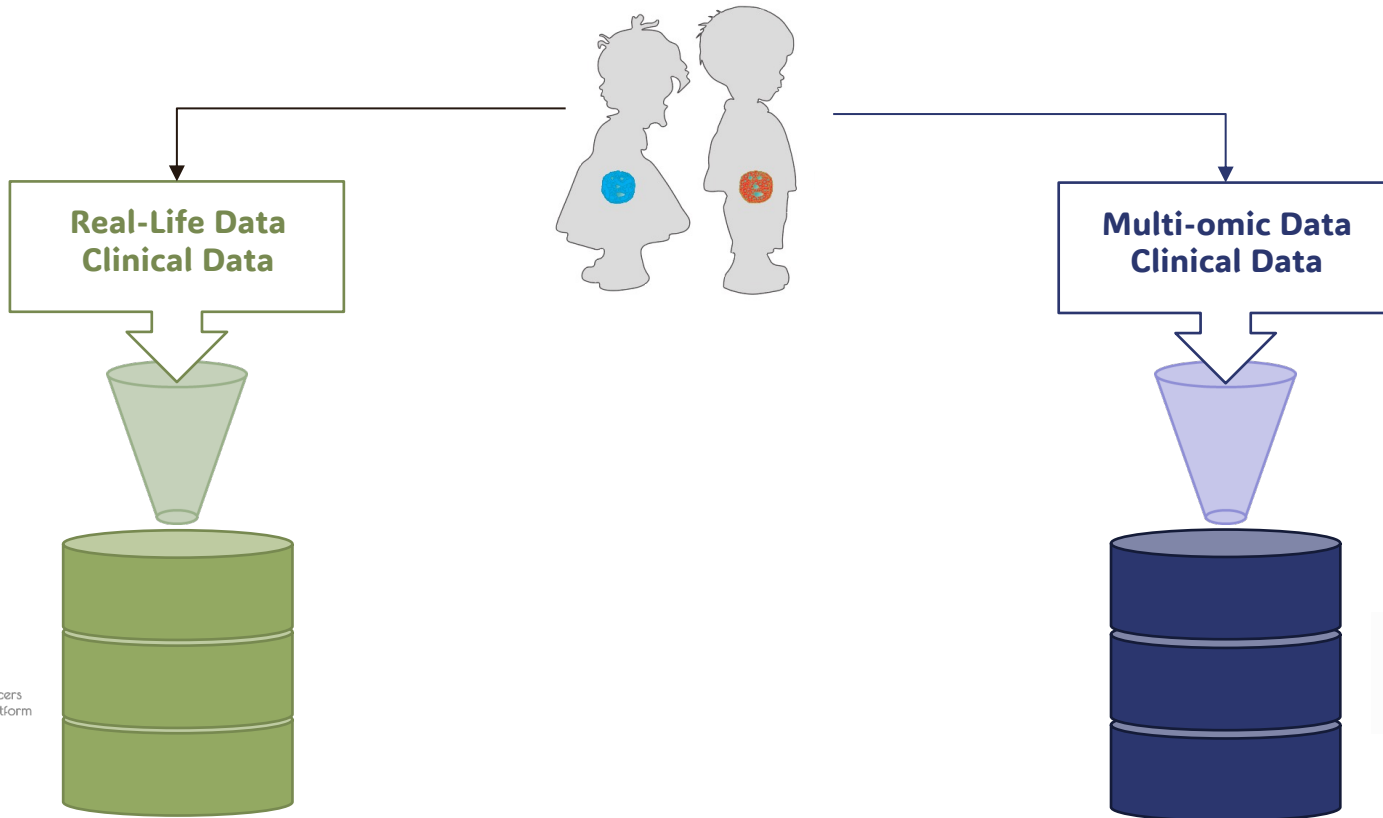
**Dr Jacqueline Clavel**  
Epidemiologist



