



Socioeconomic Data

Total population: 22 246 862 (2008)
 Area of country: 238 391 sq km
 Population density: 93/sq km (2008)
 GDP: 264 billion \$ (2008)
 GDP/capita: 12 285 \$ (2008)
 % of GDP spent on health: 5.5% (2006)
 # of physicians/100,000 inhabitants: 190 (2006)

Romania

Sections of this chapter were written with the collaboration of the Romanian Prader Willi Association and the Romanian National Alliance for Rare Diseases (RONARD).

National Initiative in the Field of Rare Diseases

Romania's healthcare system, once state-owned and tax-based, is now more decentralised. The Ministry of Public Health is the central authority, responsible for setting public health priorities. The system is now funded through two sources: (a) social insurance through the National Health Care Insurance Fund, to which employers and employees make mandatory contributions, and (b) taxes (including taxes on alcohol and tobacco) that are directed by the Ministry of Public Health policies towards the national health programmes and capital investments in health. Private health insurance has developed slowly, and due to low public funding approximately 36% of healthcare spending is out of pocket. Informal payments are very common for obtaining improved treatment. Primary healthcare services are mainly delivered by private general practitioners acting as gatekeepers to specialised services. Secondary and tertiary care are mostly publicly owned and administered by the state. Long-term lack of funding of the healthcare system during the Ceausescu regime and the low quality of medical equipment has resulted in decreased healthcare standards, in particular in rural areas.

Romanian health authorities and professionals use the European Orphan Drug Regulation prevalence of less than one in 2000 people to define rare diseases. At the end of 2007, the Romanian Prader Willi Association and the Romanian National Alliance for Rare Diseases (RONARD) (initiated by the Romanian Prader Willi Association) concluded a partnership agreement with the Ministry of Public Health (MPH) for the creation of the first National Plan for Rare Diseases in Romania. The National Plan foresees as one of its first missions the establishment of an interdisciplinary commission for rare diseases, the first priority on the MPH agenda. As a consequence of creating the National Plan, the MPH health programme enlarged coverage of orphan drugs beginning in July 2008. The creation of rare disease registries has also been a product of this work. Non-medical services exist for all patients with disabilities in Romania, but not specifically for rare disease patients.

The Romanian Prader Willi Association acts a centre of information not only for Prader Willi, but also for all other rare diseases. Through this centre, counselling services, support groups and training are also available. The National Plan will guarantee the development of the Romanian Prader

Willi Association centre into a reference and training centre. Currently neonatal screening exists for several diseases, although availability is not yet complete at the national level. Genetic counselling can only be provided by physicians specialising in genetics. Until recently all genetic testing was done abroad through foreign hospitals and clinical centre partnerships.

Access to **Medical** and **Social Services** in Romania

PARTICIPANTS IN THE SURVEY

AH	Ch11	WS (5)	PWS (29)
FRX	EB (22)	TS	CF
ANR	OI (4)	MFS	EDS
HD	MG	ATX	PAH

Figure 1
Diseases included in the survey and the number of responses in Romania

Responses from 60 Romanian families of patients with four diseases were analysed in the survey (*Figure 1*).

The proportions of female and male patients represented were 54% and 46%, respectively.

The mean age of patients was 18 years (mean age at diagnosis: 11 years).

NEED FOR MEDICAL SERVICES

Overall, Romanian patients needed 16.3 different kinds of medical services related to their disease, more than the average 9.4 medical services.

Hospitalisation occurred in 73% of patients for an average total duration of 33 days.

MEDICAL SERVICES

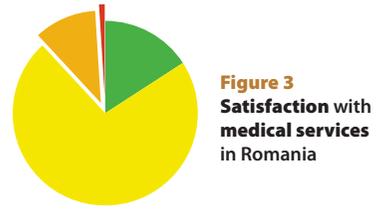
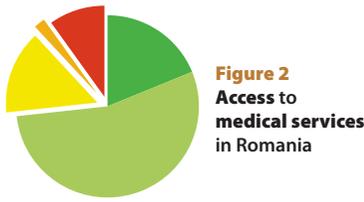
Access to the eight essential services for each disease was easy in 72% of cases, difficult in 17% of cases and impossible in 10% of cases (*Figure 2, p272*). Difficulty was mainly due to lack of referral (59%), unavailability (34%), waiting time (34%), personal cost (3%) and location of the structure, including a location too far away (52%), no one to go with (55%), cost of the journey (66%) and difficulty in travelling (7%).

When obtained, the medical services responded well to patients' expectations in 89% of cases and poorly in 11% of cases (*Figure 3, p272*).

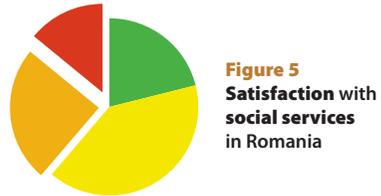
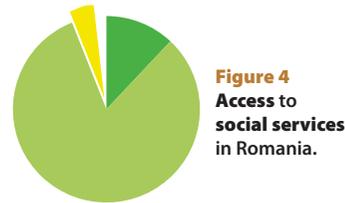
SOCIAL ASSISTANCE

Amongst the 53% of Romanian families needing social assistance, all met with a social worker, and 94% met with one easily and 6% met with one with difficulty.

In Romania, social assistance is provided mainly from ‘private’ sources, associations (71%) and religious (7%) establishments. Romanian families (61% compared to 50% overall) were satisfied with this assistance, 14% not at all (28% overall).



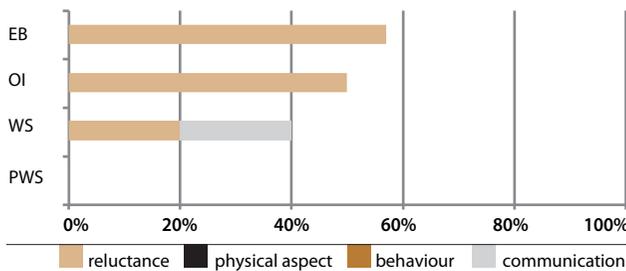
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impossible very difficult difficult easy very easy not at all poorly partially fully

REJECTION

Romanian patients experienced rejection by health professional in 25% of cases (compared to 18% overall) for the 16 surveyed rare diseases (Figure 6). The reluctance of health professionals to treat patients due to the complexity of their disease was the main cause of rejection (100%), followed by communication difficulties (7%).



CONSEQUENCES OF THE DISEASE

As a consequence of the disease, 19% of Romanian patients had to move house. Amongst these, families moved to a more adapted house (55%), to be nearer to disease specialists (9%) or to be closer to a relative (46% compared to 18% overall). As a consequence of their disease, 20% of patients had to reduce or stop their professional activity. In 73% of cases, a member of the family had to stop work in order to take care of a relative (compared to 33% overall).