Data interoperability for elderly with dementia: use case

Patient data interoperability is crucial for elderly with dementia, who rely on a number of healthcare providers, such as home care, physiotherapy, hospitals, etc. However, this data exchange is often difficult, limiting information access which is needed to make informed decisions about patient care. Making patient data FAIR, and thereby machine-actionable, is the first step towards ensuring

FAIR stands for **Findable**, **Accessible**, **Interoperable** and **Reusable**. By making data FAIR, data reuse is improved, by ensuring that one can easily find and access data, and that the data is interoperoperable so that it is usable in different places and systems.

this data interoperability, whilst protecting the privacy of the data and conforming with data regulations.
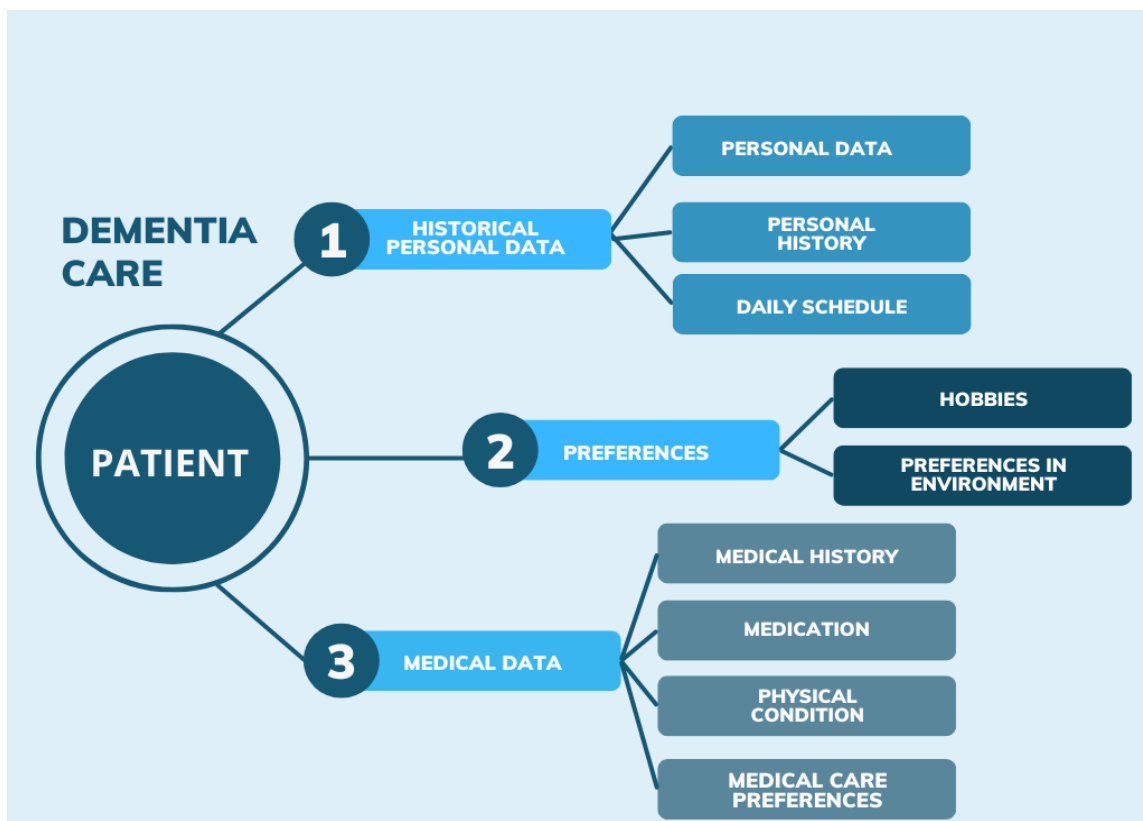

Figure 1. Overview of the data structure and hierarchies for elderly with dementia.

In this use-case, an architectural framework was developed to make this data interoperable. This consisted of FAIR data stations for each healthcare provider, ensuring that the data is held in residence, and allowing data visiting through queries for data accessibility.

RECOMMENDATIONS

1. Establish a governance framework for secure and controlled access to patient data through data visiting. The framework should clearly outline the conditions and processes for data access, prioritizing privacy, security, and transparency.

2. Implement national-level interoperability standards that ensure all healthcare providers handling dementia patients adhere to a uniform protocol for exchanging data in a FAIR format. This should cover hospitals, home care providers, physiotherapists, and any other healthcare services used by elderly patients.

3. Provide financial incentives or subsidies to healthcare providers for implementing FAIR data systems and data stations that facilitate data visiting rather than physical data exchange. These could be in the form of grants, tax relief, or infrastructure support.

4. Develop integrated patient data portals that allow healthcare providers, caregivers, and authorized family members to access up-to-date, interoperable patient data through data visiting. The portal should support querying of the FAIR data stored by each provider.

5. Implement policies that enable real-time or near-real-time data exchange for critical care updates related to dementia patients. Establish protocols for automatic alerts or updates to be sent to relevant healthcare providers when critical changes in patient status are recorded.