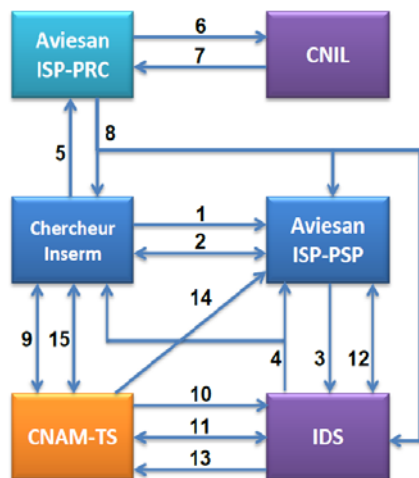


Public Health Research Infrastructure for Sharing of health and Medical Administrative data

Anita Burgun, MD, PhD

5 Apr, 2016

Organizations



1. Le(s) chercheur(s) contacte le siège
2. Formulaire mise à disposition et d'utilisation des données + protocole
3. Envoi formulaire + protocole à l'IDS
4. Décision d'approbation de l'IDS
5. Envoi de la décision au PRC
6. Demande d'autorisation CNIL (1000€ ou 3000€ si collection biologique)
7. Envoi autorisation CNIL au PRC
8. Information de l'accord CNIL au chercheur, à l'IDS et à Aviesan ISP-PSP
9. Information CNAM-TS de l'accord CNIL + expression des besoins chercheur(s) finalisée (variables etc.)
10. Information IDS de la finalisation de l'expression des besoins
11. Rédaction et envoi de la convention au service juridique CNAM-TS pour validation
12. Signature convention à Aviesan ISP-PSP
13. Signature convention à CNAM-TS
14. Envoi convention signée à Aviesan ISP-PSP
15. L'extraction des données commence à CNAM-TS avec l'équipe de recherche



Infrastructures

ESFRI

European Strategy Forum
on Research Infrastructures

ANAEE: Ecosystems
 BBMRI: Biomolecular Resources
 EATRIS: Translational Research
 ECRIN: Clinical Research
 ELIXIR: Biological Information
 EMBCR: Marine Biological Resource
 ERINHA: Highly Pathogenic Agents
 EU-OPENSOURCE: Chemical Biology
 EURO BIOIMAGING
 INFRAFRONTIER: Model Mammalian Gen.
 INSTRUCT: Structural Biology
 ISBE: Systems Biology-Europe
 MIRRI: Microbial

Standards



Opportunities

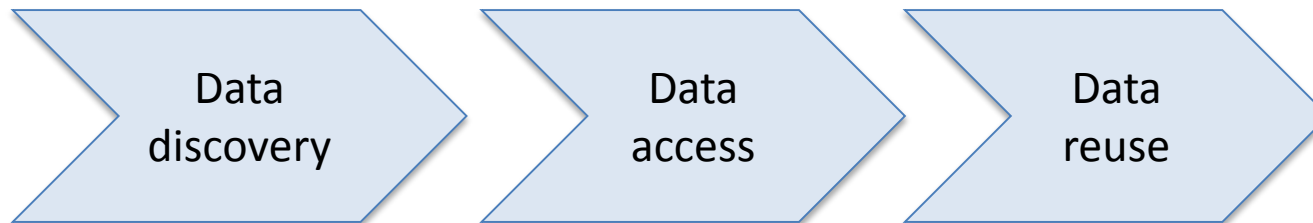
Public Health Research
 Infrastructure for Sharing of health
 and **Medical Administrative data**

INFRA-DEV 1

- Proposal for a European Public Health Research Infrastructure for Sharing of health and Medical Aministrative data
- PHRIMA
- [H2020-INFRADEV-2017](#)
- Coordination and support action
- Design study
 - Strategic work
 - Preliminary step before infrastructure design
 - Output = report : partners in EU, data owners and data sources, network with other EU initiatives (such as IMI projects), propose an infrastructure and address ethical issues
 - Medical administrative data (health insurance data), registries, cohorts and epidemiological data bases
 - Link with other ESFRI infrastructures, ELIXIR

