

**029: IMPACT OF AN INTERNET-BASED INFORMATION SERVICE ON RARE DISEASES ON THE UPTAKE OF HEALTH CARE SERVICES: THE ORPHANET INITIATIVE**

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**Objectives:**

- To assess the influence of an Internet-based information service in the area of rare diseases on the referral to appropriate health care services.
- To compare the influence of this information on the patients and their relatives vs health care professionals.
- To detect any harmful effect.

**Methods:**

In order to provide individuals with highly-effective health care in the field of rare diseases, accurate information needs to be available to patients and health care professionals both on the diseases and on the services attached to them. A database of rare diseases was established in France in 1997, jointly by the Ministry of Health and the INSERM. The current version of ORPHANET is bilingual, French and English. It currently includes detailed information on 1,200 diseases, clinical laboratories, on-going research projects, relevant support groups and specialized clinics. The inclusion of data from other European countries is on the way through a EU grant. The number of connections has been steadily increasing and reaches several thousand per day. Half of them are from professionals, and half from patients or their relatives.

A survey was sent to the 500 clinics and the 350 laboratories which are referenced in the database. The survey aims to assess the impact of Orphanet on the number of referrals to specialized clinics and specialized laboratories. It includes questions about the number of patients referred by another professional and the number of patients having personally identified the clinics through Orphanet. It also includes questions about the adequacy of referrals due to Orphanet.

**Results:**

The data collection will be completed by April 2002. The pilot phase during which the questionnaires were tested on a subset of clinicians and biologists listed in the database showed that Orphanet has a significant impact on both the referrals and their adequacy.

**Conclusions:**

This survey is likely to show that the availability of information on highly specialized health resources may contribute to empowering consumers and to improve right use of these resources. The problems raised by such an information system are the validation of the information in areas where knowledge is scarce, the dissemination to the public of information which would be traditionally restricted to the professionals, the updating process, the legal issues, the criteria to classify places as expert centers and the extent to which some services can be delivered on line.