**Dr Marie Castets**  
Biologist

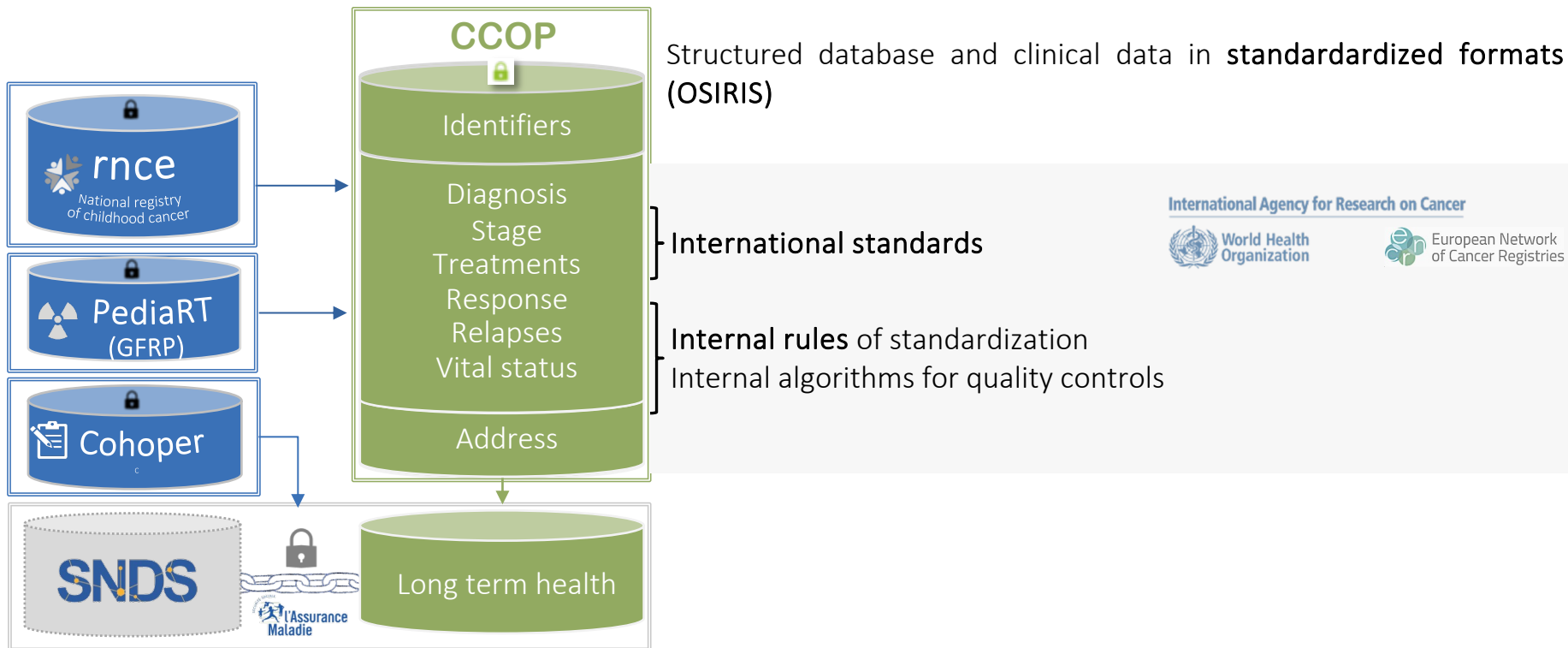


**Paul Rinaudo**  
ADLIN CEO



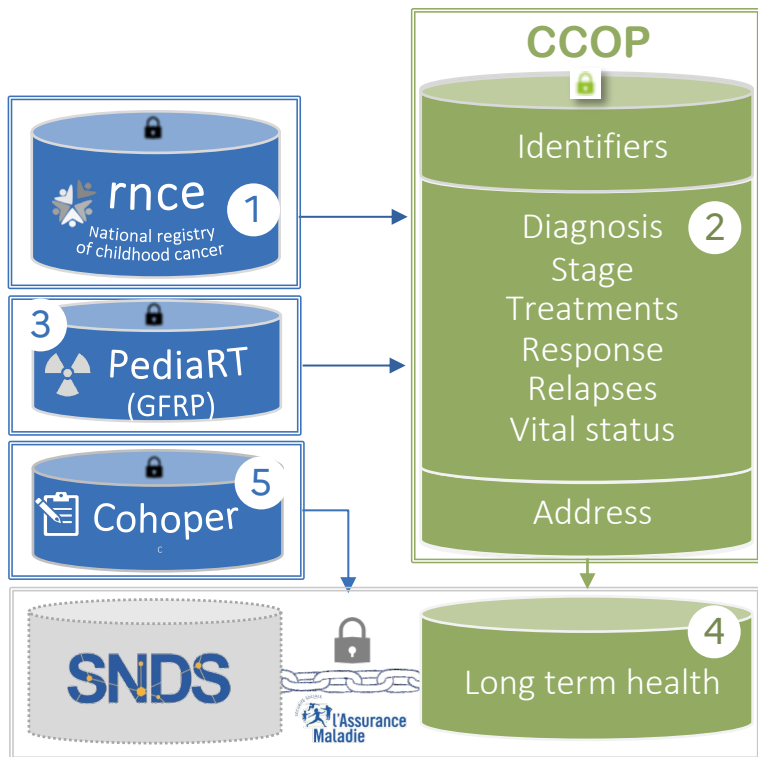


# The Childhood Cancer Observation Platform: a national population-based research infrastructure based on the national registry of childhood cancer (RNCE)





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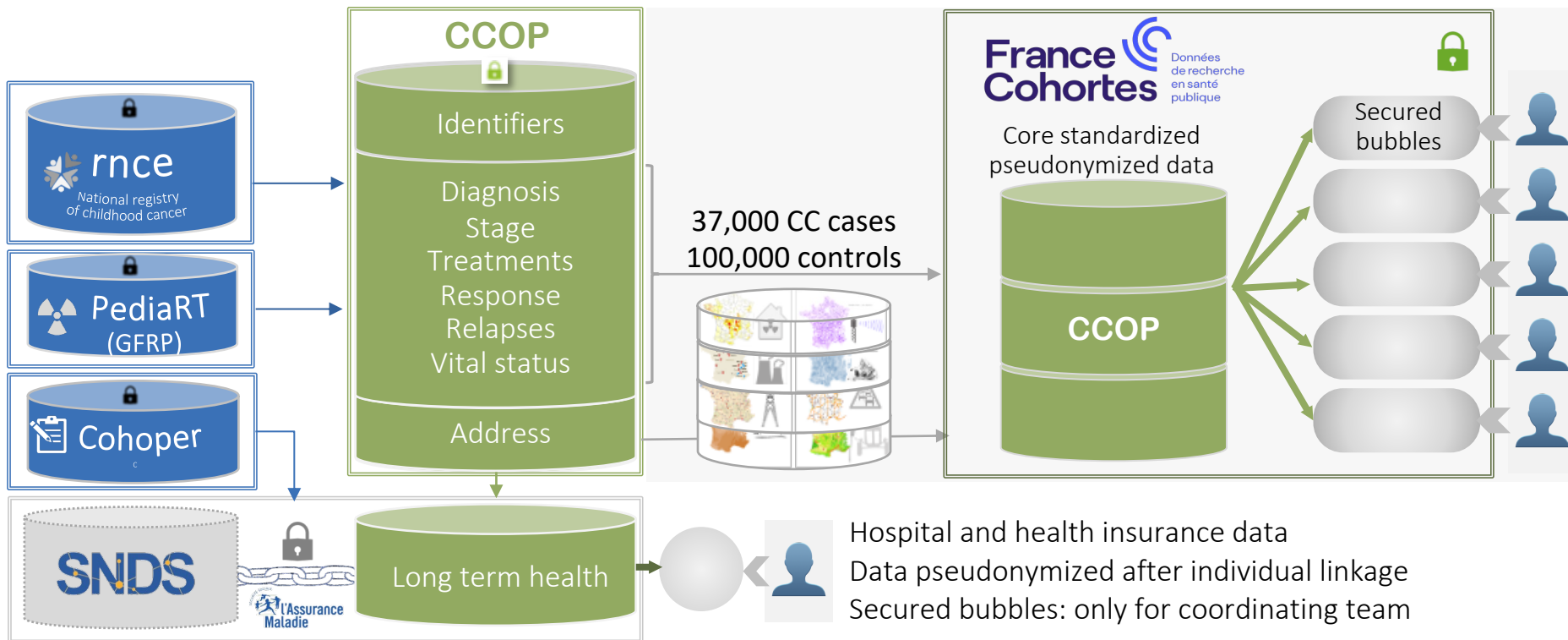