Workpackages

- **WP 1-** Management, coordination and communication
- **WP 2-** Organisational aspects of the RI construction
- **WP 3-** Technical and security aspects
- **WP 4-** Data sharing
- **WP 5-** Legal and ethical aspects
- **WP 6-** PHRIMA services and research aspects



Ethical code of practice

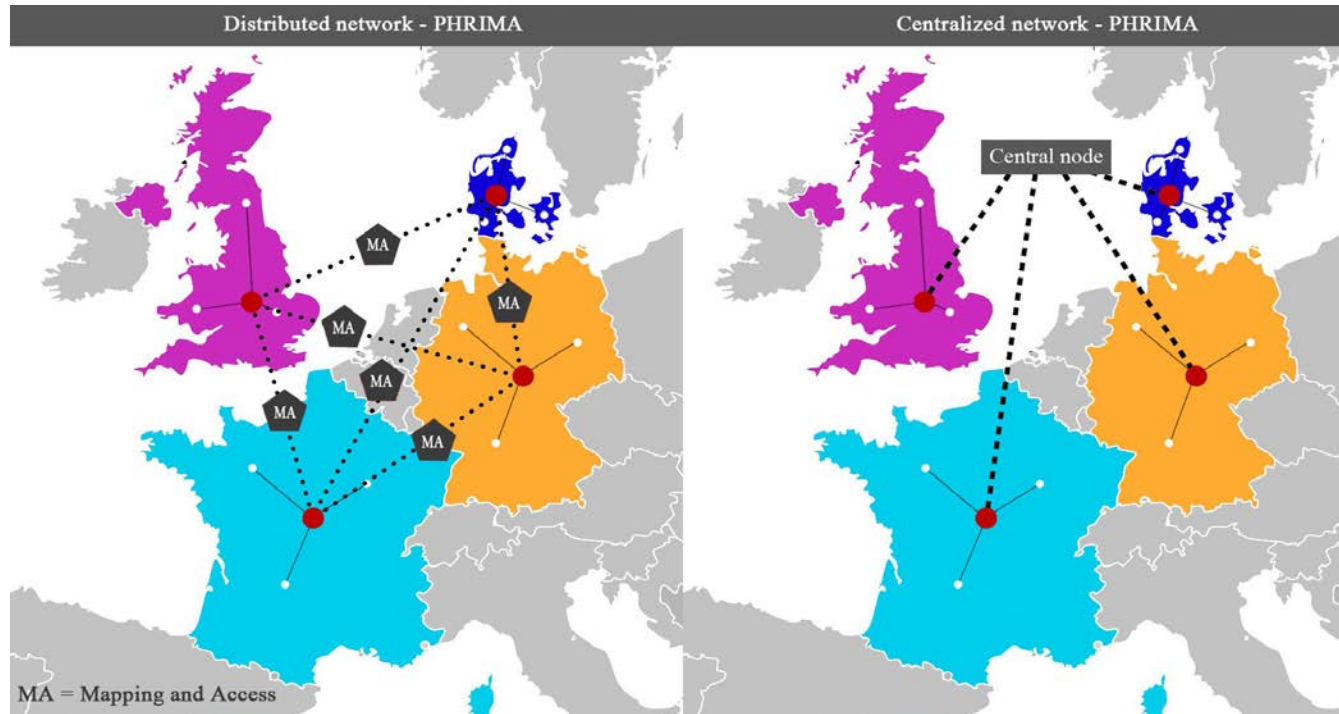
Data sources have autonomy to decide to give access or not

