

Automating a cancer registry

IKNL on FHIR

Melle Sieswerda | 08-01-2025



About IKNL

- Netherlands Comprehensive Cancer Organisation
- Non-profit, tasked by the ministry of Health
- Mission: to Reduce the impact of cancer
- Keeper of the Netherlands Cancer Registry (NCR)



The NCR

- A comprehensive national register containing data from **2.7 million patients** and **3.2 million tumours** collected **over a 30-year period**
- What we contributed in 2023:



592

data sets



221

clinical studies



285

scientific publications

The NCR

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IZA Tool



Regional reports



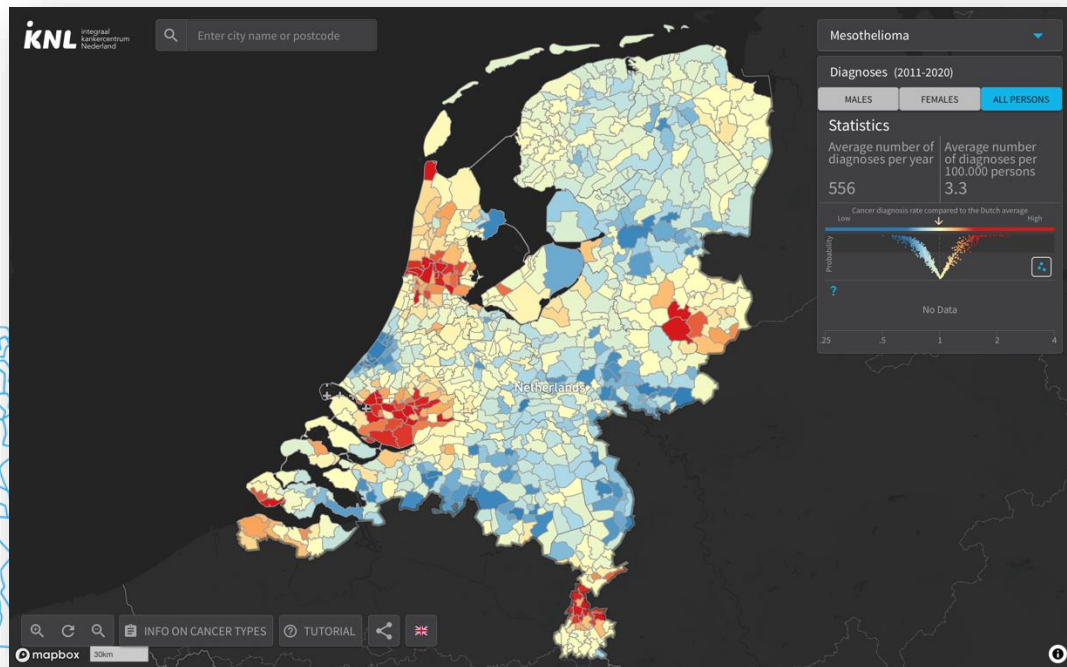
Research



Insights for improving oncological care

The NCR

- A comprehensive national register containing data from **2.7 million patients** and **3.2 million tumours** collected **over a 30-year period**
- What we contributed in 2023:



Regional reports



Research



Improving oncological care

Registration and interpretation

PALGA

National pathology database



ELECTRONIC

HEALTHCARE RECORDS



QUALITY OF LIFE (PROMS)



