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"Coming here, you will discover yourself, discovering others"
Romanian Prader-Willi Association

ASOCIACIÓN MADRILEÑA
PARA EL SÍNDROME DE
PRADER-WILLI



ASSESSMENT OF ACCESSIBILITY TO AND QUALITY OF HEALTH AND SOCIAL SERVICES FOR PATIENTS WITH PRADER WILLI SYNDROME IN ITALY AND ROMANIA

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INTRODUCTION: People suffering from rare diseases often experience the same problems: failure or delay in diagnosis, scarcity of health information, lack of referral to specialized professionals, lack of support for integration into work. Within the NEPHIRD project (Network of Public Health Institutions on Rare Diseases in Europe), a pilot study was carried out to assess accessibility to and quality of health and social services in patients affected by Prader Willi Syndrome (PWS) in Italy and Romania.

METHODOLOGY: The survey was carried out in Italy and in Romania in collaboration with PWS patients' associations: 1) La Federazione delle Associazioni Italiane per l'aiuto ai soggetti con sindrome Prader Willi (Federation of Italian Prader Willi Associations), Italy and Romanian Prader Willi Association, Romania. The questionnaire asks how often patients or caregivers had both negative and positive experiences about the quality of and the accessibility to health and social services on a 5-level scales.

RESULTS: In total 66 questionnaires for PWS were filled in (30 in Italy, 36 in Romania). In Romania, the most negative opinions expressed by the patients were on the following topics: integration of services (65%); diagnostic examination (36%); drug therapies (31%); or rehabilitation (21%). In Italy the major complains follow: vocational training (82%); information about the diseases (68%); information on laws and rights (66%).

CONCLUSIONS: Romanian patients placed access to and quality of health care at the top of their list of what makes them dissatisfied, probably due to the difficulty in diagnosing PWS. Italian patients had negative opinions on information and social care. Further studies are needed to better explore and understand such a difference.