- 1 42,000 CC cases, international networks of registries (IARC, ENCR, CONCORD)
- 2 25,000 CC cases with treatments recorded
- 3 6,000 CC cases with radiotherapy doses
- 4 35,000 CCS
- 5 6,600 adult CCS with completed questionnaires





# The Childhood Cancer Observation Platform: a national population-based research infrastructure based on the national registry of childhood cancer (RNCE)

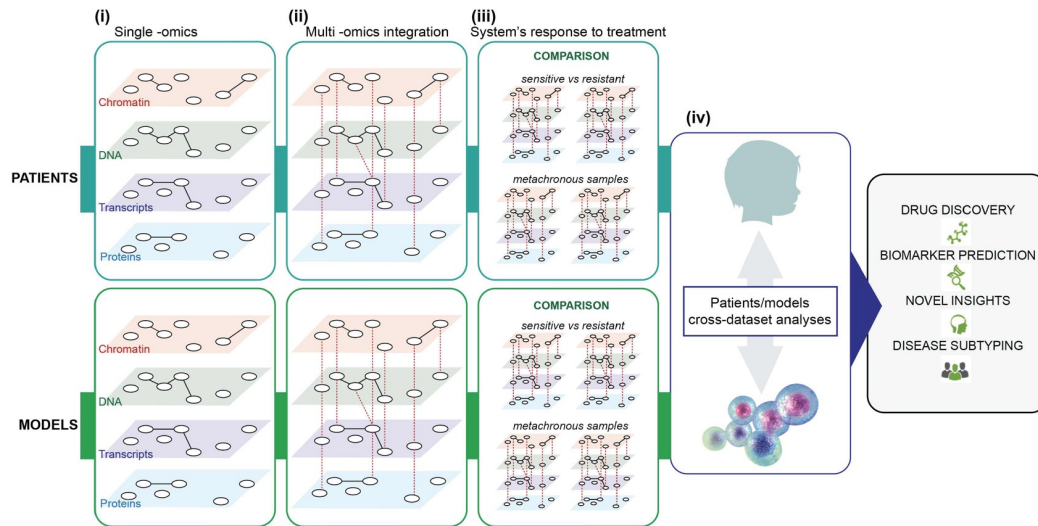
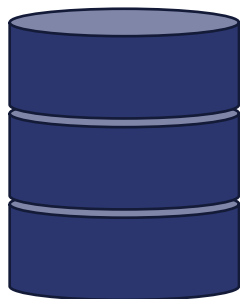




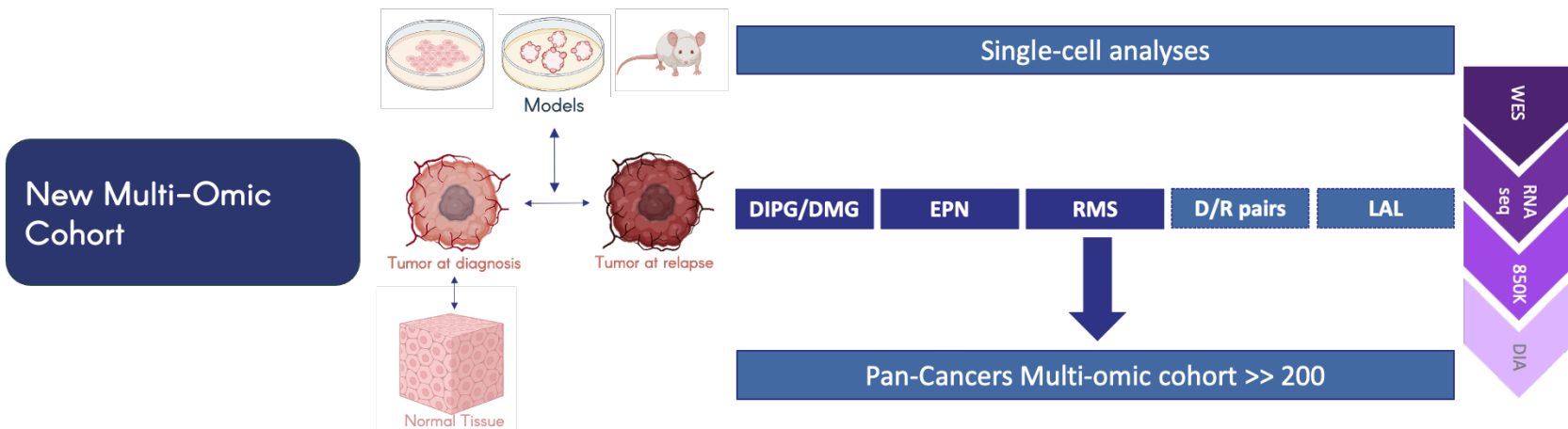
**Phase 1**  
450 french researchers  
45 teams  
**Phase 2 >> international**

Public Data

New Data



A national multi-omic data warehouse on childhood cancers



**Diagnosis**  
Histo/cytology, grade  
cytogenetic, markers  
molecular biol.  
imaging,  
stage

**Treatments**  
CT, drugs doses  
RT, doses organs  
surgery, SCT  
response

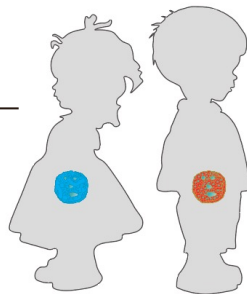
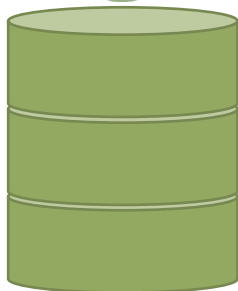
**Events**  
Relapses

