

WORKSHOP

DATA INTEGRATION: ELECTRONIC HEALTH RECORD – OMICS DATA

Strategic vision of a University Hospital about the secondary use of clinical data for advanced research

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BIOINFORMATICS
BARCELONA

CLÍNIC
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- Direction board request
- Long tradition recording clinical data on digital support
- Growing interest in using clinical data for research
 - Current data underused
 - New data sources: omics
 - New technologies: Big Data
- External requests

 **BDAR WG**



OBJETIVES

- To analyze the legal framework for the massive analysis of biomedical data in the HCB
- To establish the operation of data management and data mining
- To study the storage and integration of genetic and genomic data in the HCB
- To define the circuit of data request and following of projects
- To evaluate the possible cession of data to third parties

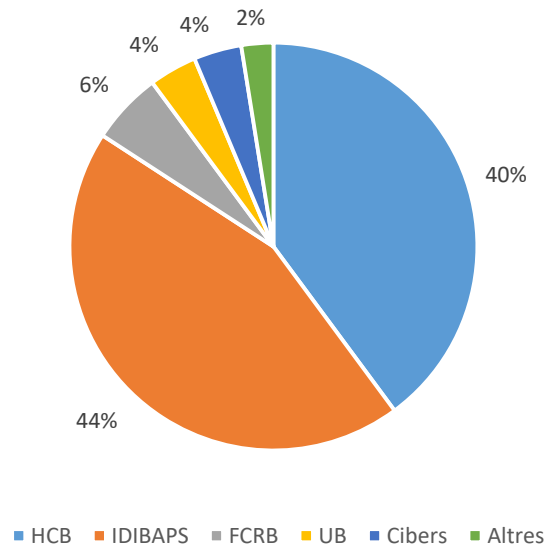


- Several subgroups
 1. Data, information and knowledge
 2. Legislation and ethics for the treatment of biomedical data
 3. Technologies for the treatment of biomedical data
 4. Procedures for the treatment of biomedical data
- Invited speakers
- Survey to know the current situation

