

THE CASTILE AND LEON CHILDHOOD CANCER REGISTRY (CLCCR). USING SEVERAL ELECTRONIC SOURCES FOR QUALITY STANDARDS

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Background & Introduction

The CLCCR is a population-based registry established in 2010. Its primary purpose is to collect data of new cancer cases in patients younger than 15 years-old throughout the Castile and Leon region (Spain). In order to report all childhood tumours, we implemented a mixed system combining a passive reporting and an active search for cases from different information sources.

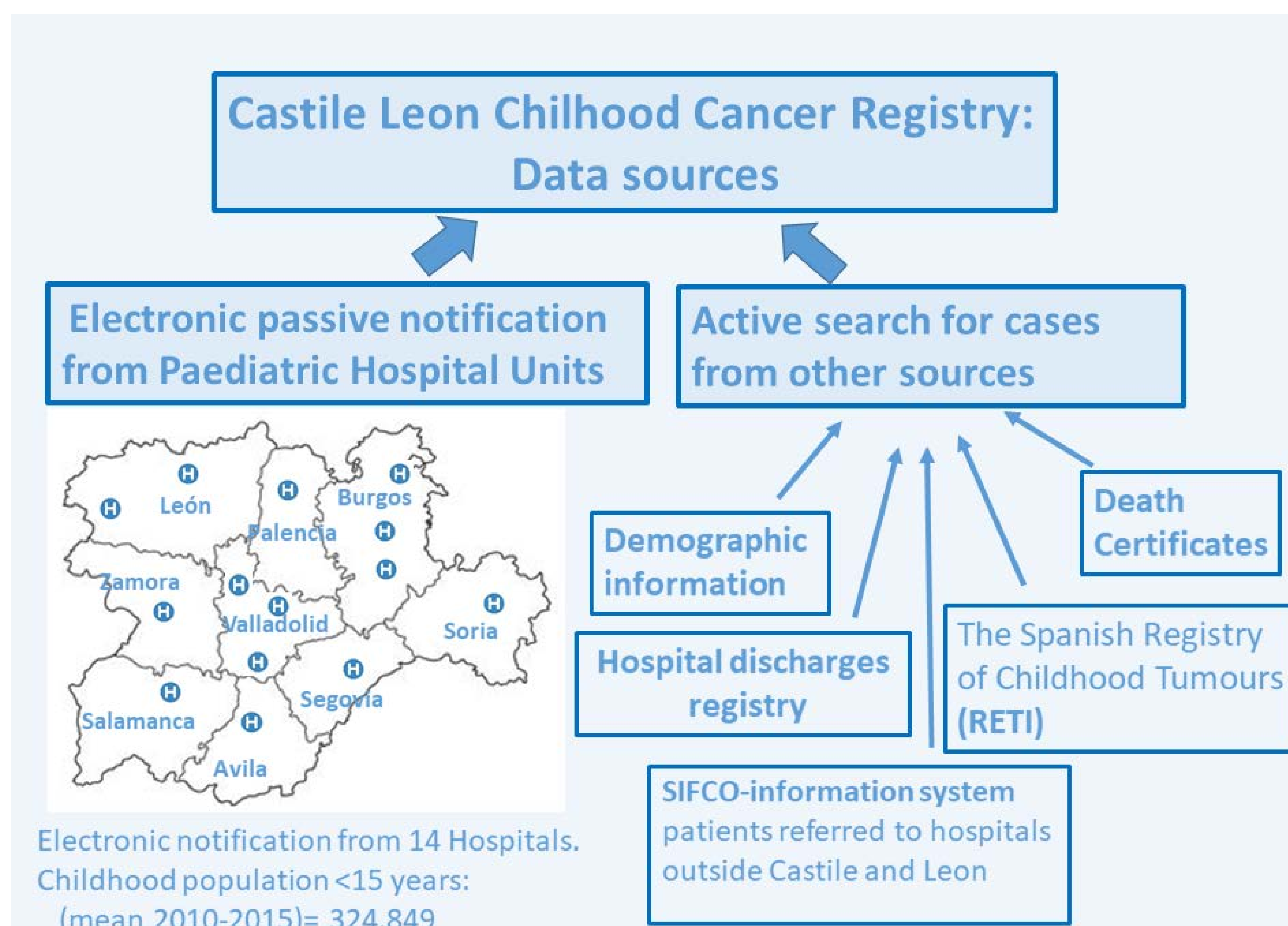
Materials & Methods

The CLCCR uses multiple **data sources**: (see Figure 1)

- 1) an **electronic passive notification** from Paediatric Hospital Units
- 2) an **active search** for cases from other sources:
 - a) hospital discharge diagnoses
 - b) patients referred to hospitals outside Castile and Leon (SIFCO)
 - c) the Spanish Registry of Childhood Tumours (RETI)
 - d) patient's demographic information
 - e) death certificates.

TUIN is a software developed for: loading electronic sources, data validation and tumour matching. In addition, some of the records need data corrections and manual resolution.