VITAL STATUS



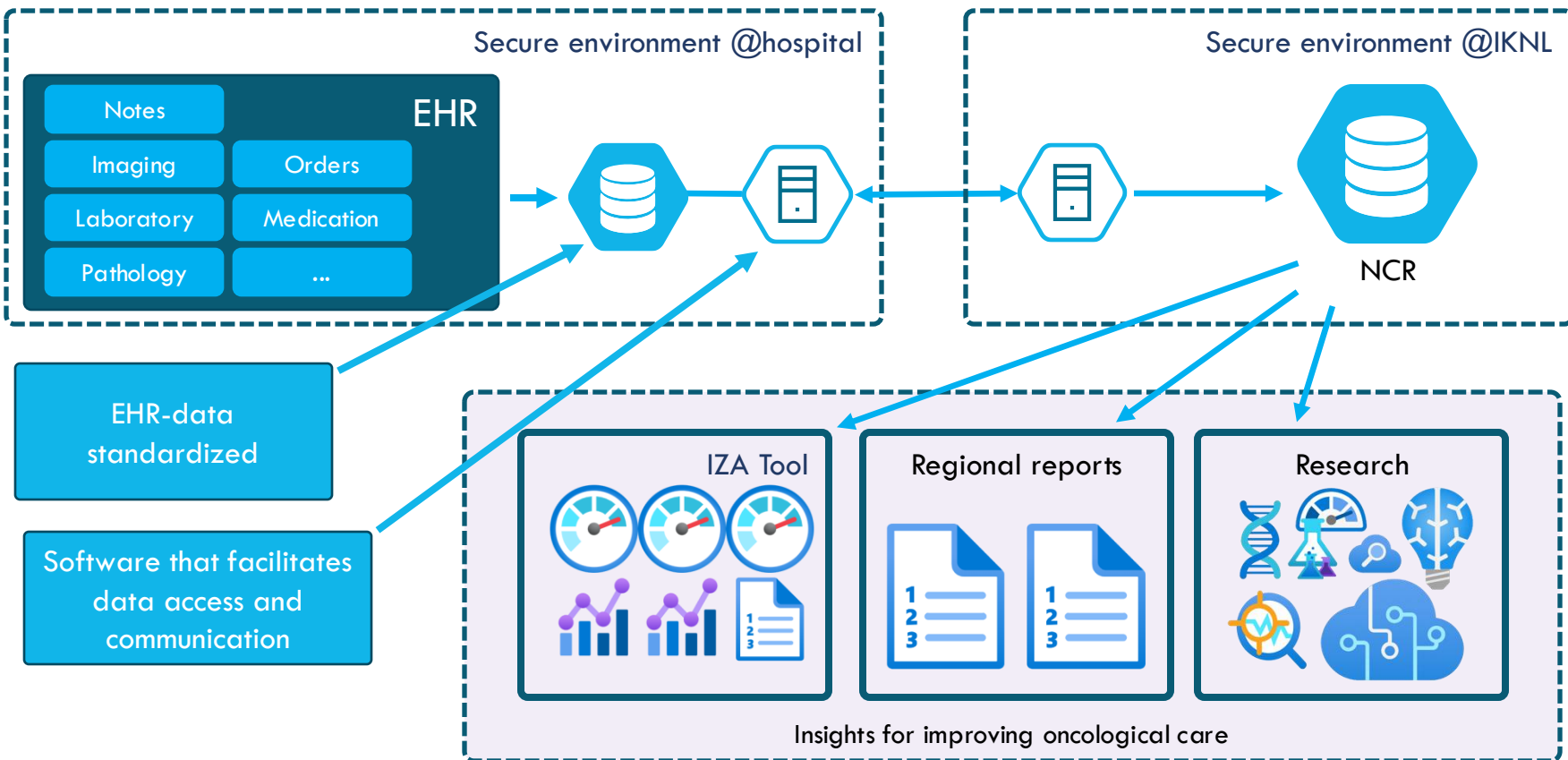
- 124 FTE registrars: independent and highly educated (regular training by field experts)
- Predominantly manual registration due to lack of EHR interoperability and standardization
- Clinical coding rules for uniform registration
- State of the art registry software

