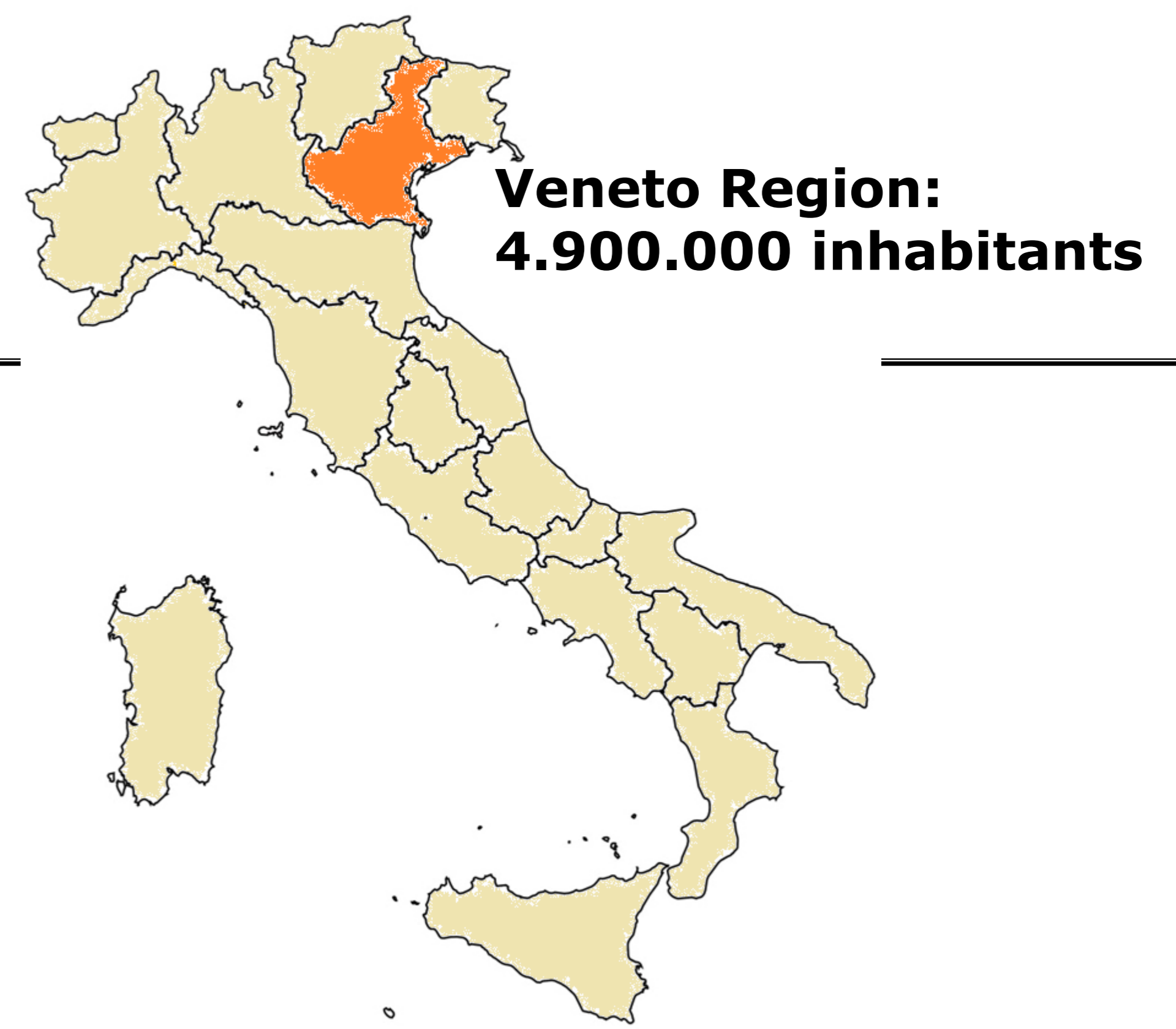


The Veneto Regional Register for Rare Disorders and Coordinating