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

ASOCIACIÓN MADRILEÑA
PARA EL SÍNDROME DE
PRADER-WILLI



THE EUROPEAN PRADER WILLI SYNDROME CLINICAL RESEARCH DATABASE

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INTRODUCTION: PWS is a rare disorder and for this reason clinical research that aims to investigate influences on development over the lifespan can be limited by the inability to recruit sufficient people with PWS of different ages, genetic sub-types and of both genders in any one country. Similarly studies in any one country alone do not readily allow the effects of different cultural influences, social policies and/or clinical practices to be investigated.

METHODS: a combined clinical and basic science PWS research consortium has been established funded under the EU 6th Framework. Clinical researchers and computer scientists have been developing an internet-based secure PWS research database. The structure and content of the database was informed by existing research databases and developed and refined by an interdisciplinary group all involved in clinical PWS research and practice. The prime aim was to enable the structured collection of clinical data in different countries in a secure and confidential manner compatible with EU law. The data can be analysed by the individual countries and also combined in a manner that protects confidentiality but also enables larger studies between countries.

RESULTS: the database is divided into six 'index sections' under the following headings: 1) Demographic, diagnostic, early development; 2) Context (living circumstances etc); 3) Physical health; 4) Mental health and behaviour; 5) Cognition and function; 6) Investigations and treatments. These sections are further sub-divided into panels, sub-panels and fields. Data on health is structured around the different organ systems of the body.

DISCUSSION: data is collected and stored in different ways using varied interview schedules and structured assessments both within and between individual countries. The use of similar assessments in different languages raises concerns about compatibility, reliability and validity. Different disciplines have different priorities and there is a tension as to whether the database is primarily for clinical practice or research. These issues have had to be considered and compromises made.