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Data Acquisition Architecture in TELE-NEURART project

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TELE-NEURART PROJECT

The TELE-NEURART project represents the first European-scale virtual pediatric network dedicated to the advanced management of childhood neurological disorders.

It focuses on four main categories of disability: brain injuries (congenital or acquired), intellectual disability, autism spectrum disorder and neuromuscular diseases.

The aim of this project is to build an advanced digital pediatric network for the diagnosis, monitoring, and rehabilitation of neurodevelopmental disorders.

Objective

- **The TELE-NEURART project aims to:**

- 🧠 **Integrate clinical and digital data**
  Collect and harmonize data from hospitals, medical devices, sensors, and telemedicine platforms.

- 📡 **Enable tele-monitoring and tele-rehabilitation**
  Support patients directly within their everyday living environment, reducing hospital visits and travel needs.

- 🤖 **Leverage AI and digital biomarkers**
  Use Artificial Intelligence models to identify biomarkers supporting personalized diagnosis and treatment pathways.

- 🏢 **Standardize clinical protocols**
  Share methodologies and rehabilitation workflows across the national healthcare network.

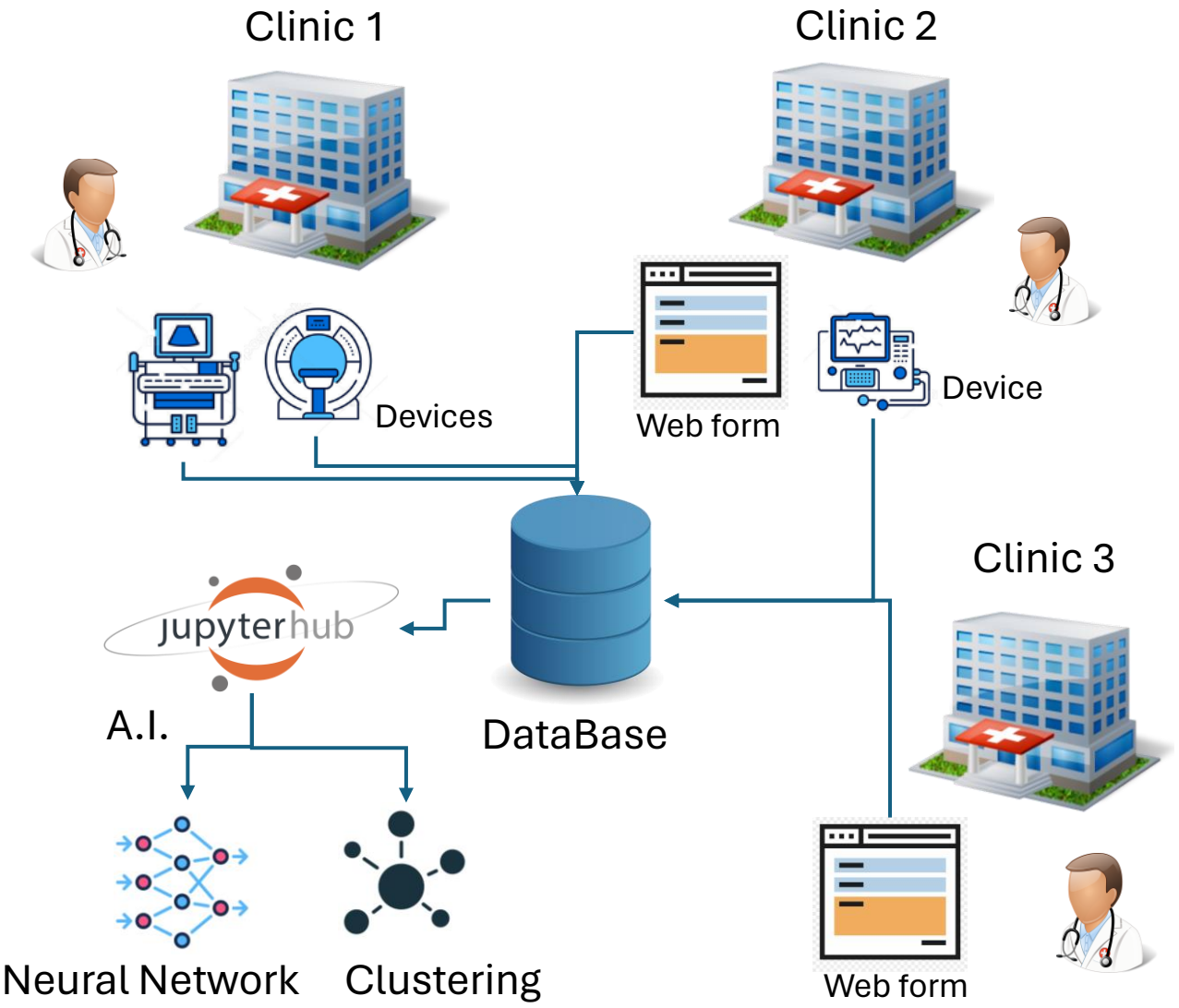
- 📊 **Create an AI-ready data platform**
  Ensure interoperability, data quality, security, and scalability for pediatric clinical data.

