

Cystic Kidney Diseases in the framework of the Spanish population-based rare diseases registry (Spain-RDR)



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INTRODUCTION

- Cystic Kidney Diseases (CKD): heterogeneous group of hereditary and acquired rare disorders in which the kidney contains one or more cysts unilaterally or bilaterally
- Severity variation: affect life expectancy/ not have specific treatment/require renal replacement therapy

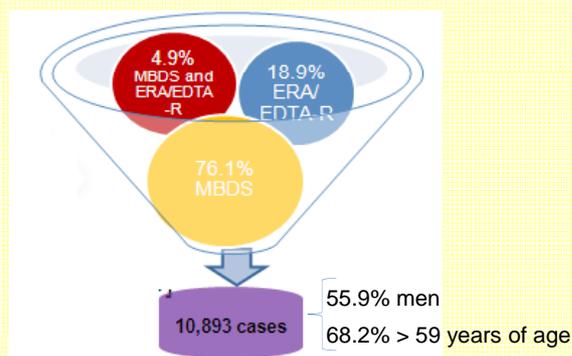
OBJECTIVE: to describe the CKD using population data from the Spanish Rare Disease Registry (Spain-RDR)

METHODOLOGY

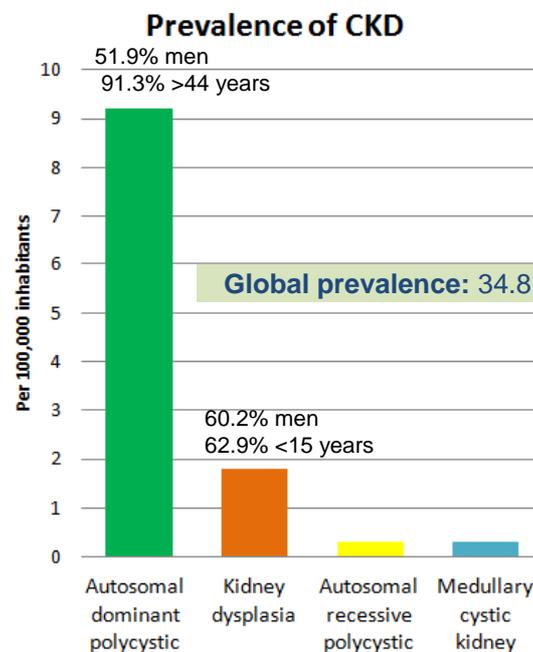
- **Study design:** Cross sectional study from 2010 to 2012
- **Population:** 13 Autonomous Communities (AC) → 31,271,471 inhabitants (66.9% of the Spanish population)
- **Data sources:**
 - Hospital discharge Minimum Basic Data Set (MBDS)
 - Chronic renal diseases registry (ERA/EDTA-R)
- **Coding:** International classification of Diseases (ICD9-CM)
- **Analysis:** Overall and specific prevalences by disease, sex and age groups

RESULTS

- **Data sources:**
 - MBDS → available in all AC
 - ERA/EDTA-R → available in 5 AC



- **Renal replacement therapy required: 53.8%** (analyzing only the AC that have both data sources)



CONCLUSION

- A large number of cases of rare kidney diseases have been identified through the Spain-RDR
- In the future we would like to perform a more in-depth analysis and to advance in the study of other rare diseases' prevalence in Spain