



LUXEMBOURG
INSTITUTE
OF HEALTH



openEHR in Luxembourg research – The Clinnova Initiative



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Luxembourg stats

DEMOGRAPHICS

Population: 660 809 (48% non-nationals, 170 different nationalities)

+ 197 000 daily cross border commuters who work in Lux

Most represented: Portuguese (15%), French (8%), Italians (3.7%), Belgians (2.8%), Germans (2%)

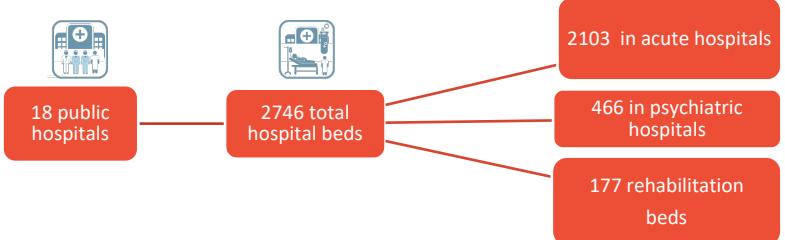
Official languages: Luxembourgish, French, German



Ref: Par NuclearVacuum — Location European nation states.svg, CC BY-SA 3.0,



Lux healthcare system



- Most doctors, including GPs and specialists, work independently.
- GPs are typically found in private consulting practices.
- Specialists split their time between private practice and hospital duties.
- Patients freely choose GPs and directly consult specialists
- Lack of a formal referral system -> Weak primary care system
- Limited population size -> the absence of certain tertiary specialty care.
- Ongoing healthcare reforms: implementation of a national health information system for hospitals, a prerequisite for DRG systems, and health technology assessment (HTA).



The LIH



Public biomedical research institute



Focus on patient-centric translational
research on cancer and immune-related
disorders



Build “inside”:
- Cinnova
- Colive voice
- Colive (PROMS)

Key figures 2022



459

Employees



25

Industrial
collaborations



20

Medical Doctors
Nurses



52

Nationalities



17

Hospital
collaborations



ISO-Certified

ISO 9001 and
ISO17025





AIM

Apply ML/AI on cohort data to find the right medication for a patient in a cross-border collaboration