**Long term FU**  
Health,  
lifestyle, QOL,  
screenings

**GIS data**  
Environment  
Socio-demo



**Real-Life Data  
Clinical Data**



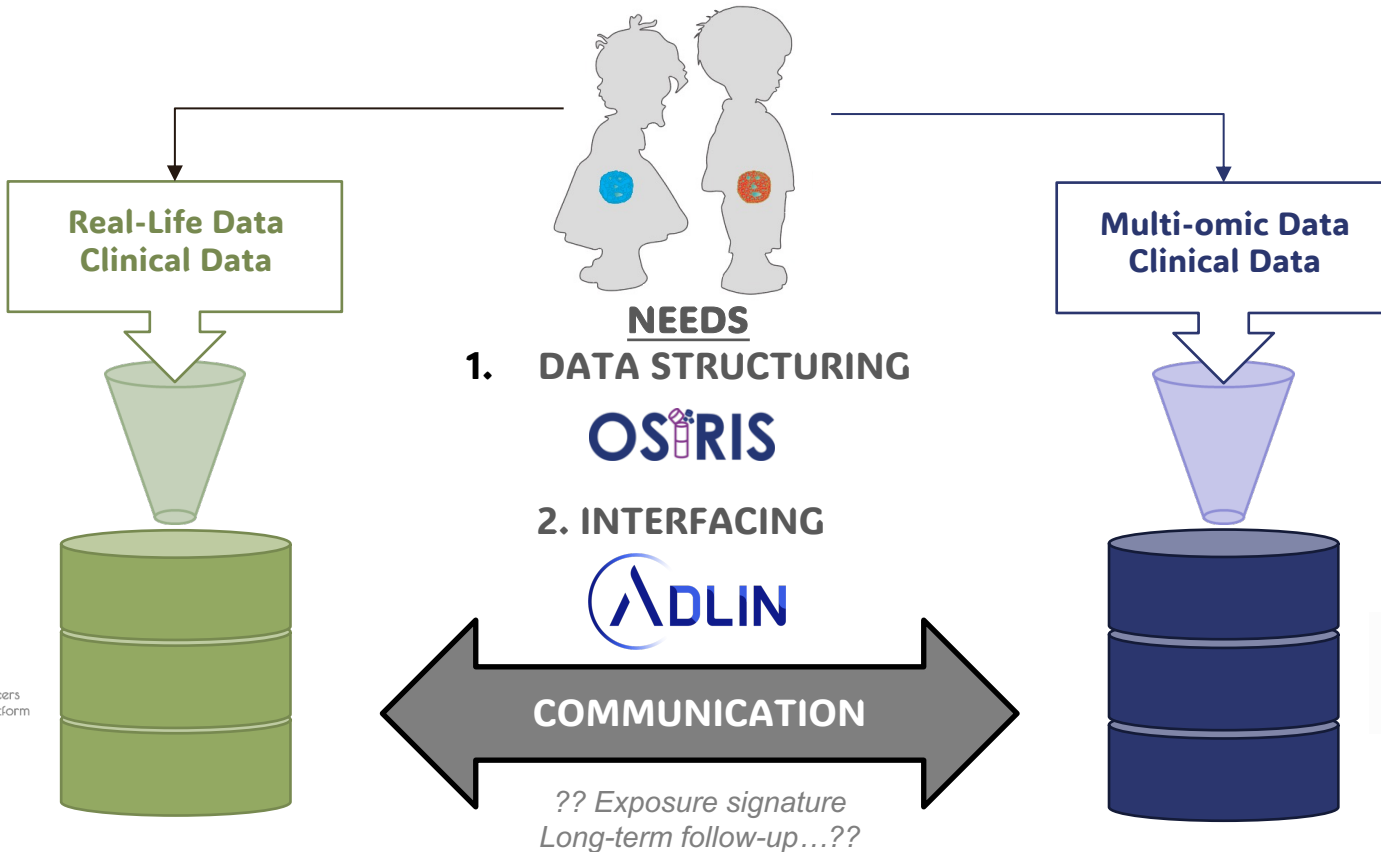
**Multi-omic Data  
Clinical Data**



**Molecular**  
Genome/Exome  
Transcriptome  
Methylome  
Proteome

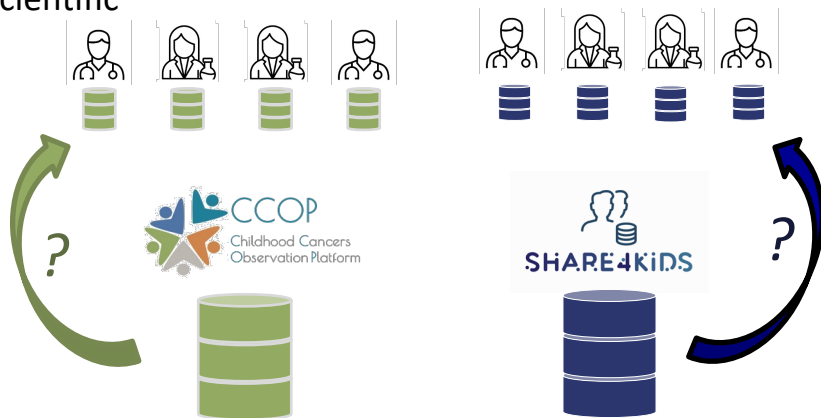
**Clinical**  
Tumor type  
Histology  
Stage/Grade  
Age/Sex  
Metastases  
Diag/relapse  
Treatments  
Overall survival





## Need 1 : Data structuration

Specific scientific context



How to make sure these data are really interoperable ?