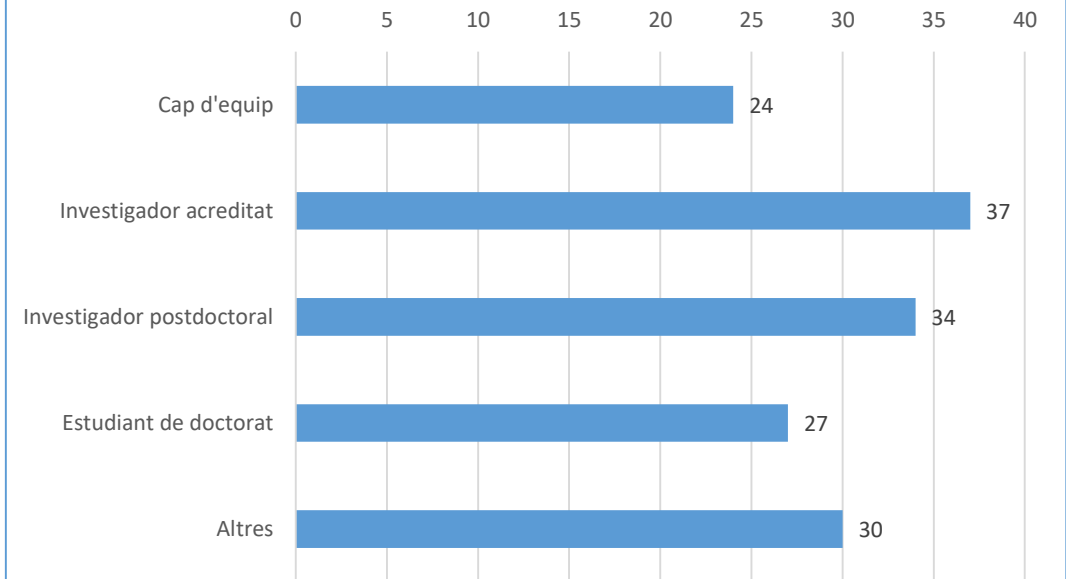
CURRENT SITUATION - Context

- HCB 63
- IDIBAPS 70
- FCRB 9
- UB 6
- Cibers 6
- Other 4

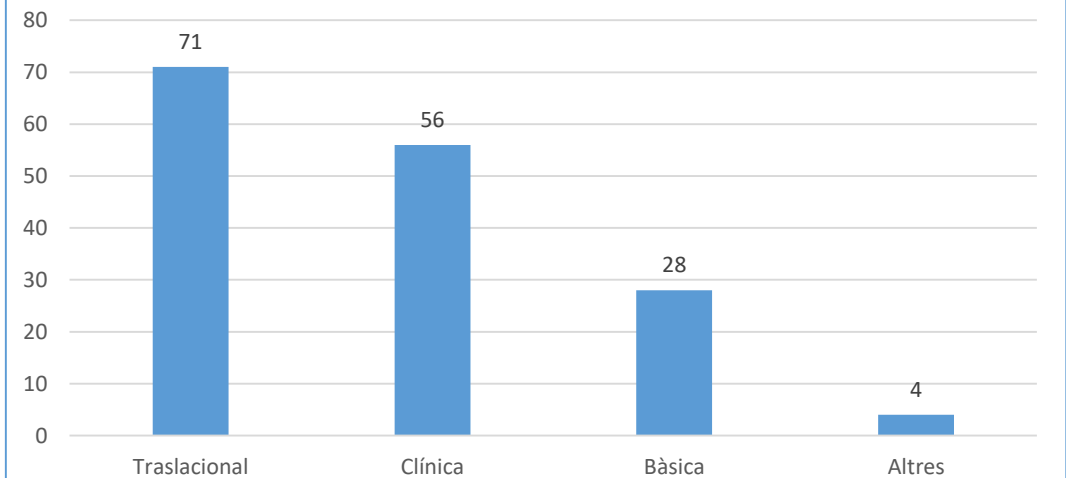
Resposta per afiliació institucional



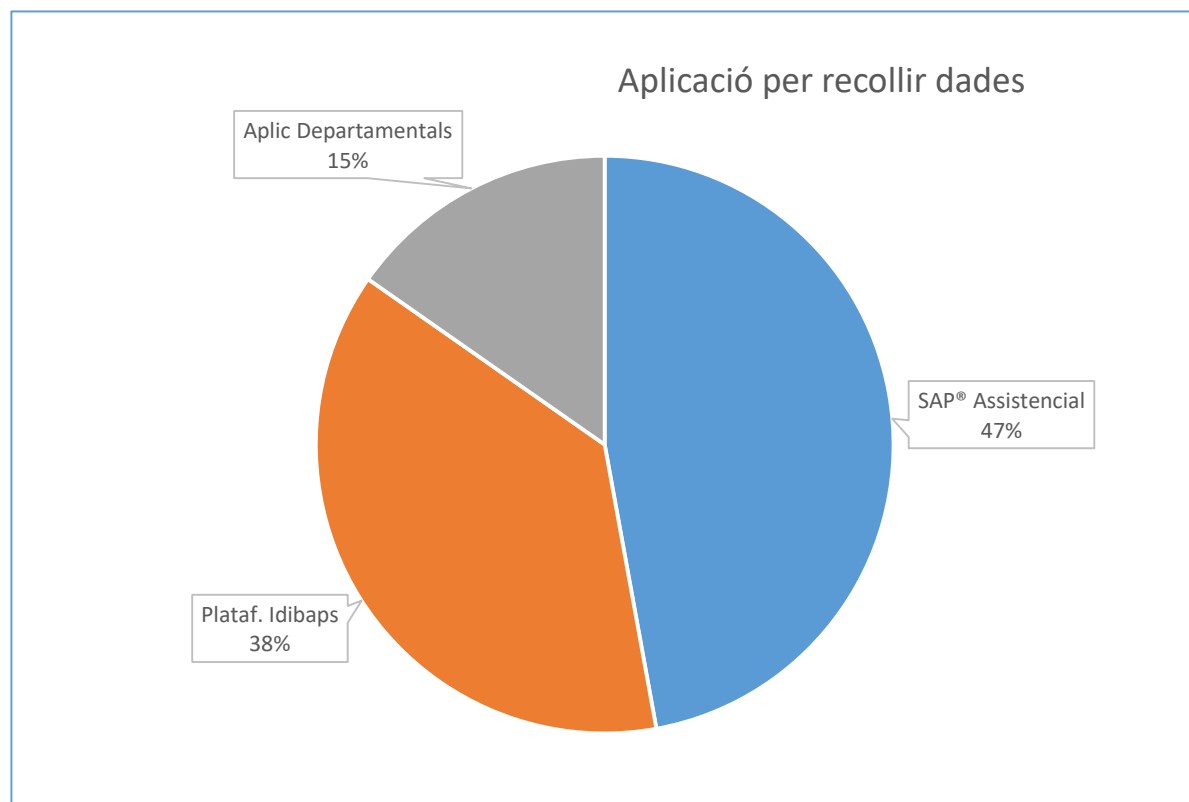