Operational context

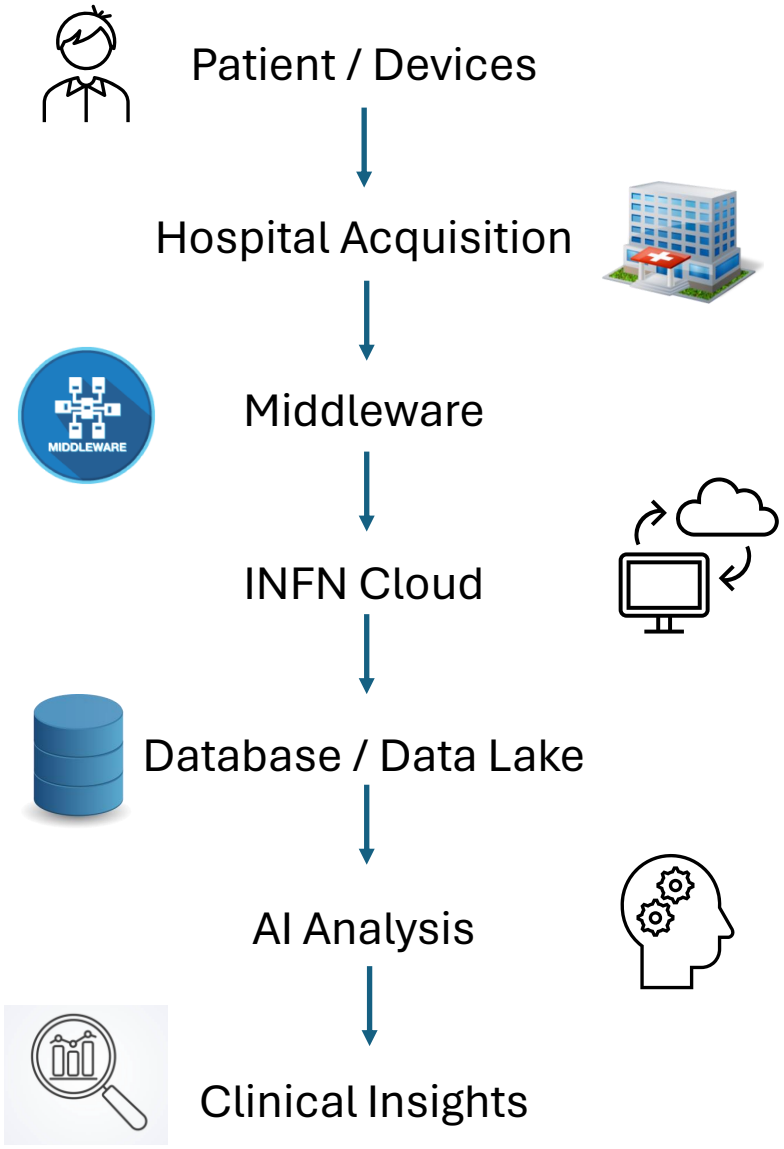
- Several partners contribute to data collection, each with specific objectives and tools.

Key points:

- Complete interoperability between data collected in different centers
- Multiple data storage (textual, numerical, spatial, temporal, multimedia)
- Distributed and synchronized data collection via HM-MM interface.