$$\frac{130.000}{256} = \sim 510/day$$

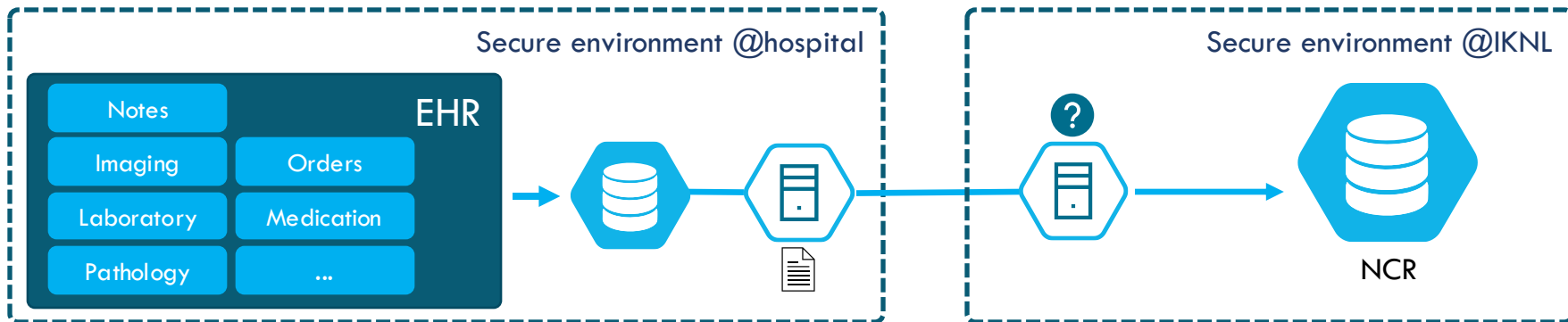
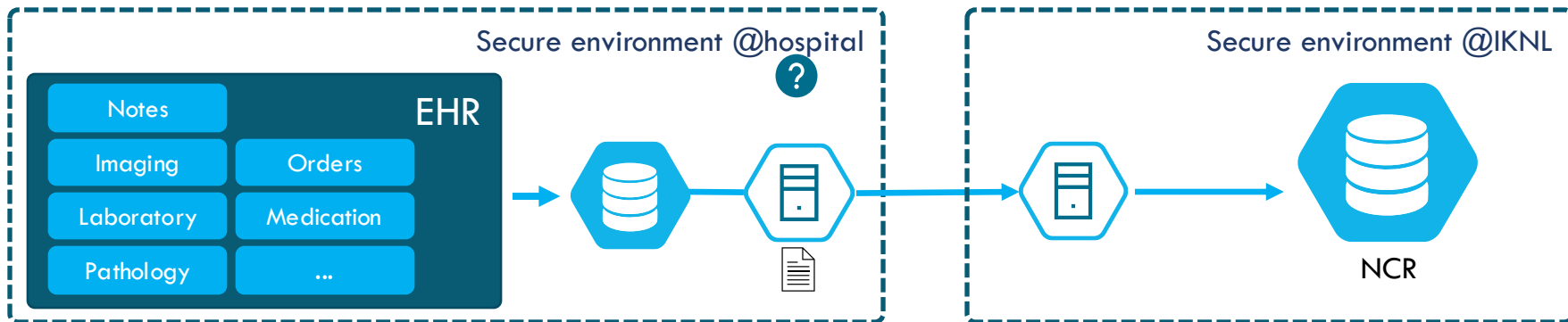
Outlook ...

- Ageing population
- Increasing population
- Increasing incidence
- Increasing “data hunger”

