

# RARE DISEASES CARD

The Ministry of Health of Portugal was recommended by the Assembly of the Republic to implement a personal card for people with rare disease in order to give them a special status in the health system.

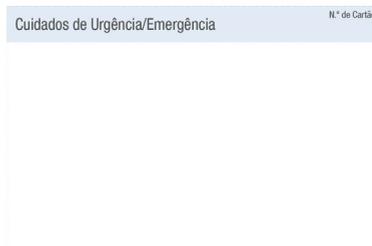
Since then, the Directorate-General of Health has made great efforts to develop this project and to involve all the stakeholders. In the end of 2013, a card of people with rare diseases was issued.

## The main objectives of this card are:

- To ensure access to relevant information, to doctors and nurses on clinical data and recommendations regarding emergencies and urgencies acts
- To improve the integrated management of the disease to avoid delay, error and harmful procedures.
- To guarantee the correct referral to Reference Centres
- To improve continuity of care, between all the levels of care



The front side of the card features the logos of DGS (Direção-Geral de Saúde) and the Departamento da Qualidade na Saúde. The title 'CARTÃO DA PESSOA COM DOENÇA RARA' is prominently displayed. Below the title, there are several fields for personal and medical information: 'N.º Utente de Saúde', 'Nome do Titular', 'Data de Nascimento', 'Unidade de Saúde', 'Médico Assistente', and 'Doença(s) Rara(s) (Código ORPHA - Doença rara)'. At the bottom, a note provides emergency contact information: 'Em caso de urgência/emergência, contacte a Linha Saúde 24 (808 24 24 24) ou o 112. Para mais informações, visite o sítio da internet da ORPHANET (www.orpha.net)'.



The back side of the card is primarily blank, with a header area containing the text 'Cuidados de Urgência/Emergência' and 'N.º de Cartão'.

This card is being distributed, since 2014, to patients and it includes relevant information such as, the name and the "orpha code" of the disease; the name and contact of the Reference Centre and it has on its back-side specific health recommendations (totally addressed for each patient) to be provided in case of emergency.

The card is available at the national web-based patient clinical record, in order to guarantee that the most crucial information on the diagnosis and emergency care is available all over the country to all medical doctors and nurses.

The card must be required by the medical doctor at the national Healthcare Data Platform (PDS) during a medical consultation and patients are given a copy of the issuing request including a personal code.

Patients must confirm this request at the Platform (PDS) using their personal code. After a final validation by medical doctors (to assure that all the steps of the process are accomplished), the card is sent to patients home (by post).

In 2015, cards are being issued by 7 differentiated hospitals across the country:

- Centro Hospitalar de Gaia-Espinho
- Centro Hospitalar de Lisboa Central, EPE
- Centro Hospitalar de Lisboa Norte, EPE
- Centro Hospitalar de São João, EPE
- Centro Hospitalar do Porto, EPE
- Centro Hospitalar Universitário de Coimbra, EPE
- Hospital da Senhora da Oliveira Guimarães, EPE

More than 380 medical doctors are involved in the project and almost 1500 cards were required.