Posició dels investigadors



Tipus de recerca



CURRENT SITUATION - Data



72% work or plan to work integrating clinical data and omics data

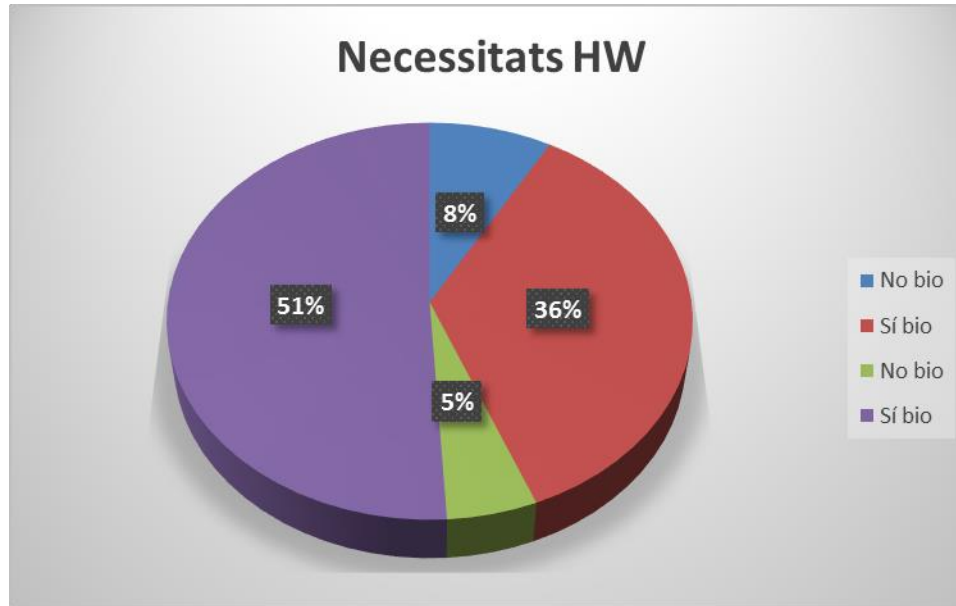
62% share data with other centers and collaborators