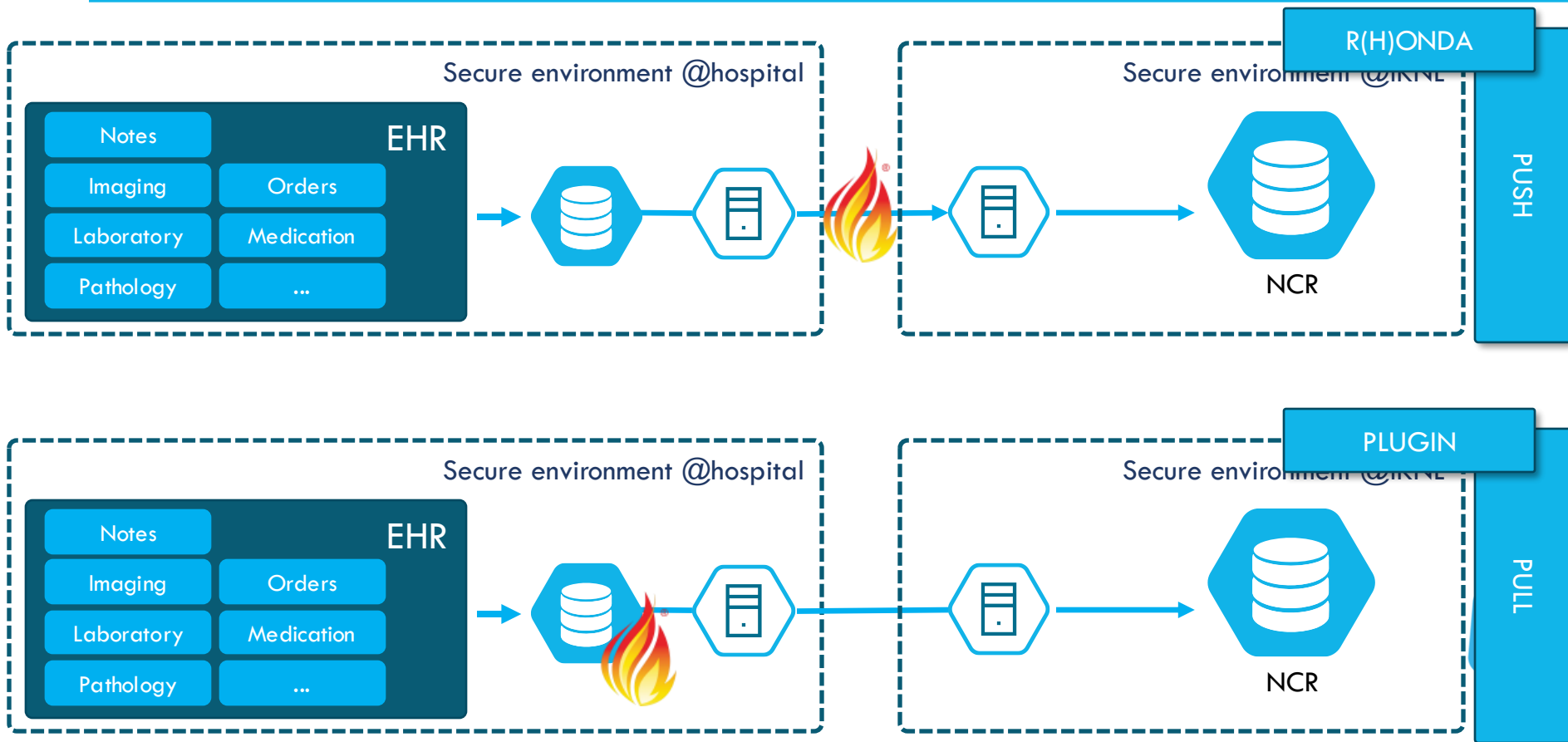
Secondary use of EHR data: potential solution?