End-to-End Data Flow



Key Technical Challenges

- 🔄 **Interoperability**:
  - Heterogeneous clinical, imaging, and sensor data
  - Different formats, semantics, and acquisition protocols
  - Cross-center data harmonization

- 🌐 **Distributed Acquisition**:
  - Multi-center synchronized collection
  - Real-time and longitudinal monitoring

- ✅ **Data Quality**:
  - Missing or incomplete data handling
  - Signal validation and preprocessing
  - Traceability and reproducibility of datasets

- 🔒 **Security & Governance**:
  - GDPR-compliant pediatric data management
  - Anonymization and pseudonymization
  - Role-based access control
  - Secure cloud storage and transmission

- 🤖 **AI-Ready Infrastructure**:
  - Feature extraction pipelines
  - Scalable storage and processing
  - Metadata-driven dataset organization
  - Support for AI and digital biomarker analysis

Operational tools

REDCap
Research Electronic Data Capture

Web-based system designed for distributed, domain-independent data collection

WebForm

- Create complex data entry forms
- Manage data security
- Use an Relational Database Management System (RDBMS) for improved data consistency

Deployment

- Requires limited HW/SW resources
- Installable on-premise (on the INFN cloud) ensuring data localization

API

- Implements M2M interface for data retrieval and dissemination
- It allows the automation of data collection processes from equipment

Process proposal

Pre-collection

1. **Functional requirements specification**
2. **Functional requirements analysis**
3. **Interface design**
4. **Software development**

Output

- Requirements Specification Document
- Interface Mockup and E-R Scheme
- System Design with RedCap and Server Configuration
- Software Delivery to Production

- **Collection**
  - Implementation of the clinical protocol
- **Analysis**
  - Use of AI approaches on the collected data

Example of operational scenario

An 8-year-old patient is evaluated for Cerebral Palsy (CP) and congenital brain injury.

Clinical objectives:

- Detailed classification of the condition,
- Analysis of cognitive and motor functions,
- Verification of any associated genetic syndromes

Specification of functional requirements

Define the data collection protocol:

- What data do we collect?
- What type of data and through what tools? E.g., web forms, machines, etc.
- What are the current data collection processes?
- Do patients undergo tests at different clinics or just one?
- Is the study longitudinal?
- Where are the data collected by the clinics stored?
- Must they be anonymized before being shared?
- Are there any data storage restrictions (e.g., unencrypted/unclear)
- …

Example of functional requirements

Diagnosis according to SCPE (Surveillance of Cerebral Palsy in Europe):

- Identifies the forms of Cerebral Palsy (CP) and describes the characteristics of the condition (e.g., spastic, dyskinetic, etc.).

Functional classifications (MACS, GMFCS):

- **MACS** (Manual Ability Classification System) describes the level of manual dexterity needed to perform daily activities.
- **GMFCS** (Gross Motor Function Classification System) assesses gross motor skills, such as walking and mobility.

Cognitive assessments (WISC-III, Rey Copia, etc.):

- **WISC-III** (Wechsler Intelligence Scale for Children) is a tool for assessing cognitive level in children.
- **Rey Copia** measures visuo-motor integration and visual memory skills through the drawing of a complex figure.

