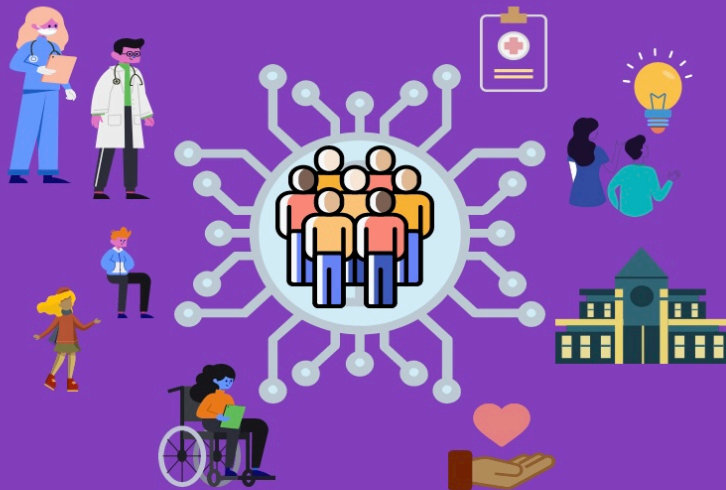


The role of Patients Associations in Monitoring and Improving Health, Health Care and Quality of Life for Patients with Rare Diseases:

The Case of Prader-Willi Syndrome in Germany and the Netherlands



- PWS affects multiple body functions: input from different fields and experts are needed to address all the needs of patients
- Coordination between experts is difficult
- Limited public knowledge: accessing financial aid and support from society is very difficult
- Existing research is limited
- Patients' daily struggles, as temper and eating disorders, significantly affect their families and are rarely comprehended by the public, with the risk of bullying behaviour and emargination

How do the German and Dutch Associations improve the care provided to their patients, its availability, quality and affordability?

01. QUALITY OF LIFE

- Workshops with experts
- Family weekends
- Community Support offered through social media groups and blogs
- Establishment of PWS Houses

02. AVAILABILITY

- Intermediary role between patients, medical experts and researchers
- Publication of booklets
- Emergency card with fast facts on the disease
- Collaborations with pharmaceutical companies

03. AFFORDABILITY

- Personal support and consultation to help accessing financial aid
- Fundraising events and campaigns
- Insurance Assistance
- Creates incentives for research to develop accessible drugs



Prader-Willi Syndrome (PWS)

A rare chronic disease caused by genes imprinting errors, originated by a defect in chromosome 15. Individuals affected suffer from hypothalamic malfunctioning which manifests in eating disorders, behavioural issues, autism-like symptoms and sterility.



Methodology

The study has a descriptive-explorative character with a semi-qualitative approach, as the data is retrieved from interviews with members of the associations' board



Future Developments

The coordination of the international network that both association have been creating so far seems promising for the development of drugs against obesity which would significantly reduce one of the diseases' burdens.