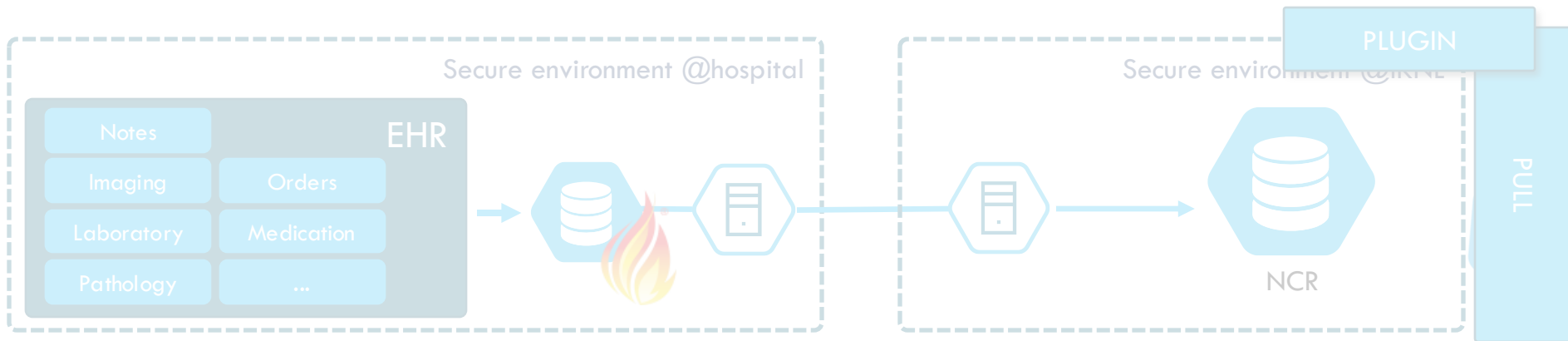
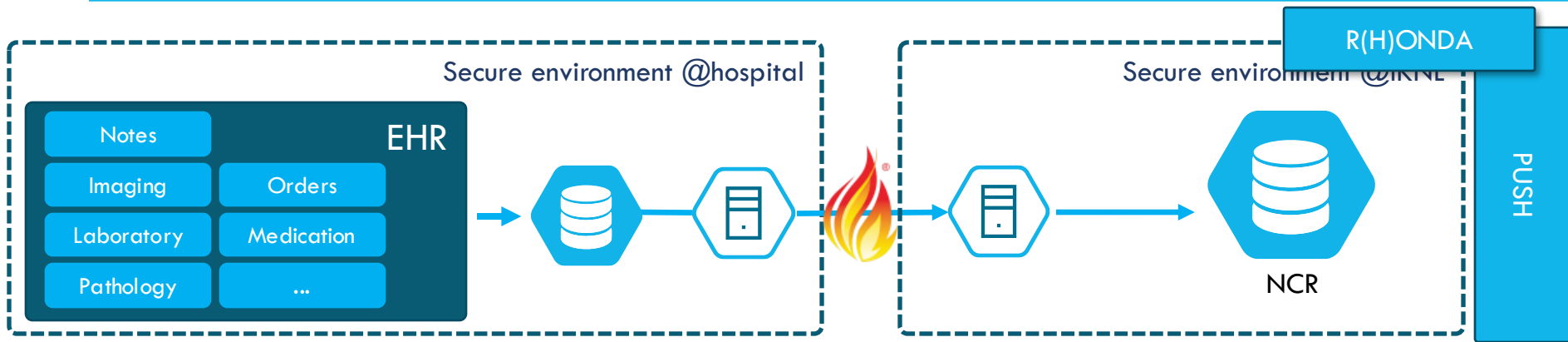
To push or to pull ...



