European Reference Network
for rare or low prevalence complex diseases
Network Adult Cancers (ERN EURACAN)

STARTER

STarting an Adult Rare Tumour European Registry

FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI

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EURACAN registry

1. Head & neck cancers
2. Sarcomas
3. Rare thoracic cancers
4. Endocrine gland tumours
5. Digestive rare cancers
6. Neuroendocrine tumours
7. Central nervous system tumours
8. Rare female genital cancers
9. Rare urological and male genital tumours
10. Rare skin cancers & non-cutaneous melanoma

EURACAN Registry health care providers involved

ALLEANZA CONTRO IL CANCRO

rythmic.org
Réseau tumeurs et THYMiques et Cancer

NetSarc-ResOs
Réseaux de référence Cliniques
Sarcomes - GIST - Desmoïdes - Tumeurs osseuses rares

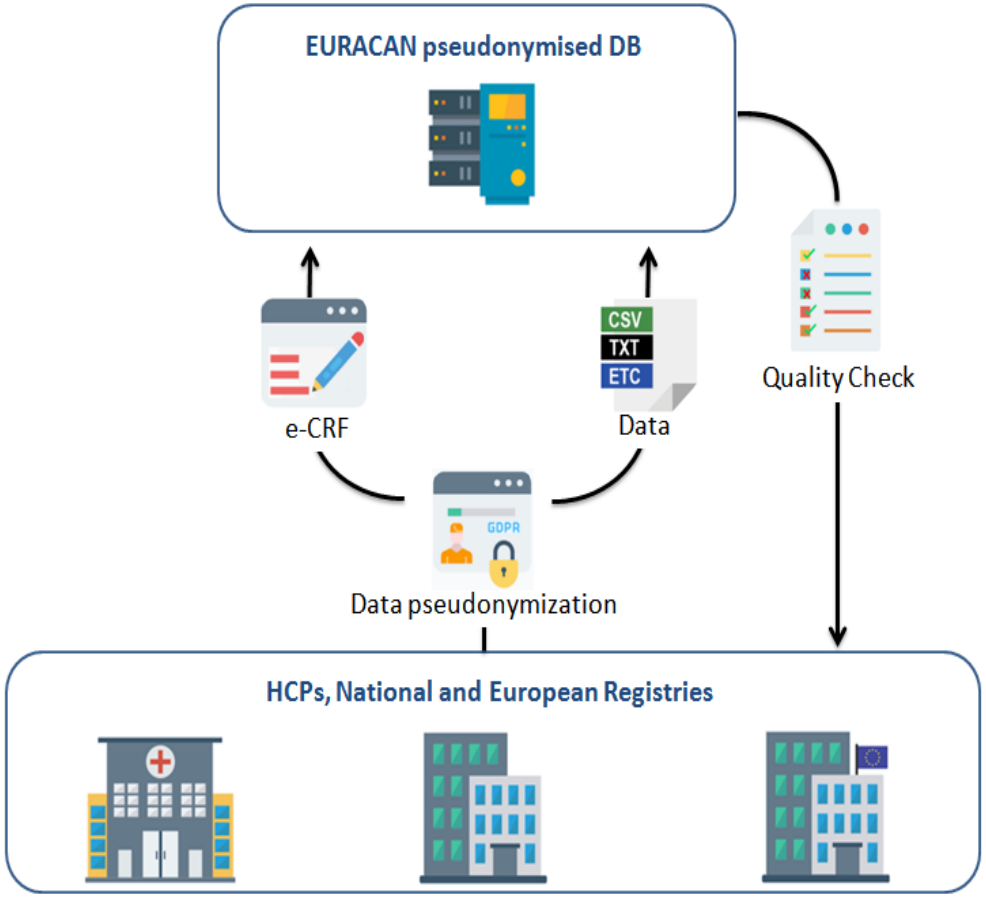
REFCOR

Open to Not EURACAN health care providers

Contribution from national DB/network already available welcome

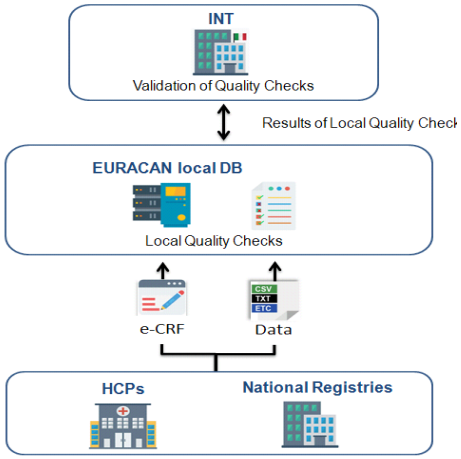
	Registry-based study	Patient registry