**Technically** and **scientifically**



OMOP

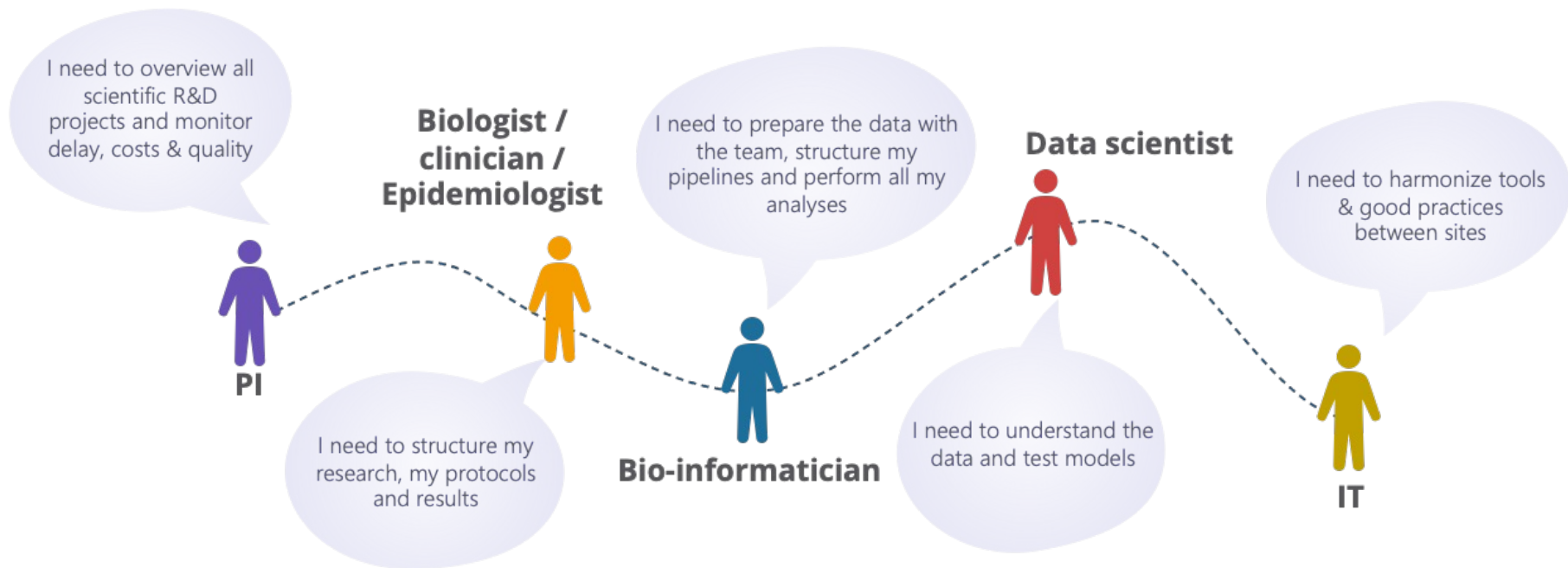
...

Keep the scientific context

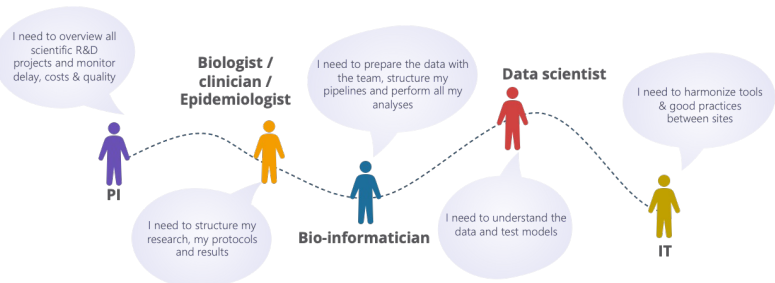
*First to Last mile :*  
Provide adequate structuring tools from day one of the project up to the publication + enabling collaboration

Push contextualized interoperability criteria :  
not the 100+ fields detailed in each standard

## Need 2 : Interfacing



## Need 2 : Interfacing



Freedom to structure the project, and thus the data

Provide a framework where structuration will be facilitated,  
not imposed

Push relevant *data* of one or several *standards*

Structuration and interoperability is a team effort!

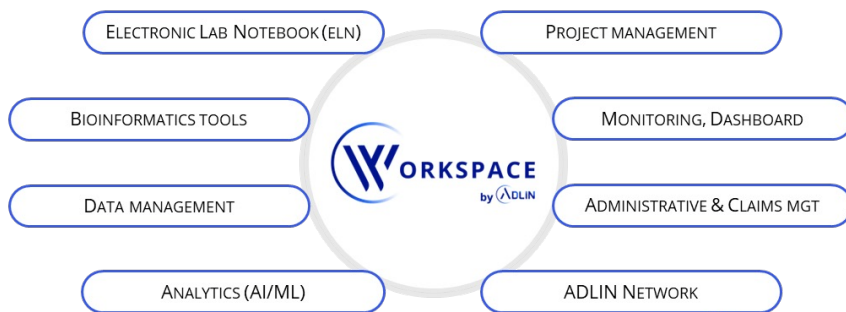
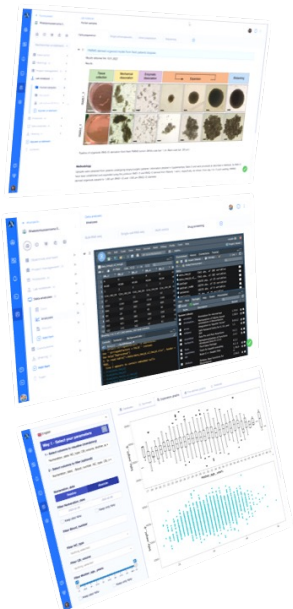


## Need 2 : Interfacing



# DIGITAL RESEARCH ENVIRONMENT

supporting researchers across the entire value chain: from ideation to scientific results, generating structured and FAIR-by-Design data.