76% own generation of data and its manual introduction,

more than 80% use general application tools,

and 66% belongs to the two groups

CURRENT SITUATION - Hardware



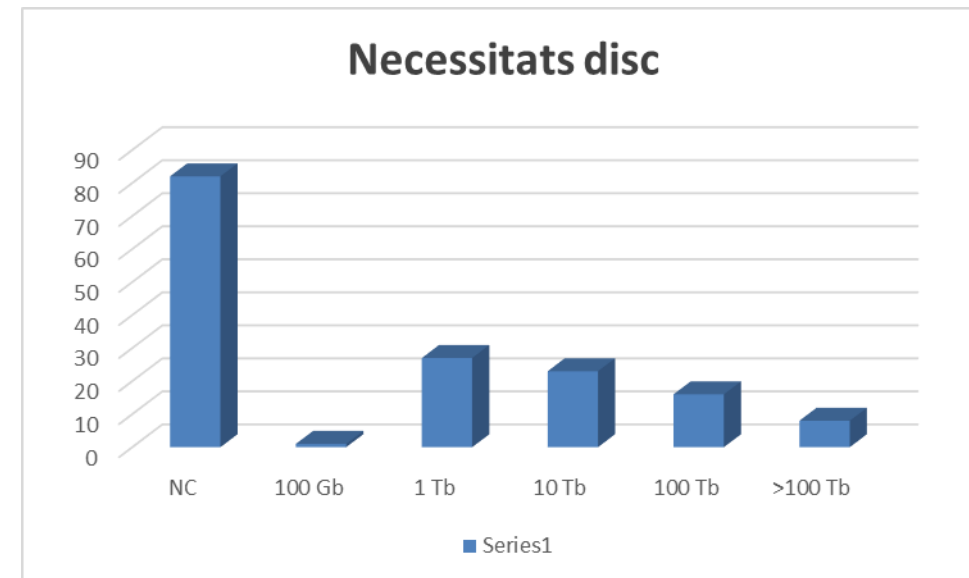
56% have hardware needs not covered,

most of which, 51% of the total, are users of bioinformatics techniques

Half of researchers, 48%, manifest some need for storage.

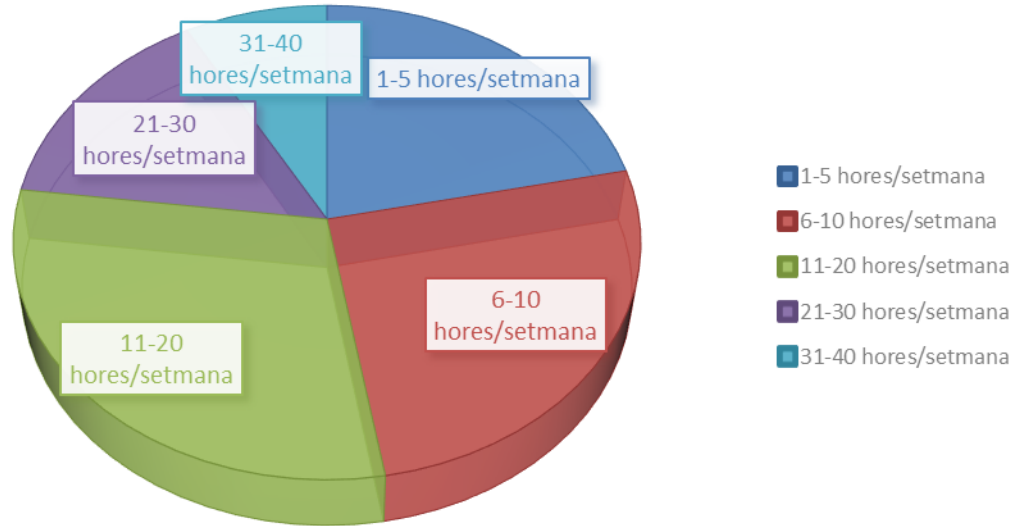
15% need 10 Tb, and another 15% need 100 Tb or more.

Only 5% are not users of bioinformatics techniques.