1. Definition	Investigation of a research question or hypothesis using data from an existing patient registry or from a registry newly set-up for the study.	Data collection system on a group of people defined by a particular disease or condition, established for a specific purpose and used to conduct a registry-based study.
2. Timelines	Timelines driven by the collection/extraction and analysis of the data relevant for the specific study objective(s).	Generally planned to be long-term; timelines driven by schedules for routine data collection and any anticipated data analyses which prompted the registry.
4. Data collection	Restricted to what is needed by the research question including data on potential confounders and effect modifiers; additional data collection may also be required; if such additional data includes subject monitoring outside SmPC and normal clinical practice, the legislation for clinical trials apply; study may involve primary data collection or secondary use of data.	Wide range of data may be collected depending on the purpose of the registry; there should be an agreed core set of data elements to be collected with harmonised definitions, common coding system and common data entry procedures.

Original registry model



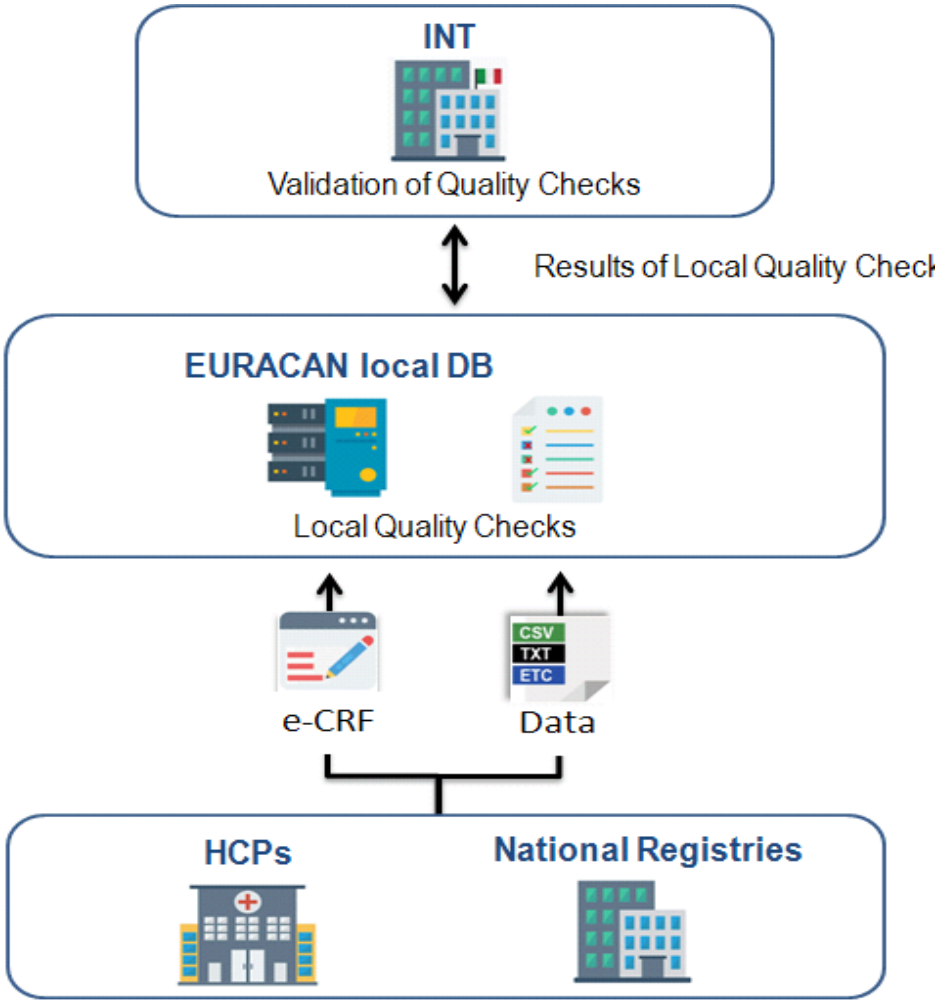
- Indeterminacy
- Too long timeline
- Too risky

