

3 projects, 3 ways of collecting, retrieving and analyzing data

Helena Canhão

NOVA Medical School, EpiDoC Unit, CEDOC, Portugal.

helenacanhao@nms.unl.pt

Abstract

Non-communicable chronic diseases are major causes of morbidity and mortality in western societies. Even though we are living longer, last years' quality of life is distinctive in different countries. In this presentation we will talk about 3 different projects and 3 different types of collecting and retrieving data. Reuma.pt (www.reuma.pt) is the national registry of rheumatic diseases, which follow more than 17,800 rheumatic patients with more than 140,000 medical appointments. Online, structured collection of data with easy data export to statistics software makes this registry a powerful research tool. EpiDoC cohort (<http://cedoc.unl.pt/epidoc-unit/>) is a closed population based study that follows since 2011, 10,661 adult individuals representative of the Portuguese dwelling population. These subjects were randomly selected across Mainland and Islands and act as a barometer of the population living in the community. Finally, Patient Innovation Project (<https://patient-innovation.com>) is an open, free, online platform that gathers and facilitates sharing of innovations and solutions developed by patients and informal caregivers. It acts like a social network, but the solutions are published only after clearance from the medical screening. 800 innovations from 50 different countries are available to help patients suffering from different diseases and disabilities.