To push or to pull ... it needs standardization



To push

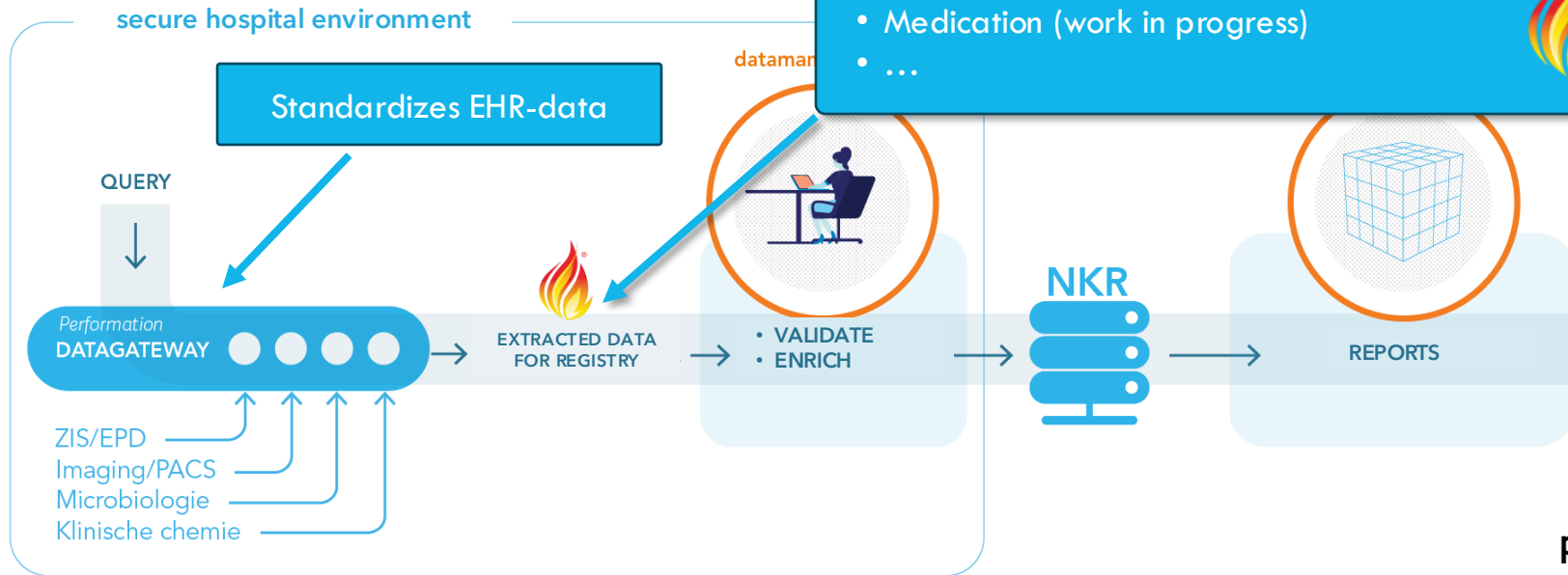


R(H)ONDA: Real-time (Hemato-)ONcology DAta

- Collaboration with Performance; uses Performance Datagateway
- Queries extract data relevant for NCR: result transformed to FHIR
- Originally hematology; expanded scope

Creates FHIR **Bundles** with ...

- Diagnoses (incl. tumor morphology)
- Procedures
- Medication (work in progress)
- ...



