



# THE ITALIAN REGISTRY OF CYSTIC ECHINOCOCCOSIS (RIEC)

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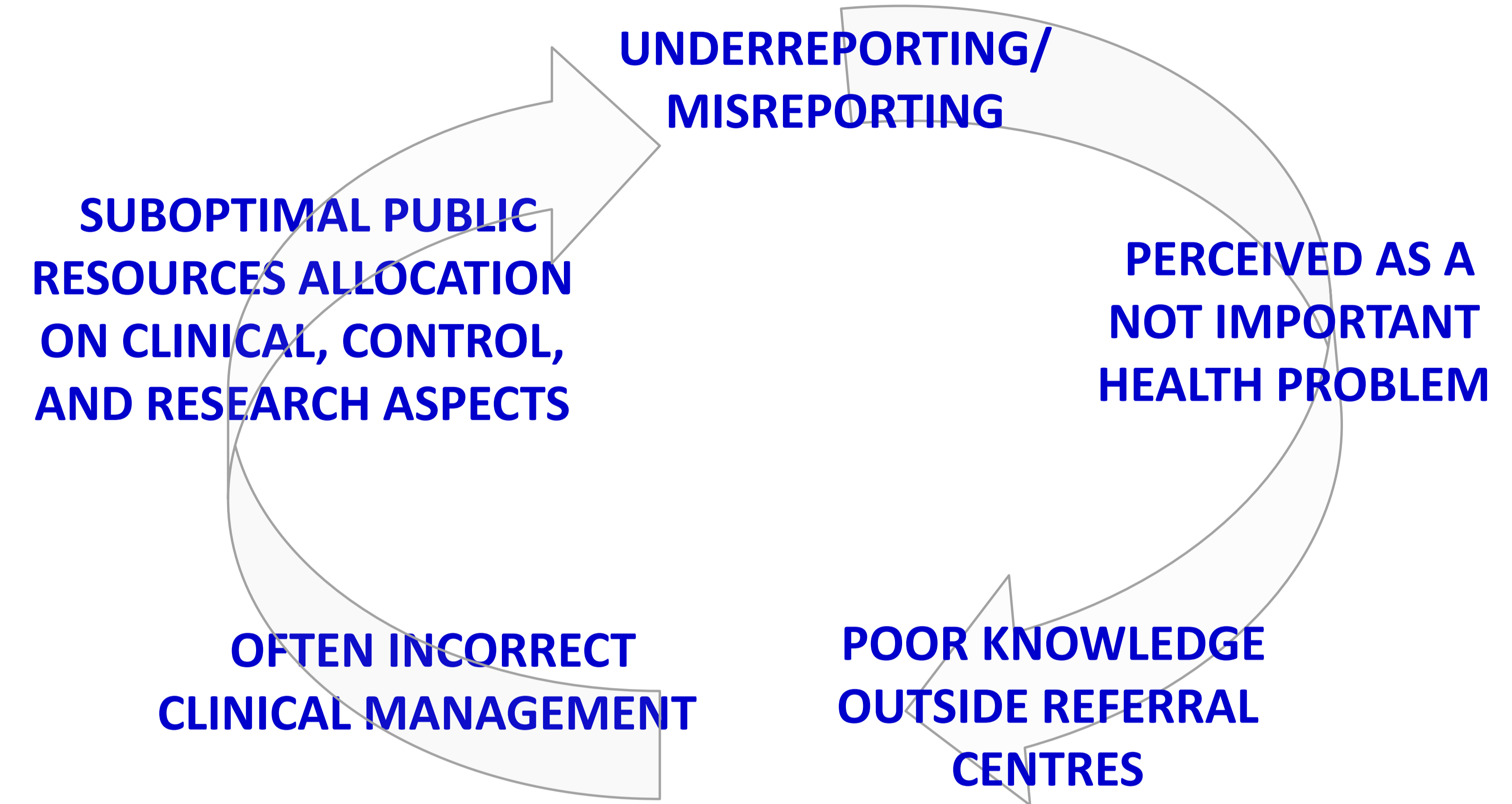


## THE PROBLEM

- Cystic Echinococcosis (CE): **chronic, complex and neglected**
  - Multidisciplinary approach in referral centres needed
  - Italy: endemic country but lack of efficient reporting systems
  - Prevalence and incidence of CE hugely underestimated
  - No official data transmitted to European authorities
- notwithstanding mean 1686 Hospital Discharge Records for CE in 2001-2011

## THE PROJECT

- Launched in October 2012 on ISS website: [www.iss.it/riec](http://www.iss.it/riec)
- **Prospective, observational, multicenter registry** of patients visited from January 2012 onward in Centres adhering voluntarily
- **Structured taking into account the peculiar features of CE**
- Unique identification code of patients allowing movement from one centre to another with **no data loss or duplication**
- Patient with possible, probable or confirmed CE (**WHO-IWGE classification**) hospitalized or in outpatient setting
- **Clinical history, treatments and follow-up** data recorded
- Available in Italian and English



