What is the full cost of rare disease to you? How does it affect your quality of life?

Help us to find out!

BURQOL-RD Project is a 3-year-project that addresses crucial questions for the rare diseases community. The aim of the study is to give an accurate estimation of the cost of the condition per patient, and its impact on quality of life for patients and carers. The project goes beyond any previously implemented surveys by considering the 'overall cost' (direct and indirect) to caregivers, who dedicate their time and energy to look after patients.

The Project has been implemented in **eight European countries**: Spain, Bulgaria, Germany, Italy, Hungary, United Kingdom, Sweden and France. In the UK the recruitment of patients and carers is still open!

The data gathered from rare disease patients and carers in the UK will be collated and compared with the cost across the other seven European countries which will be crucial in defining the current effects of rare conditions on society, and to assess the effectiveness of new policies, opening a way to study the cost-effectiveness of new treatments, including orphan drugs.

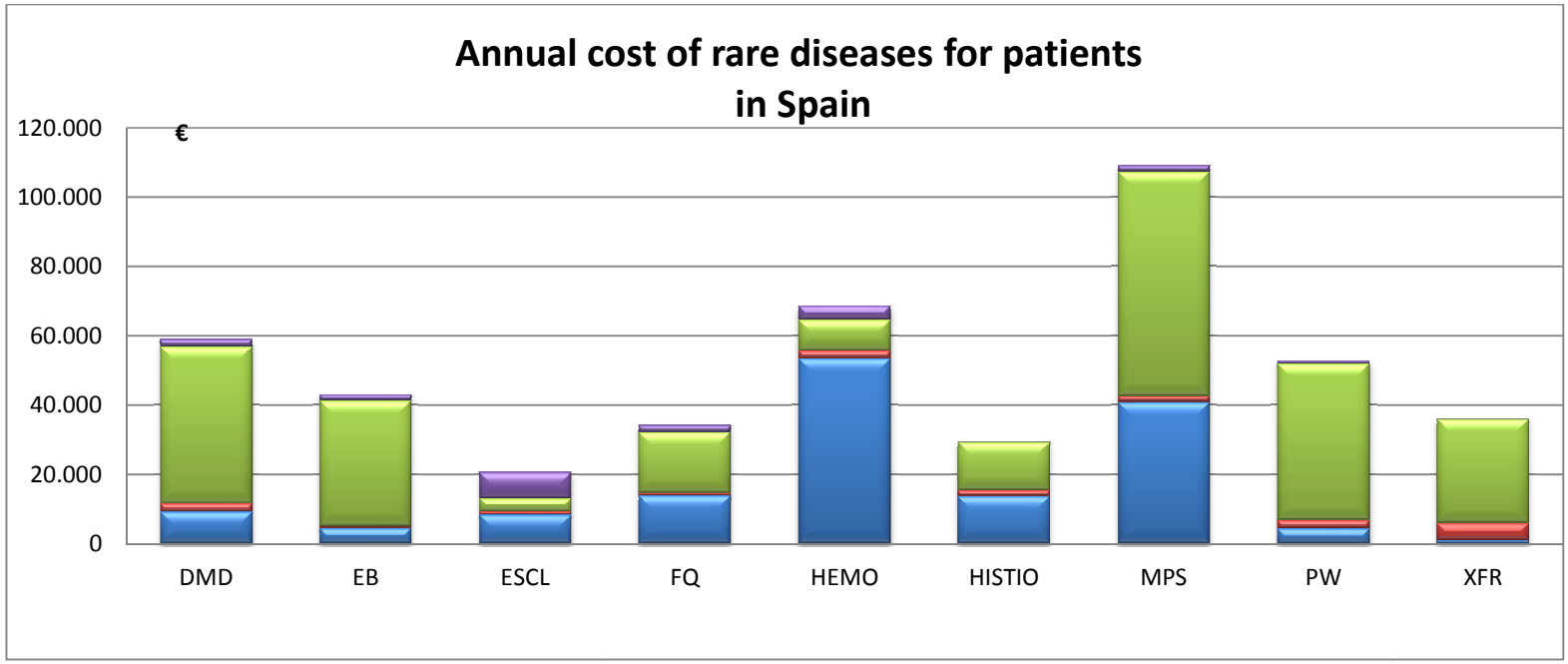
What are the direct and indirect costs of rare diseases for patients and their carers?

The evaluation of the research data is already at advanced stage in Spain. In this analysis over 700 responses from patients and carers were considered. Taking a look at the cost figures helps understand how high the burden of selected rare diseases is for the affected families and the whole society. The graphic shows the annual cost of each patient that ranges on average between 20,000€ - 105,000€.

Informal costs, representing the value of the support provided by the carer who is normally a family-member, account for a major part of the overall costs in almost all studied diseases. Although this item seems to be crucial, it is often omitted in economic evaluations used to justify the use of a specific treatment or care pathway. Usually, the emphasis is placed upon direct healthcare costs in these models; these also show to be very significant but should be considered alongside informal costs. In the evaluation phase indirect costs are divided into three categories that are explained in details under the following graph.

Below, you can see the costs of ten researched rare diseases and the results of the study of these conditions in Spain.

Studied diseases: DMD – Duchenne Muscular Dystrophy, EB – Epidermolysis Bullosa , SCL – Scleroderma, CF – Cystic Fibrosis, HEMO – Haemophilia, HISTIO – Histiocytosis, MPS – Mucopolysaccharidosis, PW – Prader-Willi Syndrome, XFR – Fragile X Syndrome.



Direct healthcare costs:	**Direct non-healthcare formal costs:**	**Direct non-healthcare informal costs:**	**Indirect costs:**
-Drugs and health material -Medical tests and visits -Hospitalisations -Health transport	-Professional carers -Non-health transport -Health-social services	-Main informal carer -Other informal carer	-Loss of productivity and early retirement of the patient(only adults) -Loss of productivity and early retirement of the main carer

The Project is led by the Canary Foundation of Investigation and Health (FUNCIS) with the collaboration of 11 Associated Partners, 8 National Alliances, 3 Umbrella Organizations, as well as hundreds of experts. The collaboration of these groups will be crucial to define the current burden of rare diseases for society, and to assess the effectiveness of new policies and interventions, opening a way to study the cost-effectiveness of new treatments (e.g. orphan drugs).

We want to hear from your experience

We are asking patients and carers in the UK to take the time to fill out the survey. The survey is completely anonymous. As the project aims to get meaningful and reliable results, the survey is quite long (it will take about 20 minutes to complete) but survey respondents can save their answers and return to the survey to fill it out in more than one session if necessary. The Project in the UK is supported by Genetic Alliance UK and by the London School of Economics and Political Science - Health research centre (LSE Health). The survey is expected to be open until 31st March 2013. The results of the survey will be publicly available at the end of the project.

Patients can access the questionnaires through the project's web page - http://www.burqol-rd.com/uk.html.

To follow the up-dates of the project, you can join the community on Facebook under 'Burqol-rd International'.