Center



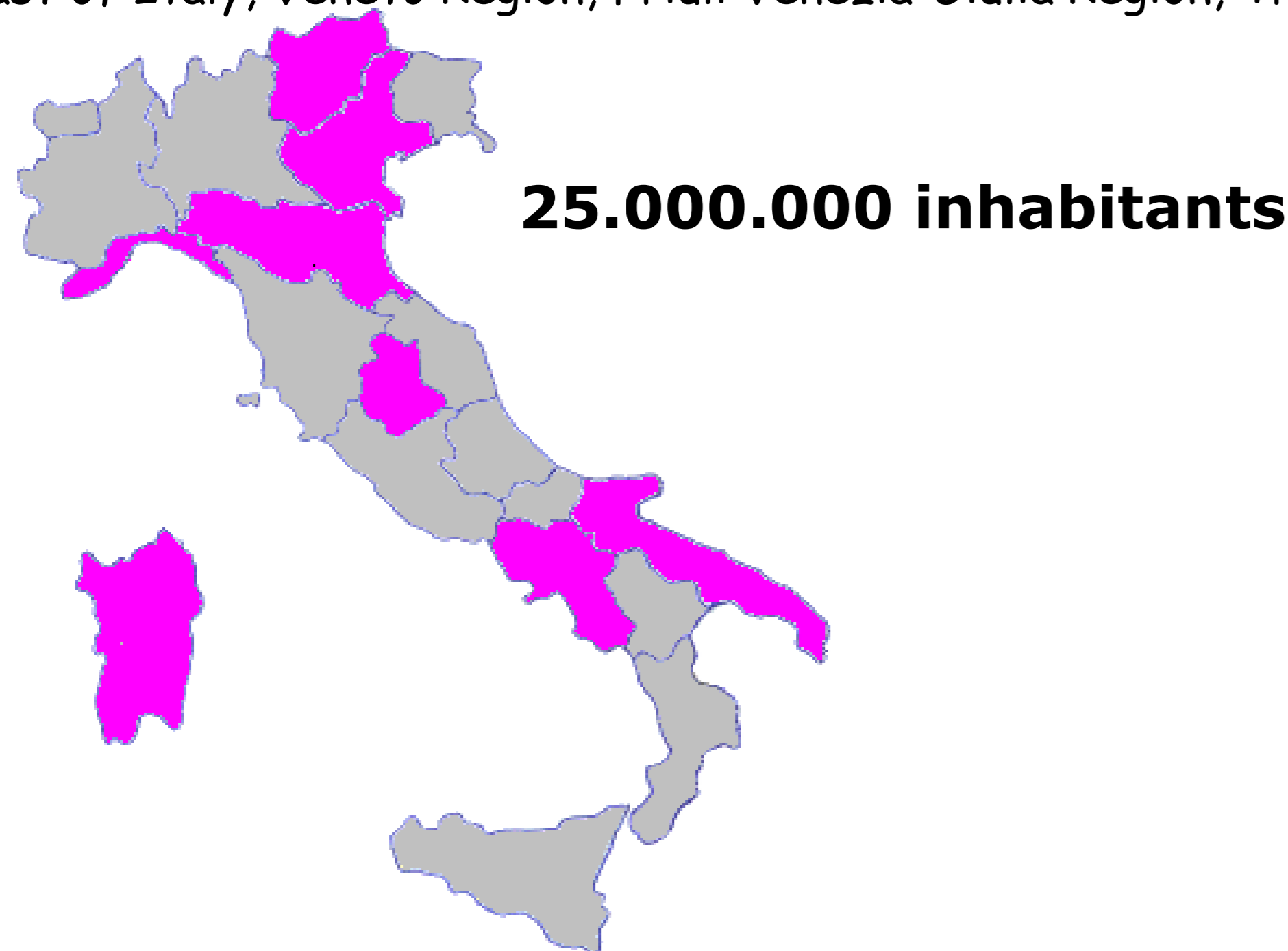
RARE DISEASES in ITALY AND IN VENETO REGIONI