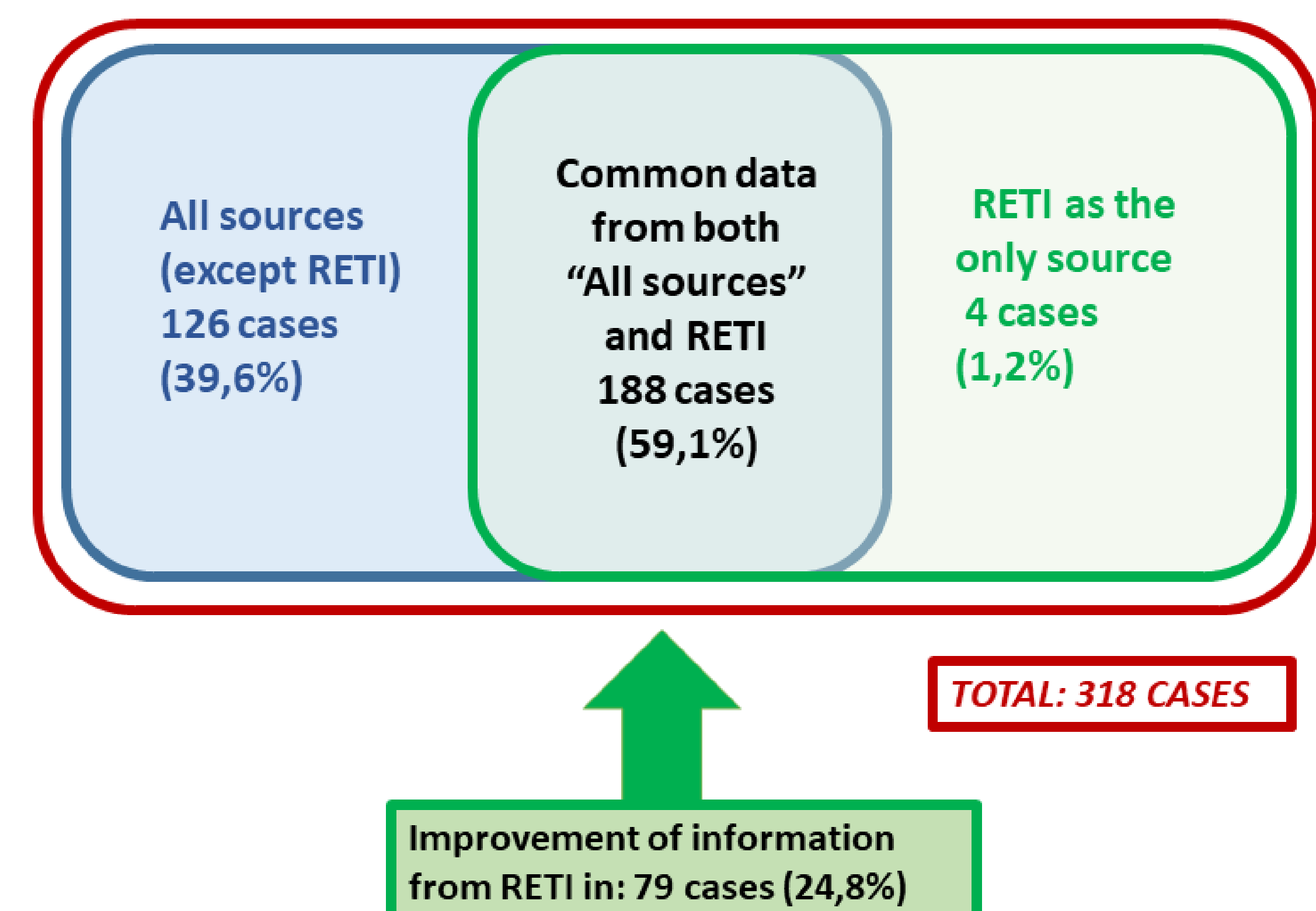
Figure 1. Information sources for the CLCCR.



Results

Each year around 60 childhood cancers cases are reported. The main information source is the passive electronic notification which covers 97% of all reported cases. Discharge diagnoses from hospitals add a 2% and SIFCO and RETI contribute with a 1% to complete all reported cases. However, both are important sources for retrieving information on patients from Castile and Leon who have been diagnosed and treated outside our region.

Figure 2. Information sources for childhood tumour cases: Overlapping data and data improvement.



RETI retrieves a small percentage (1,2%) of new cases not previously reported. However the overall RETI's contribution is estimated to be around 60%. In addition, the information of some of the cases already reported (24%) is improved completing tumour's site, morphology, treatments or tumour's stage (figure 2).

Using linkage procedures, we could confirm that all cases of childhood cancer reported from death certificates were already included in our registry database.

Quality indicators in the CCLCR are described in Table 1.

Table 1. Quality indicators for the CLCCR.

Quality Indicators	%
Microscopic Verification	94,20
Death Certificate Only Cases	0,00
Mortality to Incidence	18,00

Conclusions

Our results suggest that these mixed methods yield appropriate coverage and quality standards (completeness and validity) for the CLCCR and a high level of ascertainment.