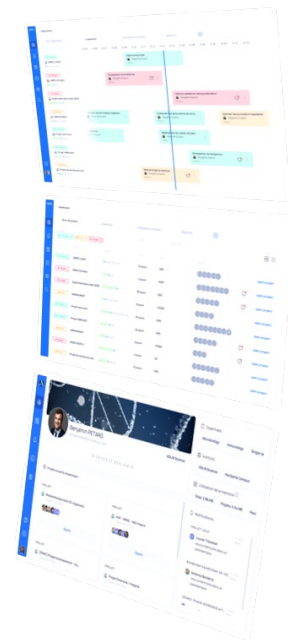


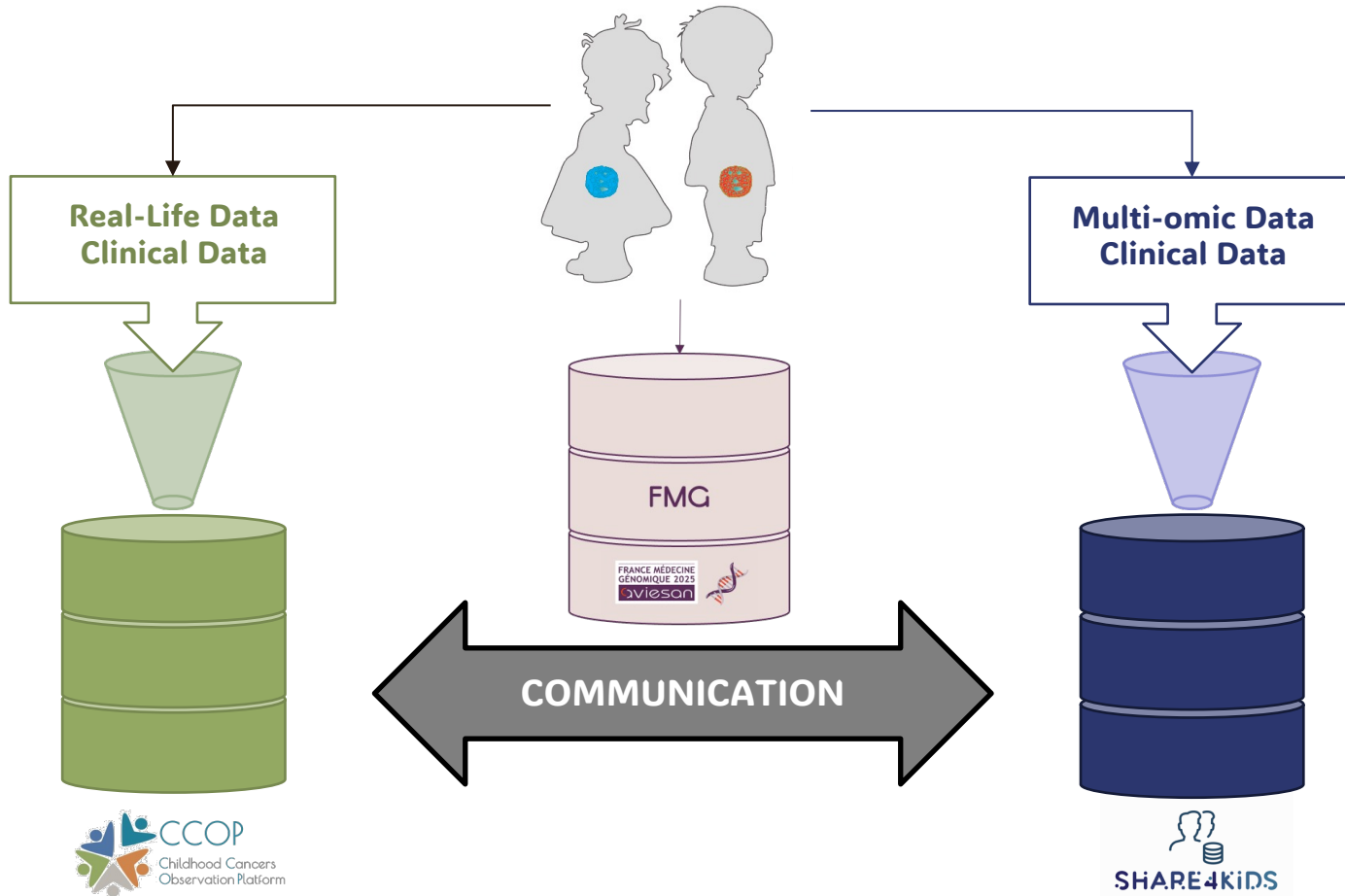
### Standard features

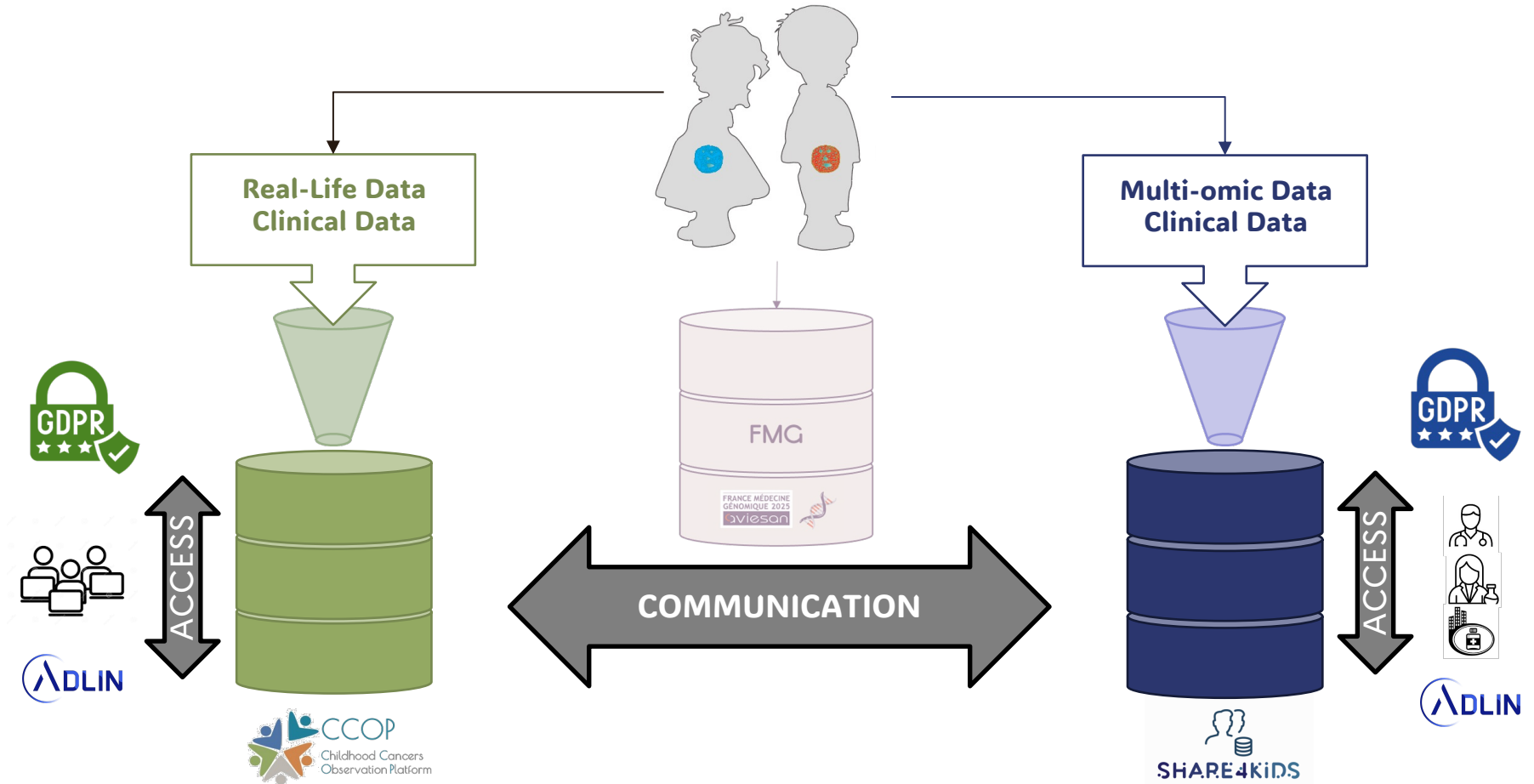
- ✓ Users management
- ✓ Communication, notifications
- ✓ Files manager
- ✓ Security