Italian law on Rare Diseases

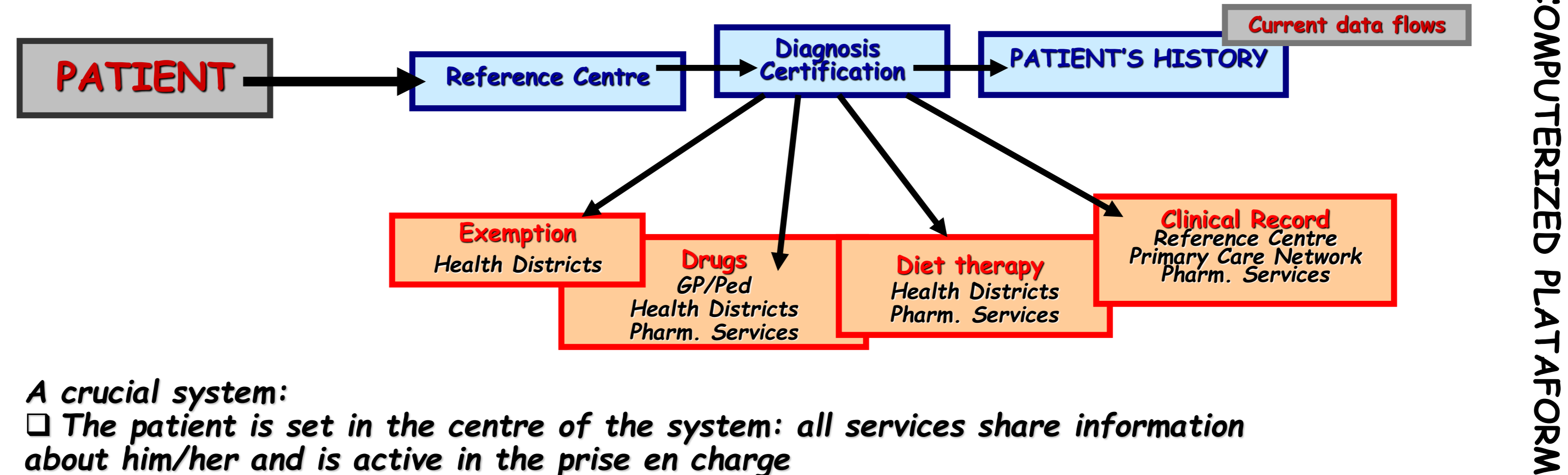
In 2001 in Italy, a specific law on rare diseases was issued (DM 279/2001), providing specific benefits to entitled patients, and submitting to the Regions the assignment of creating a care network based on the existing structures of proven excellence in the care and research field.

Since 2002, the Veneto Region, North-East of Italy, 4,9 millions inhabitants, has been implementing the Regional Register of Rare Diseases, based on an unique monitoring system completely computerized, allowing diagnosis recording, exemption leading to benefits' entitlement and cases' enrollment in the Register. The system connects all the identified Centres of Reference, the Health Districts and the Pharmaceutical Services, territorial and hospital ones. The patient enters the surveillance system after a specific diagnosis of rare disease has been made, obtaining the exemption issued by the local Health Districts. In this way the patient can receive the benefits provided by law, such as diet products free of charge for metabolic patients, or specific drugs listed in a personal therapeutic plan defined by the Reference Center. The system provides patients data collection through synthetic clinical records filled on-line by the referral Centres

Since 2004, the area involved in the same health planning strategies have become wider and wider comprehending all the North East of Italy, Veneto Region, Friuli Venezia-Giulia Region, Trentino Alto Adige (Trento and Bolzano Provinces), Emilia-Romagna, Liguria, Umbria, Campania, Puglia, Sardegna.