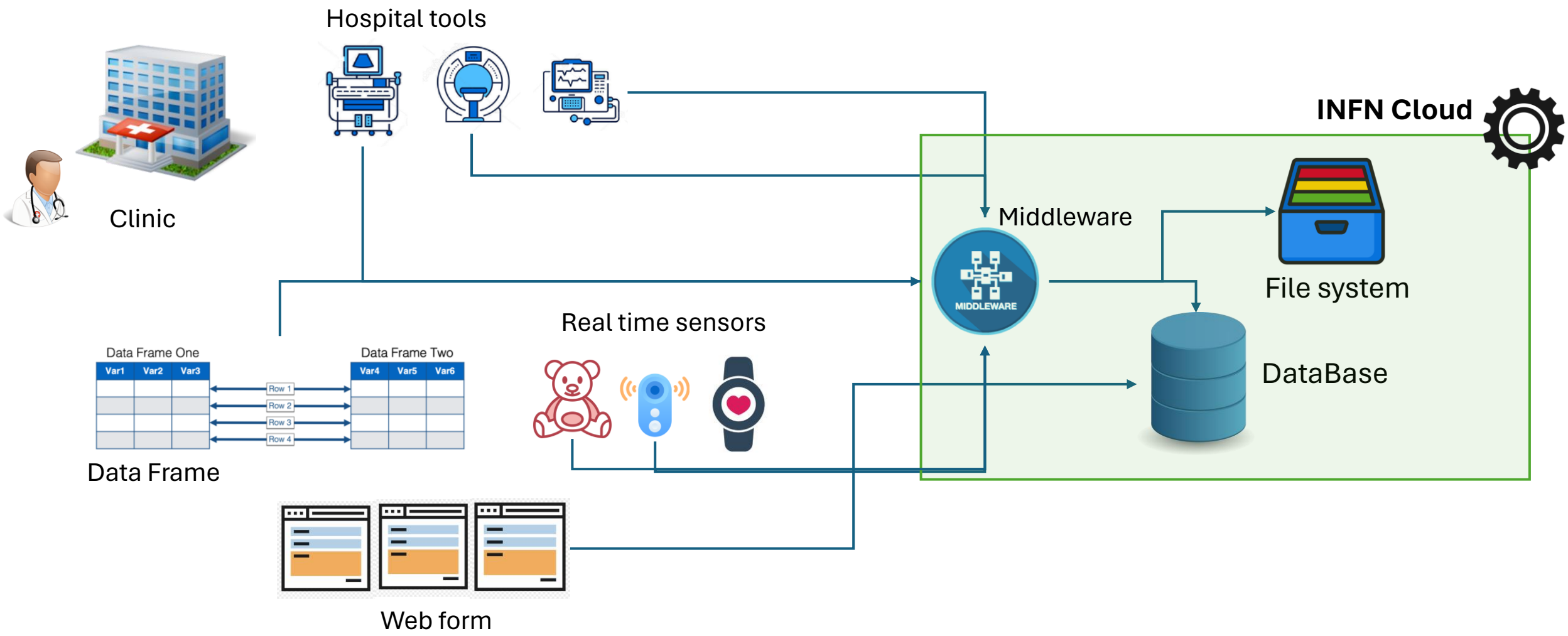
Diagnostic imaging

- **Magnetic resonance imaging**
- **Computed tomography**

Real-time tracking of parameters of interest

- **Motion sensors and accelerometers**
- **Neurofeedback and Brain-Computer Interface (BCI)**

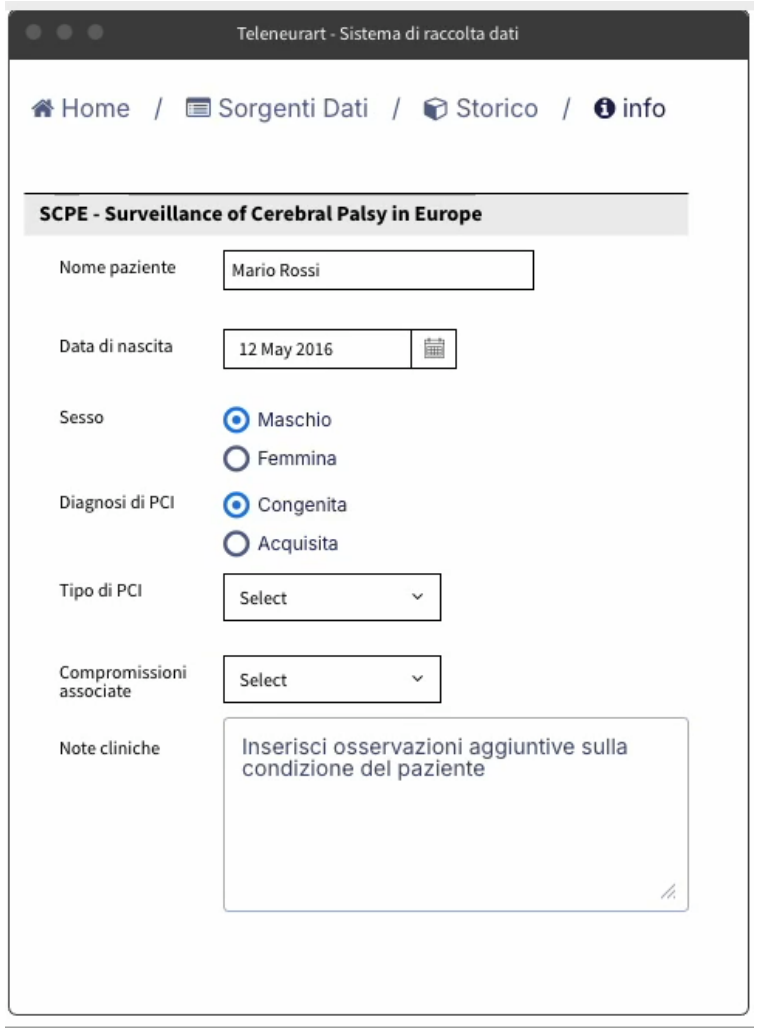
Data collection system architecture



Interface mockups

Diagnosis according to SCPE (Surveillance of Cerebral Palsy in Europe)