= No registry



Registry model

Federated model



Federated Learning

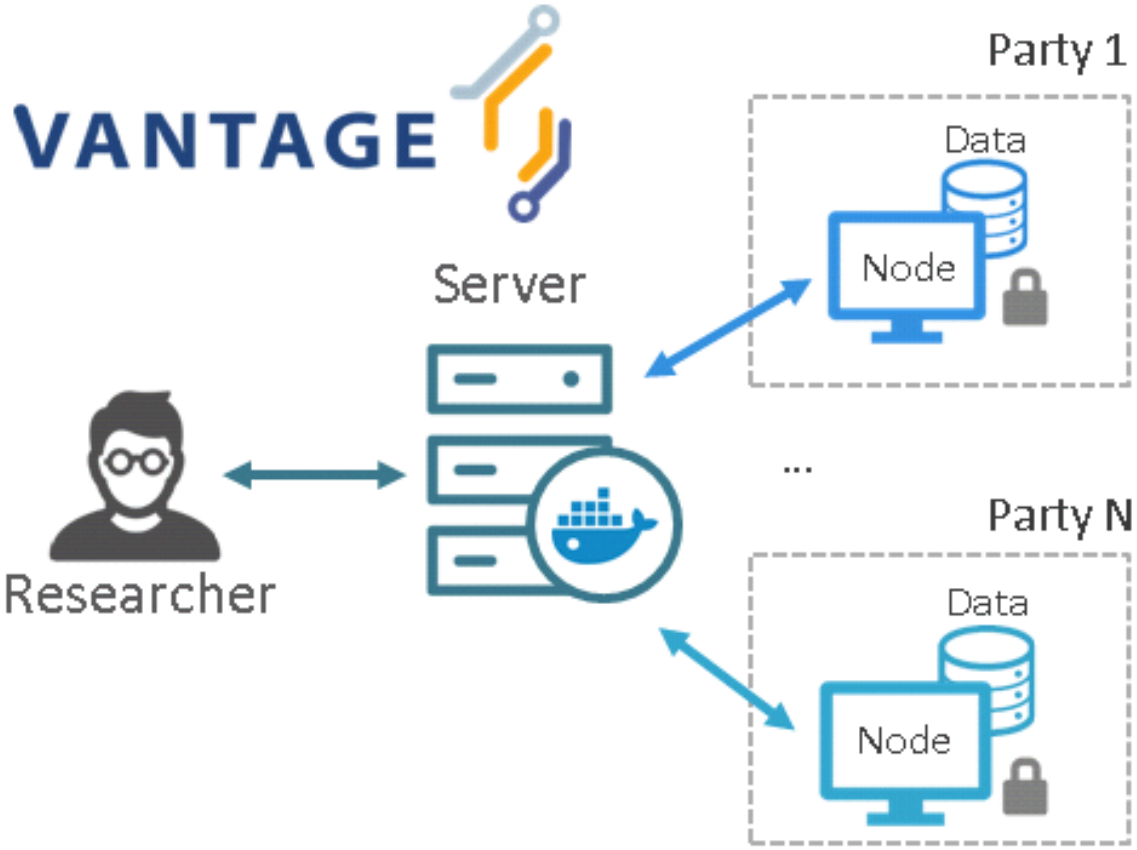
~~Bring data to the algorithms~~

Bring algorithms to the data

Maximize the potential of multiple datasets without sharing data

Minimize data leaks and privacy risks

Infrastructure



Legal Basis of the Registry

- Patient consent
  - For data
  - For biological sample

Indeterminacy

Timing of the data collection?

Consent of death patients = data protection authority opinion

Re-contacting to participate in research projects