CURRENT SITUATION – Data Management

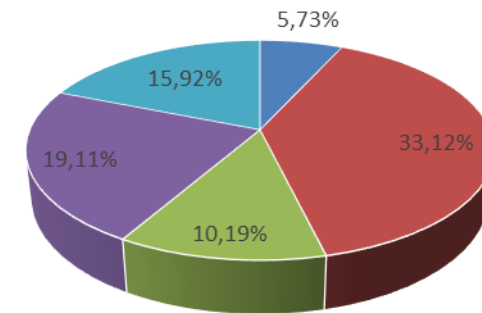
Dedicació a GD



47% report weekly dedication to data management tasks

How they solve the needs of personnel for data management

Personal GD



- Col·labora amb grans instal·lacions
- Col·labora amb altres grups
- Ha contractat a una entitat externa
- Ha contractat personal específic
- Ha format al seu personal



CURRENT SITUATION – Genetic data

- Centralized lab at HCB
 - Standard process
 - Consistent results
 - Integration with EHR: only as report
- Research projects at IDIBAPS
 - No standard process
 - Results depend on the algorithm used
 - No integration with EHR



OUR CAPITAL

- Patient data in highly integrated information systems since 1987. All data have a time stamp, although an important part are in text or image format.
- Data from research studies without integration
- Knowledge about data semantics, its quality, and its informatic management
- Knowledge of the Biomedical world, of the challenges that arise to improve assistance
- Experience on the representation of biomedical knowledge
- Knowledge of the legal framework on the treatment of personal data of patients and intellectual property of professionals



- Creation of technological infrastructures to provide data exploitation services
- Organizational actions
- Actions to strengthen the human resources of the Hospital Clínic - IDIBAPS
- Dissemination actions



TECHNOLOGICAL INFRASTRUCTURES

- Computerized recording of the patient's informed consent in the clinical workstation
- To address a global project of secondary use of clinical data in two different scenarios :
 - Self-service data *in-house*
 - Exploitation of patient information by pathologies and specific data existing in the system under basic criteria
 - Physicians and nurses of the HCB, requires dissociation of data with a capacity for re-identification
 - Extraction of data to attend external requests
 - Clinical and Biomedical Research Platform (CBRP)
 - Generation of high quality data collections
 - Enriched with knowledge
 - To address powerful biomedical research projects
 - Potential collaboration with other institutions