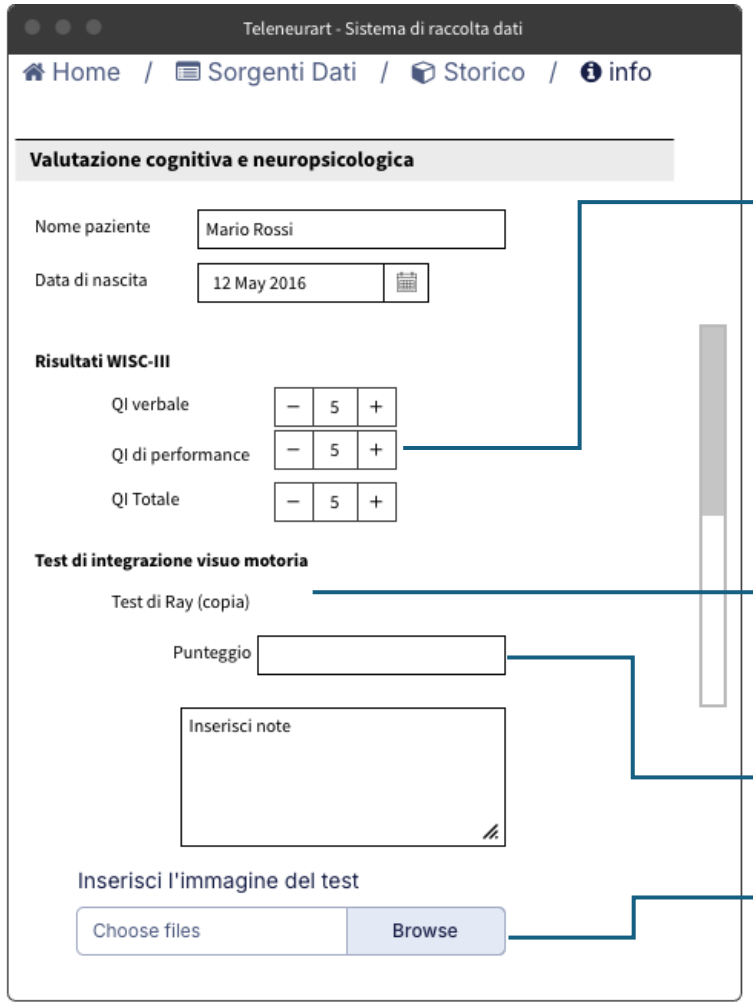
Field	Description
Patient name	
Date of birth	
Sex	
Diagnosis of CP (congenital/acquired)	
ICP type	Choice between unilateral spastic, bilateral spastic, dyskinetic, ataxic
Associated Compromises	Please indicate if any and specify epilepsy, visual, hearing, intellectual disorders, etc.
Clinical notes	Additional observations on the patient's condition



Interface mockups

Cognitive and neuropsychological assessment

Patient name	
Date of birth	
WISC-III results	
Verbal QI	
Performance QI	
Total QI	
Visual-motor integration test	
Rey's Test (copy)	Score and notes on the ability to copy a complex figure
VMI	VMI Scale Score
Memory	
Rey test (memory)	Selective Verbal Memory Test Score
Attentional functions	
Visual attention BVN	Score and observations
Auditory attention BVN	Score and observations
Executive functions	
Tower of London Test (TOL)	Score and performance level
BRIEF	Global and specific score for each executive function assessed
Neuropsychological notes	Additional observations on observed performance and behaviors



Domain control

Computed data

Dynamic
and conditional form

File uploads

Next steps

Define the data collection protocol:

- What data do we collect?
- What are the current data collection processes?
- Do patients undergo tests at different clinics or just one?
- Is the study longitudinal?
- Must they be anonymized before being shared?
- Are there any data storage constraints (e.g., clear/encrypted)
- Do data from different pathologies need to be communicated? Will analyses be performed across different pathologies?
- Do the hospital's Data Protection Officer and the INFN need to communicate (what requirements are there for data retention? Certification?

We propose to proceed with a pilot project, defining the pathology and starting with a single hospital before extending the collection to the rest of the clinics.

Start collections on datasets to be converged in the overall architectural design.