## AIMS AND STRUCTURE

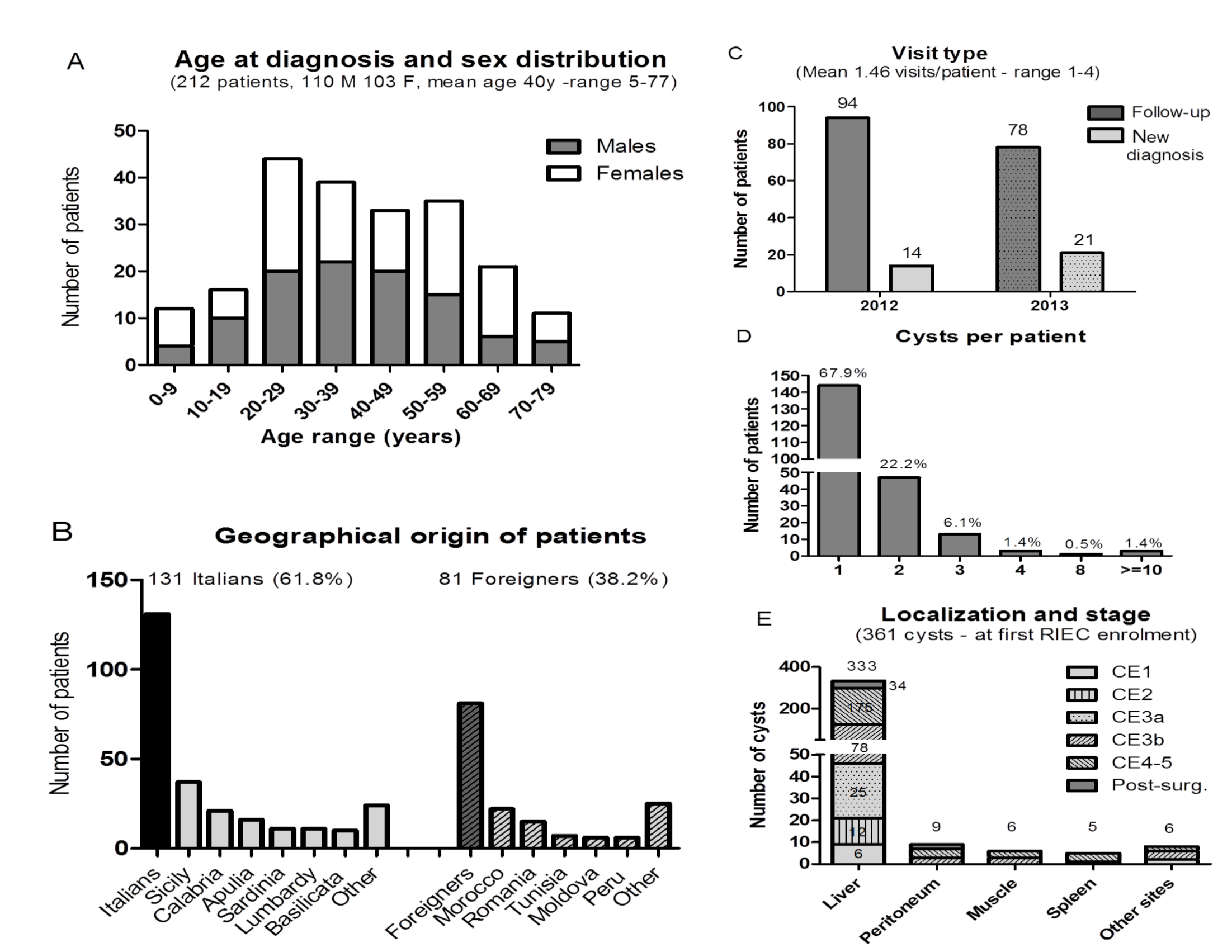
- Indicate the burden of CE in Italy
- Bring to the attention of health authorities the importance of CE
- Encourage public health policies toward CE control
- Stimulate biological, epidemiological and clinical research on CE

<b>Birth and Residency data; Contact details</b>
<b>Epidemiology</b>
- Residence and visits to endemic areas
- Field of employment at and before CE diagnosis
- Rural at-risk activities carried out before CE diagnosis
- Risk factors: contact with at-risk dogs, or potentially contaminated soil, food, or water
- Known relatives with CE
<b>Clinical history</b>
- Patient classification (first diagnosis, follow-up, relapse)
- Year, place and modality of first CE diagnosis
- Past and present symptoms
- Past and current therapies/management modality of CE (including length and complications)
<b>Cysts characteristics at diagnosis and at each visit</b>
- Number
- Organ and localization within the organ (e.g. liver segment)
- Size (S <5 cm; M 5-10 cm; L >10 cm)
- Stage (according to the WHO-IWGE classification)
- Complications
<b>Serology</b>
- Test (manufacturer, antigen, format)
- Result including titre where applicable

Data acquired in RIEC, using drop-down menus and multiple choice questions, and organized in multiple data sheets

## AS OF FEBRUARY 2014

- **16 centres** adhered and 11 enrolled patients
- **346 patients** enrolled
- Majority of patients from Pavia Hospital (WHO-CC)



Preliminary data from CE patients enrolled in RIEC Registry January 2012-February 2014 in Pavia WHO-CC.

## PERSPECTIVES

- HERACLES project (Human cystic Echinococcosis ReseArch in Central and Eastern Societies) with FP7 Grant Agreement (n° 602051).
- **RIEC is the template of ERCE → European Registry of Cystic Echinococcosis**
- Data from Bulgaria, Romania, Turkey and other European Countries



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