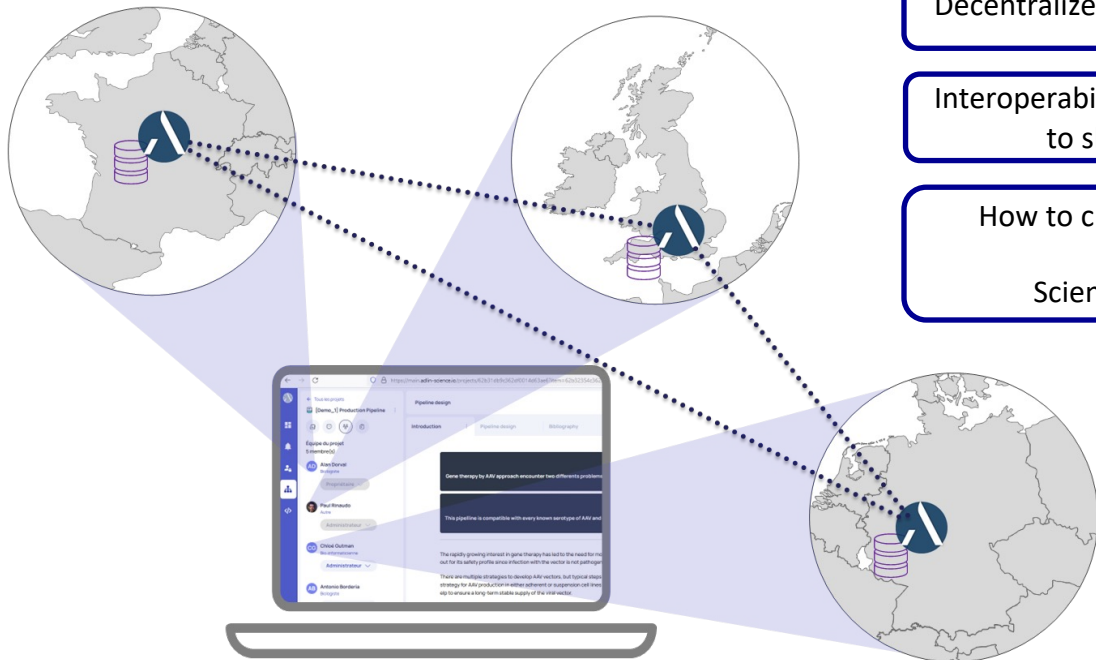
### Additional features

- ✓ Multi site management
- ✓ Teams management
- ✓ Audit trail
- ✓ Connectivity (API)









Decentralized system : researchers and institutions keep control !

Interoperability starts within each institution and their willingness to share data according to the scientific use case

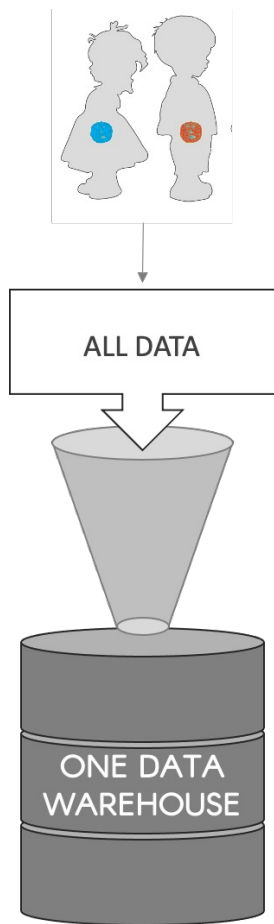
How to create an incentive for research to structure data ?  
Cannot be only for the sake of sharing !  
Scientific needs and objectives ought to be central

Developing *Data Visiting* concept

Digital tools are only enablers

## OUR VIEW

Not a unique data warehouse...