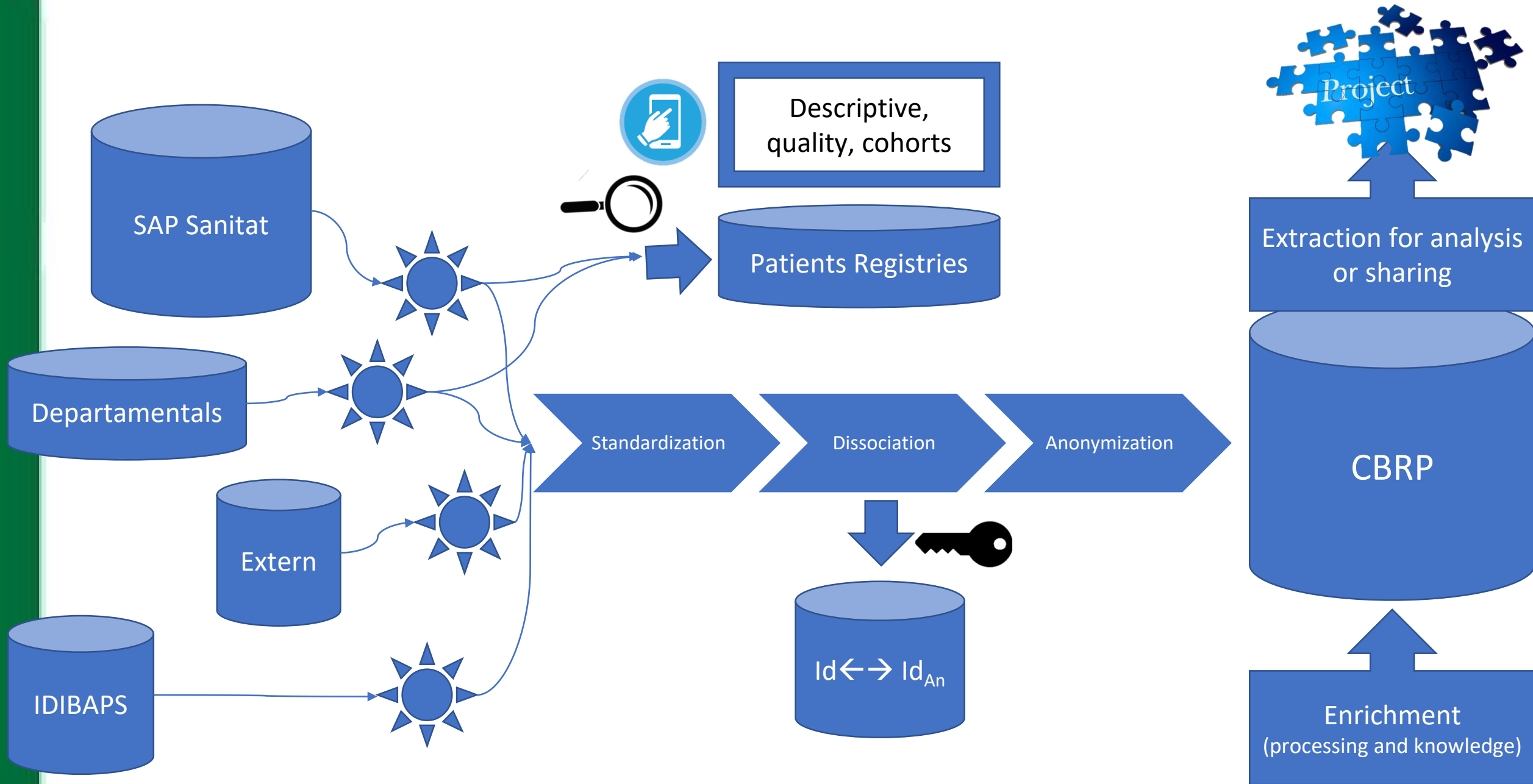


TECHNICAL REQUIREMENTS

- Storage of **large volumes** of data
- Data and access **security**
- **Easy** access, including self-service
- **Friendly** user interface
- **Integration** of clinical data, genetic data, omic data, etc.
- **Semantic interoperability**
- Ability to **adapt to the change** in the structure of the data
- **Processing** capacity with both traditional and new methods
- Representation and integration of **knowledge**
- **Anonymization** and dissociation of personal data

- System architecture
 - **Centralized** repository
 - **NoSQL** Database
- Data model
 - Conceptual model of the domain:
ISO 13940 Health Informatics - System of concepts to support continuity of care
 - Data models for sharing: **OMOP**
- Coding: **SNOMED CT**
- Interoperability: **ISO 13606**
- Other standards: Ontology Web Language (**OWL**)
- **Information management** services
 - Feeding from corporate applications
 - Capabilities for new data definition

PIPELINE: FROM DATA SOURCES TO PRCB





ORGANIZATIONAL ACTIONS

- Development of policies and work methodologies
- Design of new committees (Feasibility, Technological) and necessary adaptations of the existing ones (CEIm)
- To establish partnerships with technology partners
- To know similar international initiatives
- To drive the collaboration with external companies



- Strengthen internal resources in existing units, especially Medical Informatics
- To include training in management of clinical data in the eligibility criteria of newly recruited clinical staff
- New professional roles related to Data Science



DISSEMINATION ACTIONS

- Internal sessions for information, training, and dissemination
- Stimulation of ideas arising from the professionals themselves
- Promotion of the results
- To establish an information and communication policy on this subject with total transparency
- To sensitize patients in the benefit of the cession of data for research

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THANK YOU VERY MUCH

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