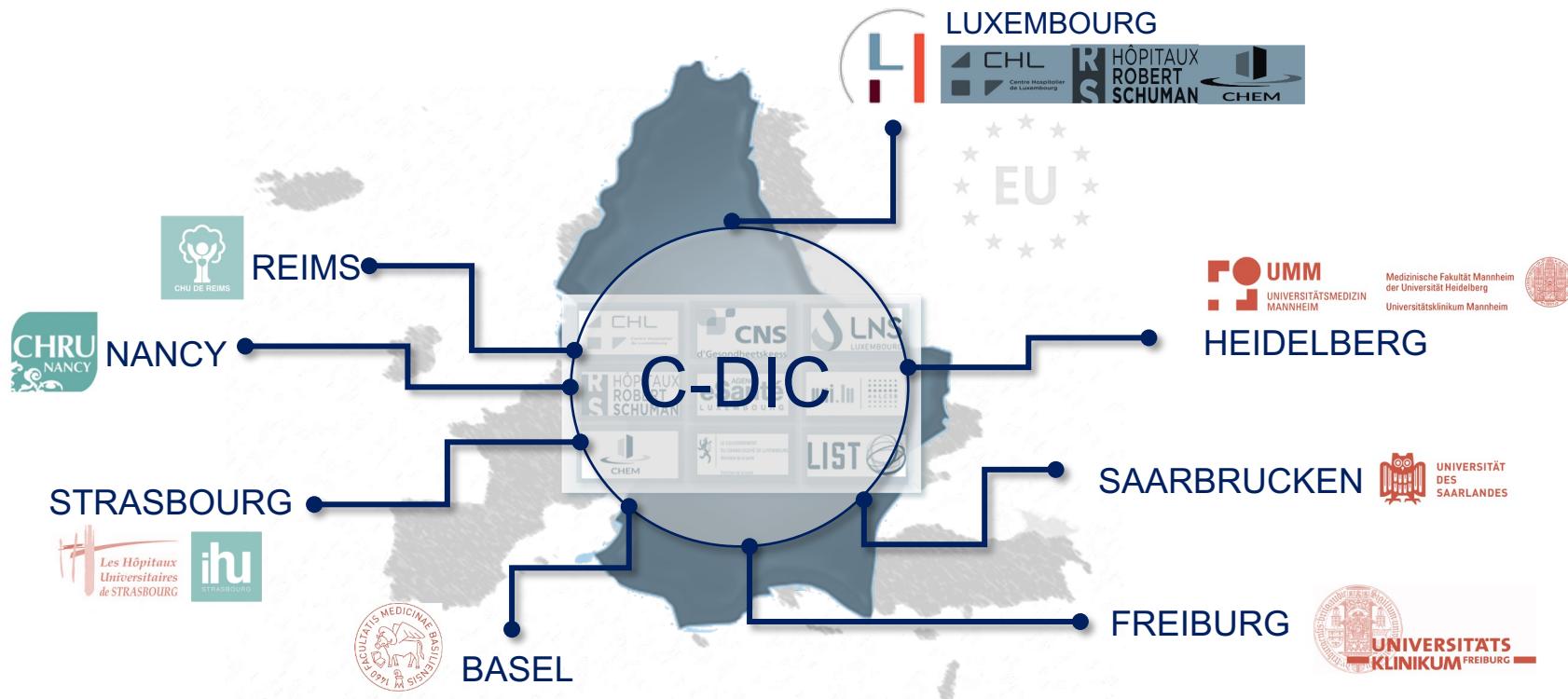
ISSUE

ML/AI does not work if you don't have *contextual health data* properly structured and coded.



<https://www.lih.lu/en/article/clinnova-to-launch-precision-medicine-initiative-across-europe/>

Clinnova – cross border partnership



“Full interoperability” between trusted data hubs

The tooling



Pros:

- Almost free
- All partners have
- Works as a full suite to deploy cohort studies
- Available web and mobile

Cons:

- As a low-code tool, anyone can use it.
- Anyone can define variable ids differently for the same clinical concept
- Limited data structuring and types
- Should be used for simple cohorts
- API gives PTSD
- UI not the best

This screenshot shows a REDCap web application interface. At the top, there's a navigation bar with links like 'My Projects', 'REDCap Messenger', 'Help & Support', 'Administrator', 'Project Home & Design', 'Data Collection', and 'Clinical Trials'. Below the navigation, there's a section titled 'Clinicova-IDB' with a 'Pending' status button. The main content area is a form titled 'Disease History and Characteristics'. It includes fields for 'Clinicova ID' (with a dropdown menu), 'Event: Screening and Inclusion Visit' (set to 'test'), 'Diagnosis' (with a dropdown menu for 'Crohn's disease'), 'Date of first symptoms' (set to '01-11-2023'), 'Date of diagnosis' (set to '14-11-2023'), and 'CD Classification' (with a dropdown menu for 'Age at diagnosis'). There are also sections for 'The Minimal Classification for Crohn's disease (CD) and ulcerative colitis (UC)' and 'CD Classification' (with a dropdown menu for 'Location, endoscopic or macroscopic estimation'). At the bottom of the form, there's a note about 'Must provide value'.



Pros:

- Internal tool – full control of it



Cons:

- As a low-code tool, anyone can use it.
- Anyone can define variable ids differently for the same clinical concept
- Limited data structuring and types
- Some data recorded in REDCap will also be recorded here → different structuring and formats

This block contains three screenshots of the colive mobile application. The first screenshot shows a welcome screen with a user profile picture and the name 'Hello Johnny'. The second screenshot shows a language selection screen with options for English, Français, and Deutsch. The third screenshot shows a survey titled 'FACIT - Fatigue Scale' with a question: 'Below is a list of statements that other people with your illness have said are important. Please choose one answer per question to indicate your response as it applies to the past 7 days.' Below the question are five radio button options: 'Not at all', 'A little bit', 'Somewhat', 'Quite a bit', and 'Very much'. At the bottom of the survey, there's another question: 'I feel weak all over *'.