## OUR VIEW

**...But a connected and accessible network with common standards and tools**



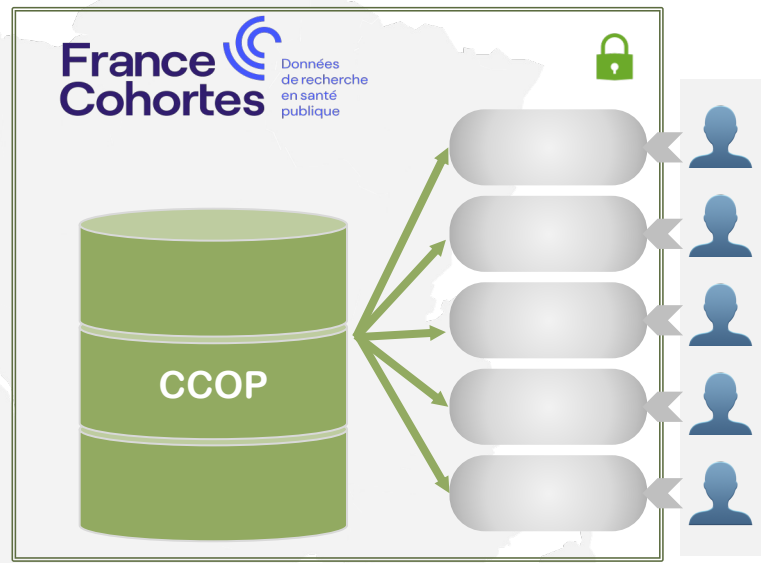
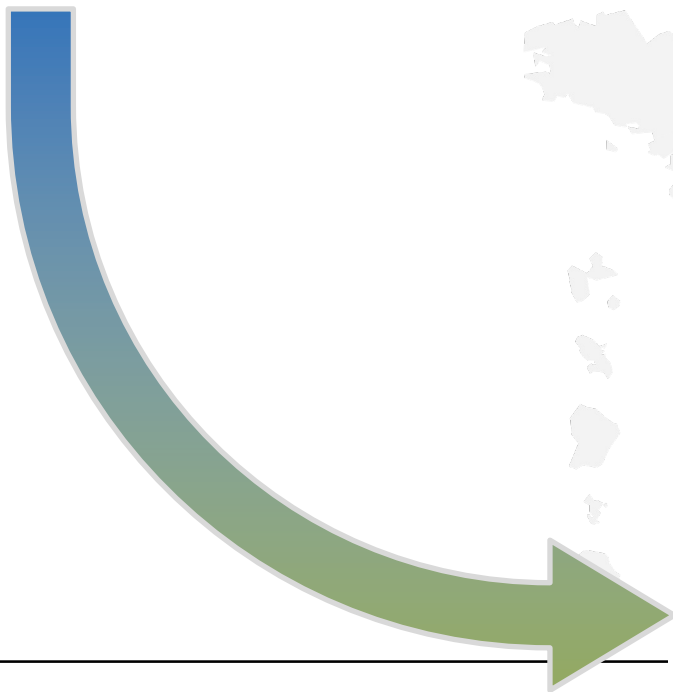
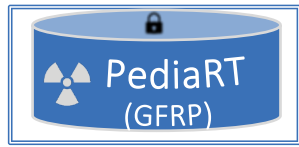
# Appendices

## Past investment

Bring together and harmonize native clinical data

Build specific databases

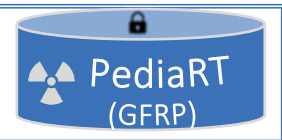
Link different databases



## CCOP Platform

national, exhaustive, all childhood cancers  
standardized, evolutive, flexible, reactive  
secured access to researchers and physicians



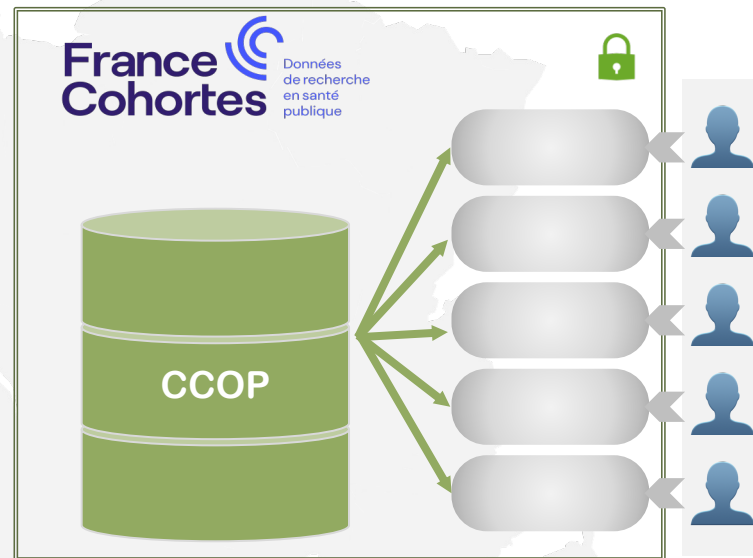


### And next?

- timely integrate developments of research and cares
- be able to connect with relevant databases (e.g. genomics, imaging),

### Need for innovative solutions for data structuring and sharing

- without loss of quality
- respecting intellectual property
- in compliance with regulatory constraints





National project initiated by the **Integrated Cancer Research Sites** accredited by the **French National Cancer Institute** (SIRIC Marseille; CARPEM; ONCO LILLE C2RC; SOCRATE; SIRIC MONTPELLIER; BRIO; SIRIC-Curie; LYrican).

**Reference system of 130 clinical and omics items**, the "OSIRIS Set", constituting a minimum dataset for sharing clinico-biological data in oncology.

List based on a shared conceptual and temporal model of cancer disease.

Organized within a **terminology designed to be scalable** (e.g. other genomics fields) and modular.

**DATA ARCHITECTURE AND MODEL**

OSIRIS: A Minimum Data Set for Data Sharing and Interoperability in Oncology

*Guérin et al., JCO Clin Cancer Inform.  
2021 Mar;5:256-265.*

Already deployed in Centre Léon Bérard, Institut Curie, Institut Bergonié, Hôpital Européen Georges Pompidou, Institut du Cancer Montpellier, Institut Paoli-Calmettes, Gustave Roussy, UNICANCER, Hôpital Saint Louis, with the **aim of creating a network of federated databases, searchable in the form of counts by each institution.**

Currently based on the **open source tools I2B2 and SHRINE.**