Current status – R(H)ONDA

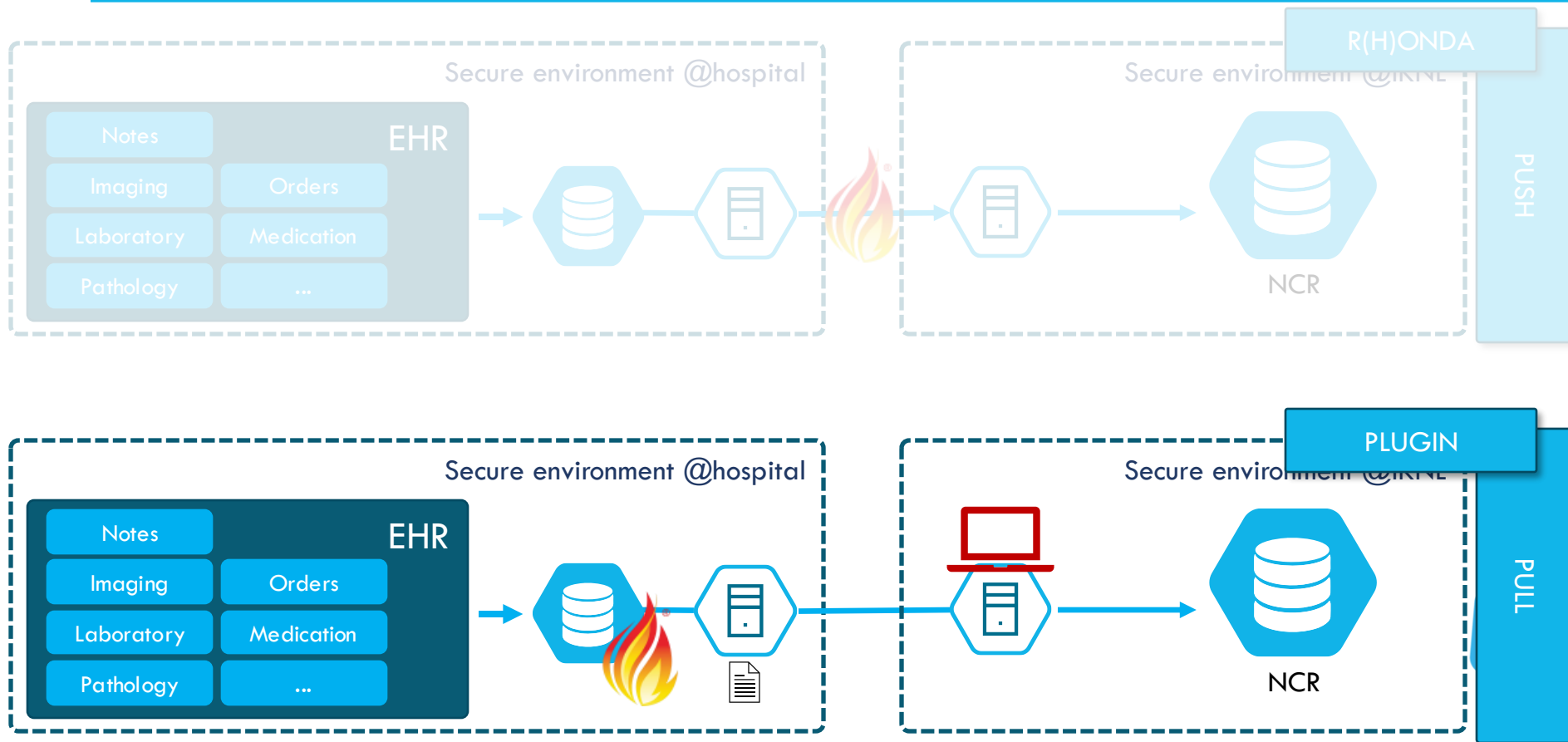
Current status

- In production since August 2024 (This works! 🥳)
- 5 Hospitals connected
- Onboarding additional sites in progress
- FHIR IG In progress

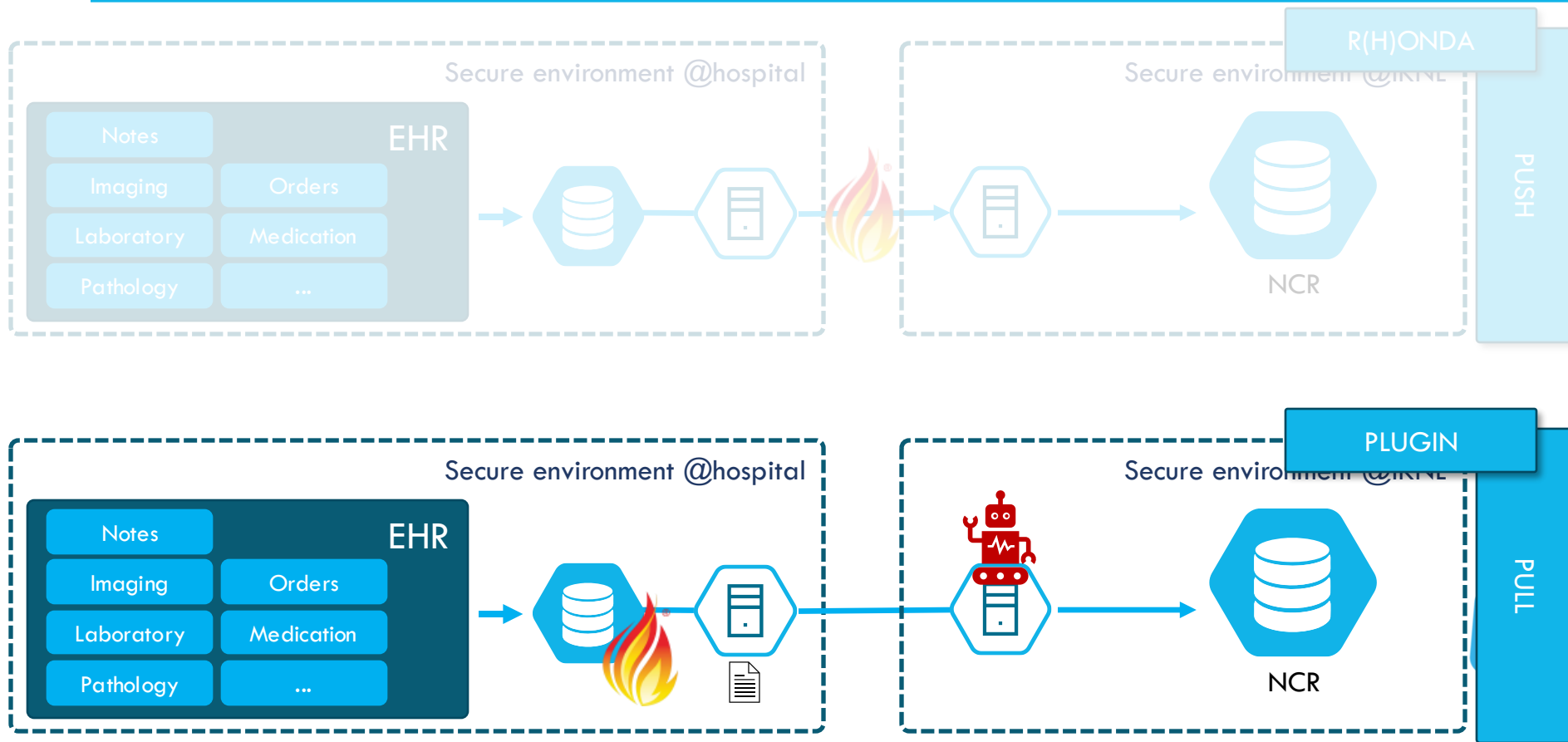
Lessons learned (“confirmed?”)