WITHTINGS

Pros:

- Pretty watch that does the job

Cons:

- Limited data structuring and types
- variable ids different for the same clinical concept
- Some data recorded in REDCap and colive will also be recorded here → different structuring and formats



The tooling

(how the data looks like underneath the surface)

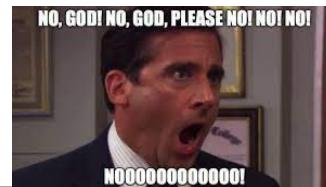


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<ItemData ItemOID="seated_vsorres_271650006" Value="80" />
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<ItemData ItemOID="weight_vsorres" Value="47" />
<ItemData ItemOID="height_vsorres" Value="161" />
<ItemData ItemOID="height_vsorres_dev" Value="" />
```

WITHINGS

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  "gender": 1,
  "shortname": "ABC",
  "measures": [
    {
      "value": 85,
      "unit": -2, //kg
      "type": 4 //Weight
    },
    {
      "value": 2,
      "unit": -2, //m
      "type": 1 // Height
    }
  ],
  ...
}
```

```
{
  "q1": "1",
  "q2": "0",
  "q3": "0",
  "q4": "1",
  "q5": "0",
  "q6": "0",
  "q7": "0",
  "q8": "0",
  "q9": "1",
  "q10": "3"
}
```



Different ways of recording the same clinical concept and not consistent at all...

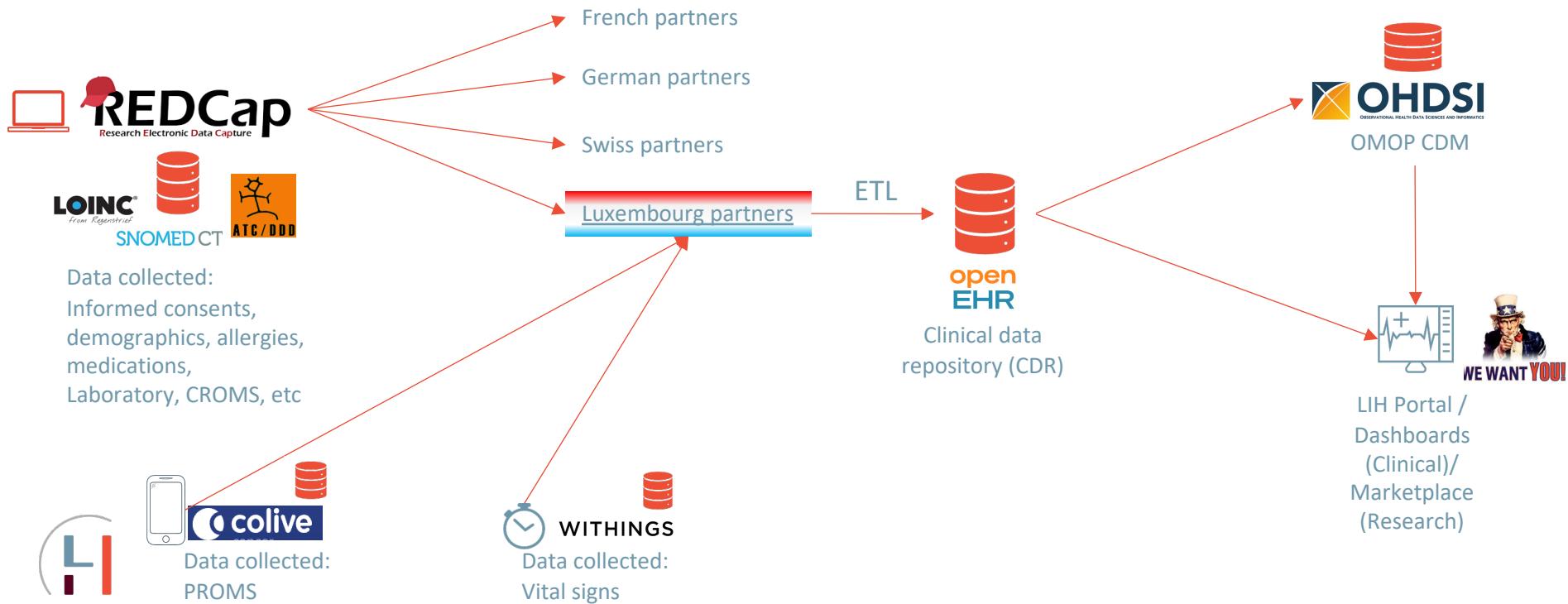


How to harmonize?