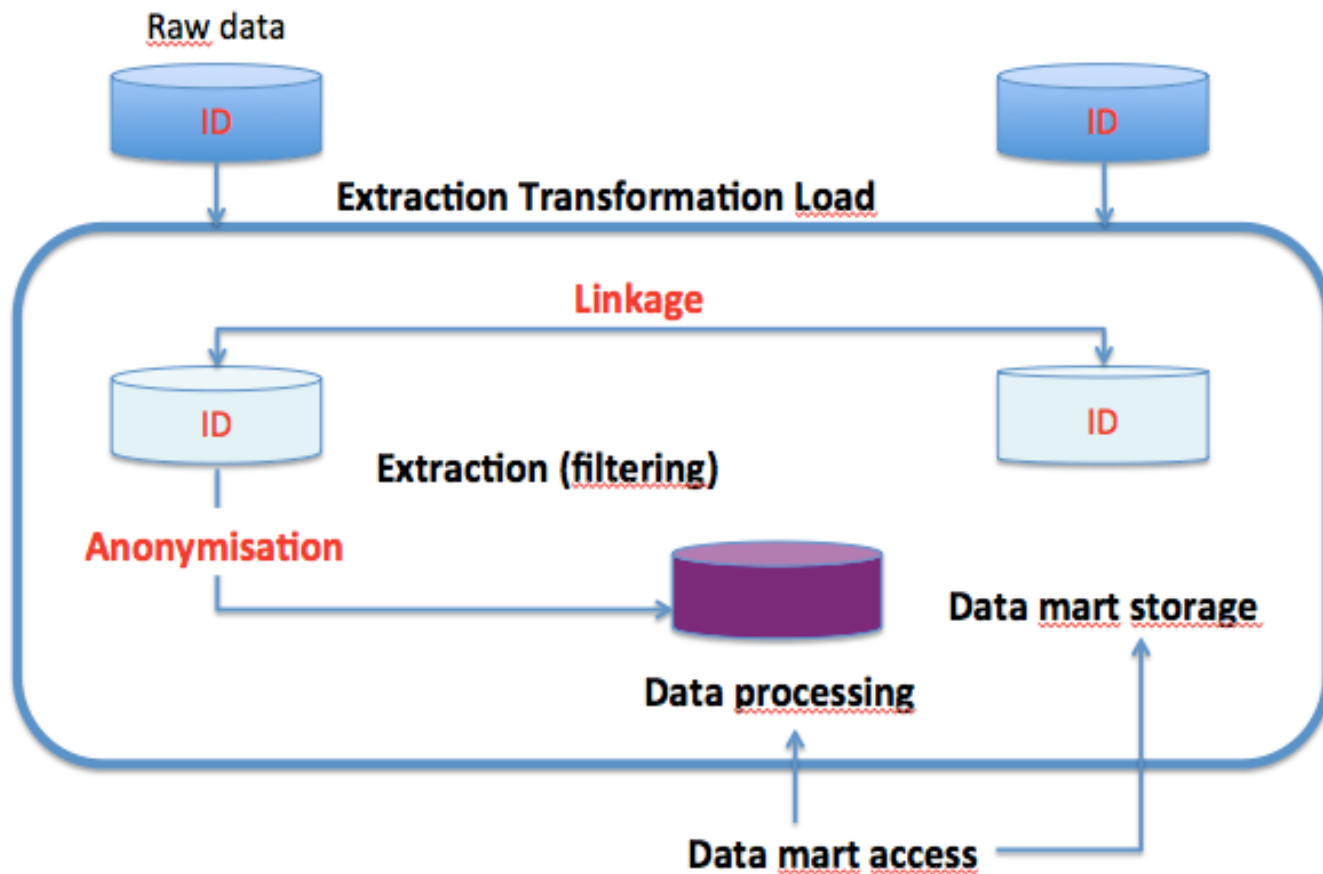
Public access on catalog descriptors

Data sources and data users are responsible for guaranteeing compliance to the rules regarding data reuse

Both centralized and federated models

Centralized vs decentralized





- Proposal for a European Public Health Research Infrastructure for Sharing of health and Medical administrative data (PHRIMA)
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