THE VENETO REGISTER



Our main aims have been: How to organize centres of expertise and how to link them to the other health and social system actors
 A Unique informative system linking all actors has been the answer utilizing patients' information

The contents of the informative system are:

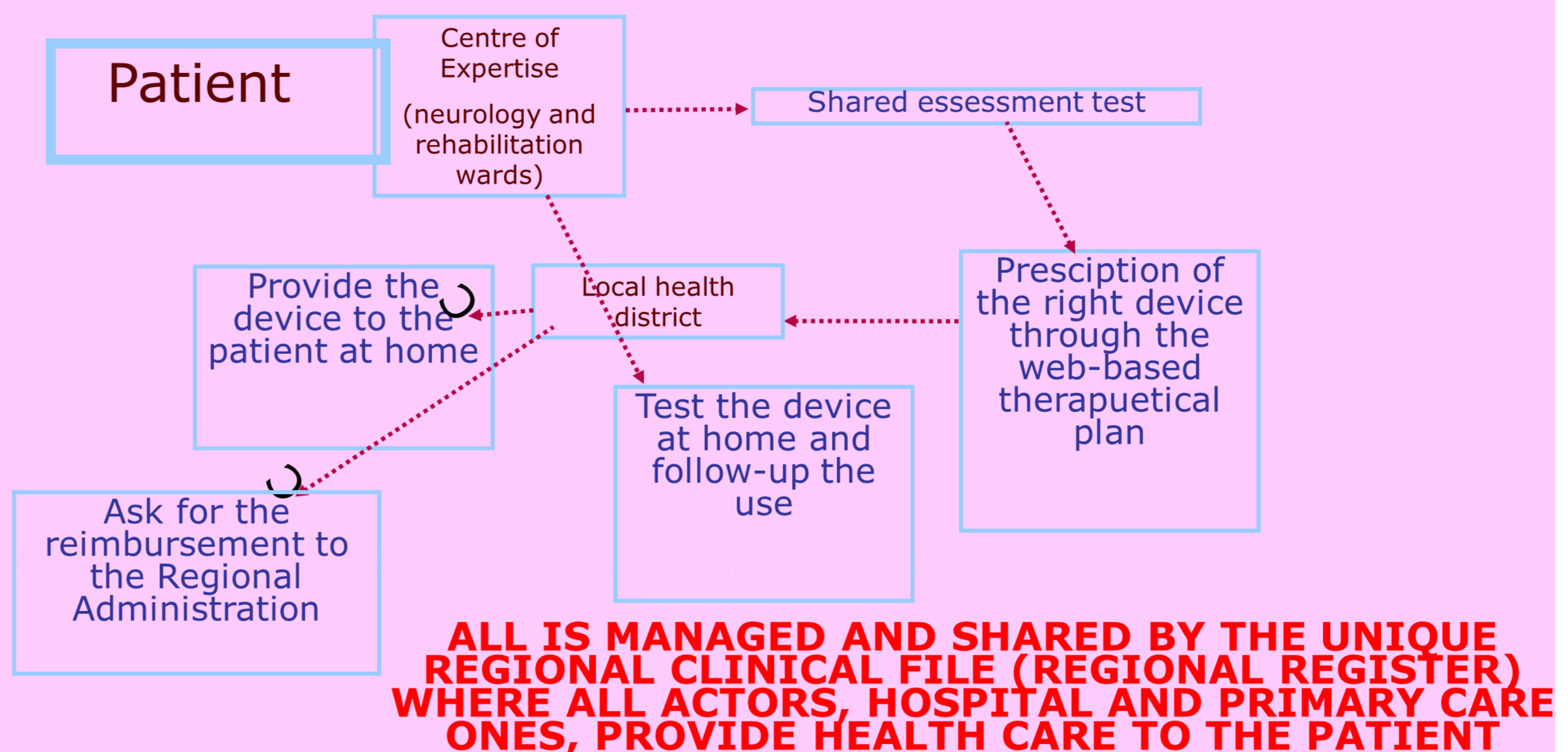
The protocols: 359 drugs/free products (even medical device such as eye tracking communicators) are given in addition to the national levels of assistance thanks to regional acts for 1954 diseases

The health care pathways: about specific disease or groups of diseases (for example: HCP for ALS patients)

Registro Malattie Rare
Ambiente DEMO



Health care pathway for communication needs for ALS patients



Some numbers

Prevalence or rare diseases: 5/1.000

- 122,000 patients in the IS
- 7,200 professionals
- 1200 connected social and health services
- 44,000 online therapeutical plans
- 57,000 given products