Clinnova IT data flow (AS-IS)

IBD, RD, MS cohorts



Reasons to use openEHR



Huge clinical content already available for usage



Can make the modeling world more understandable for non-tech people



Active community



Best and powerful healthcare data modelling (structures, types, terminologies bindings)



Translations



Reliable ecosystem/tooling



Fast development and deploy



Easy to use for secondary data



The contribution for openEHR models

Short IBD-Disability Index (IBD-DI-SR)	Harvey Bradshaw Index Crohn's activity index (HBI)	The Montreal classification	Patient Health Questionnaire-9 (PHQ-9) (translation update)	Limberg score	Health Assessment Questionnaire (HAQ)	ACR/EULAR Classification Criteria for Systemic Sclerosis (SSc) (2013)
Brief Illness Perception Questionnaire (Brief IPQ)	Crohn Disease - Patient reported outcome (CD-PRO-2)	Nancy histological index	Perceived Stress Scale (PSS)	Clavien-Dindo Classification	Modified Rodnan Skin Score (mRSS)	Disease Activity Score-28 (DAS-28) (update)
Jorge and Wexner faecal score incontinence	Ulcerative Colitis - Patient reported outcome (UC-PRO-2)	5-item Medication adherence Scale (MARS-5)	Cutaneous Lupus Erythematoses Disease Area and Severity Index (CLASI)	Manual Muscle Testing 8 (MMT-8)	American College of Rheumatology Damage Index for Systemic Lupus Erythematosus (SLICC)	Swollen and Tender Joint Count (SJC/TJC 66/68)
Mayo score (update)	Simple Endoscopic Score for Crohn Disease (SES-CD)	Functional Assessment of Chronic Illness Therapy - Fatigue (FACT-Fatigue)	Work Productivity and Activity Impairment Questionnaire V2.0 (WPAI)	Myositis Disease Activity Assessment Tool (MDAAT)	Systemic Lupus Erythematosus Disease Activity Index (SLEDAI-2K)	Connor's Criteria of Antisynthetase Syndrome
Crohn's Disease Activity Index (CDAI)	Ulcerative Colitis Endoscopic Index of Severity (UCEIS)	Pittsburgh Sleep Quality Index (PSQI)	International physical activity questionnaire (IPAQ)	Hospital Anxiety and Depression Scale (HADS)	ACR/EULAR Classification Criteria of Rheumatoid Arthritis (2010)	Simple disease activity index (SDAI)
Lémann Index	Simple Clinical Colitis Activity Index (SCCAI)	Health questionnaire (EQ-5D-5L) (update)	Short Form Dietary Questionnaire (SFFQ)	Clinical Disease Activity Index (CDAI)	ACR/EULAR Classification Criteria of Systemic Lupus Erythematosus (2019)	MORE TO COME!

41 new Archetypes

Translation: DE, FR

70% of needs already provided by CKMs



Our GitHub:

Currently at: <https://github.com/vanessa-pereira/Clinnova/tree/main/openEHR>

To be moved to: <https://github.com/liihub>

Lessons learned (Overall)



Not all research institutions are prepared for a new IT transition that focuses on data



Everyone will always tell you they have the best data



Use the standards that matter for your Project



Saying you use standards doesn't automatically qualify that you are using them right!



Early medical informatics training is key!



Have the right people with the proper background working on the project



The source/references of information are fulcral (e.g. discrepancies between scoring and classification tools)



Be sure the tool you will use makes your work simpler and fits the job (beware of tooling hype!)



Lessons learned / advice (openEHR)



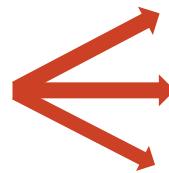
Training! Training!
Training! + very
curious mind



International CKM,
openEHR discourse and
community members will
be your best friends



You need IT knowledge
even if you are only
working in the
modelling part



Archetypes and Templates are software!

All the queries (AQLs) done later will be dependent on your modeling!

You're responsible for how the data system will mostly work



Lessons learned / advice (openEHR) (cont)



Getting an openEHR platform/CDR and using only archetypes you created = more silos and you're only interoperable with yourself



openEHR has so much to offer – be aware of the limitations of certain tools, be wise!



When choosing tooling (models designers, “low-code” form builders, CDRs) be sure they are compliant to specs!



Get acquainted with the modelling patterns and read the openEHR documentation. The world of openEHR is not archetype designer + some form builder



The archetype editorial guides are freely available on openEHR confluence – follow them ☺



Don't forget to send your new archetype to international CKM





THANK YOU

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