- Start earlier with documentation (yes, I know ...)
- Linking data is difficult (e.g. linking treatment to tumor)
- Data quality differs per item (correct diagnosis code is crucial)

To pull ...



To pull ...



PLUGIN

- Platform for reUse and exchanGe of cLINical data in the Netherlands
 - Collaboration between DHD, EZA, and IKNL
- Standardizes EHR data using **FHIR**
- Uses **federated** techniques to provide access

Which results in a **single** infrastructure for ...

- Management reports, process improvement, ...
- Research & development of (AI) models, and
- Data exchange



Current status – PLUGIN

Current status

- First PoC with Radboudumc just finished (This works! 🎉)
 - One use-case (NCR)
 - Diagnoses, tumor stage & morphology
 - Uses Patient, Condition, DiagnosticReport, Encounter, ...
- Working on broadening the scope & number of participating hospitals
- FHIR IG In progress

Lessons learned?

- Linking data is difficult (e.g. linking pathology report to diagnosis)
- Data quality differs per item

Why FHIR?

- FHIR's data model closely **aligns with clinical processes**, making it easier for hospitals to adopt.
- Its ability to **support both primary and secondary use** sets it apart from other standards
- FHIR's **emphasis on data exchange** allows storage decisions to remain flexible and localized
- Being **mandated by governments** in regions like the US (with HIPAA) and the EU (Xt-EHR) provides the stability and assurance required for long-term adoption

In summary

- Automatic registry population is feasible!
 - Necessary to keep the NCR relevant; and
 - Continue cancer research
- This requires:
 - Standardization of the interface (RHONDA)
 - Standardization of EHR-data (PLUGIN)
- FHIR plays a key role in both domains
- Future steps:
 - Align FHIR-profiles with other organisations & initiatives
 - Work towards (inter)national standards

Links

R(H)ONDA: <https://iknl.nl/projecten/rhonda>

PLUGIN: <https://plugin.healthcare>

vantage6: <https://vantage6.ai>

FHIR Profiles IKNL/PALGA: <https://simplifier.net/iknl-palga-r4>

FHIR Profiles IKNL/NCR: <https://simplifier.net/iknl-ncr-ehr-r4/>

FHIR IG PLUGIN: <https://plugin.healthcare/fhir/>

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