

The wide landscape of existing databases on rare diseases in France, a national survey



BNDMR

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This poster only presents a few results extracted from the survey.
The full report is available (in French) on our website:

bndmr.fr



Context and objective

French rare diseases (RD) centres must concurrently carry out missions of care, research and epidemiological surveillance. To meet these requirements, a multitude of databases, for different purposes, were created. A national survey was launched to establish an overview of the many data entry points available in RD centres in France. It aimed to better describe the databases, their purposes, the categories of data collected and the induced workload so that national strategies could be built. RD centres were asked to answer a 40-questions online survey, established and disseminated by the French national data repository for RD (BNDMR) team with the support of the French RD health networks (which are organised around homogeneous groups of diseases). This investigation concerned any database in which they collect data about RD patients.

Warning

This survey was not mandatory and was based on personal statements. Each RD network and expert centre was free to use the tool made available in the way that seemed best suited to its needs. Some of them developed their own questionnaire and provided us with the results. Thus, it was not always possible to identify duplicate entries. Others did not participate to the national study. As a consequence, there is a selection bias whose importance was not assessable. Moreover, if on one side the centre data were not exhaustive, on the other side, given the absence of deduplication, an overestimation of the expected number of cases could not be ruled out.

1 A large disparity between the 23 French RD health networks due to the high heterogeneity of the networks themselves and to biases in the data collection.

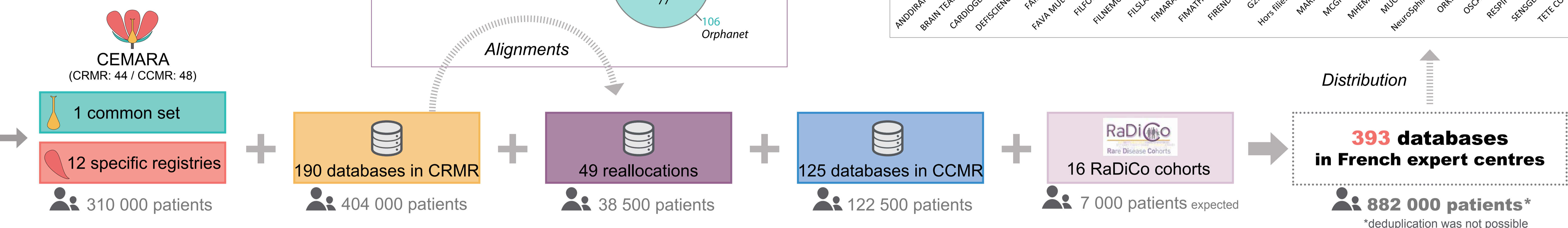
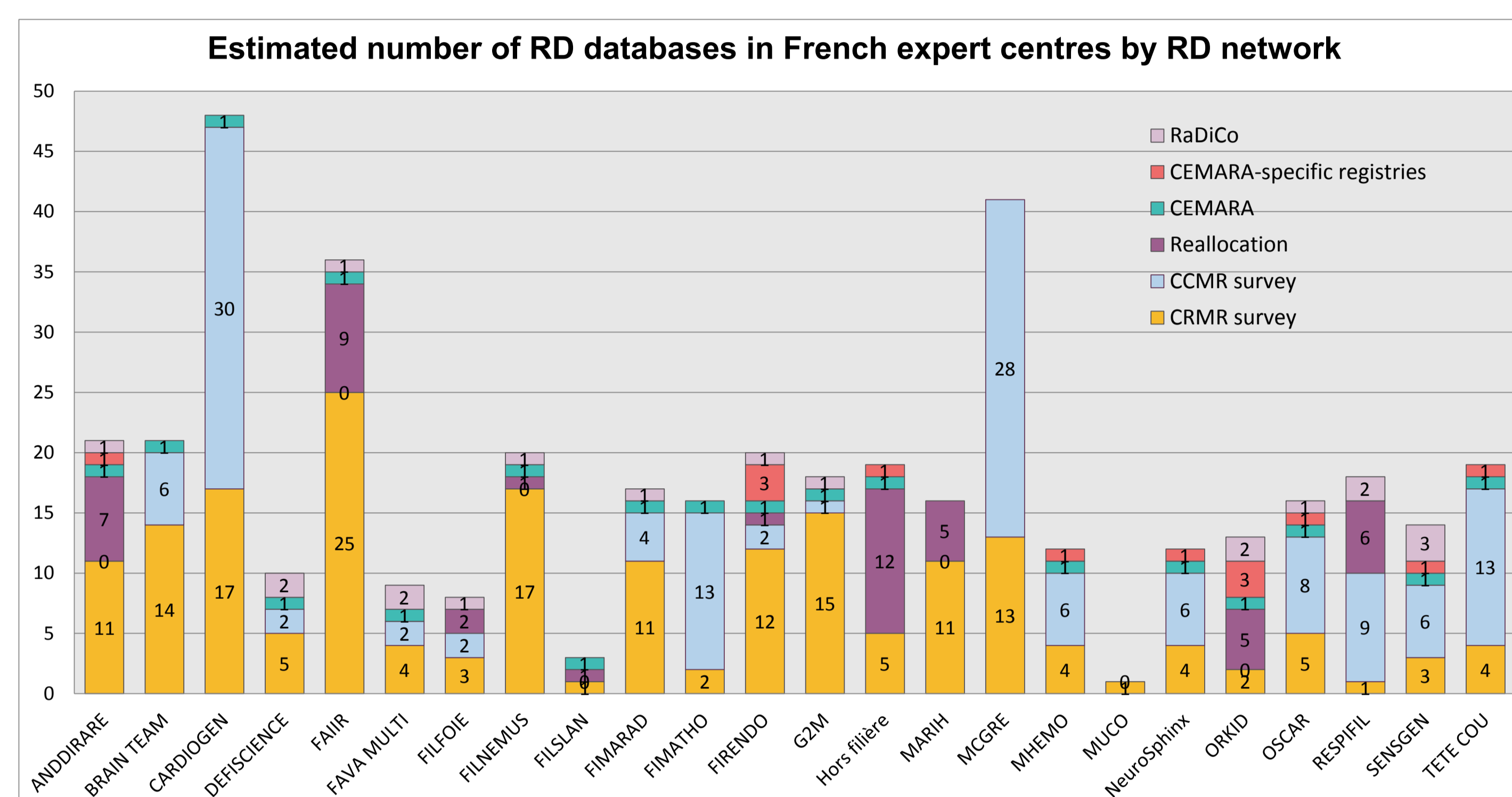
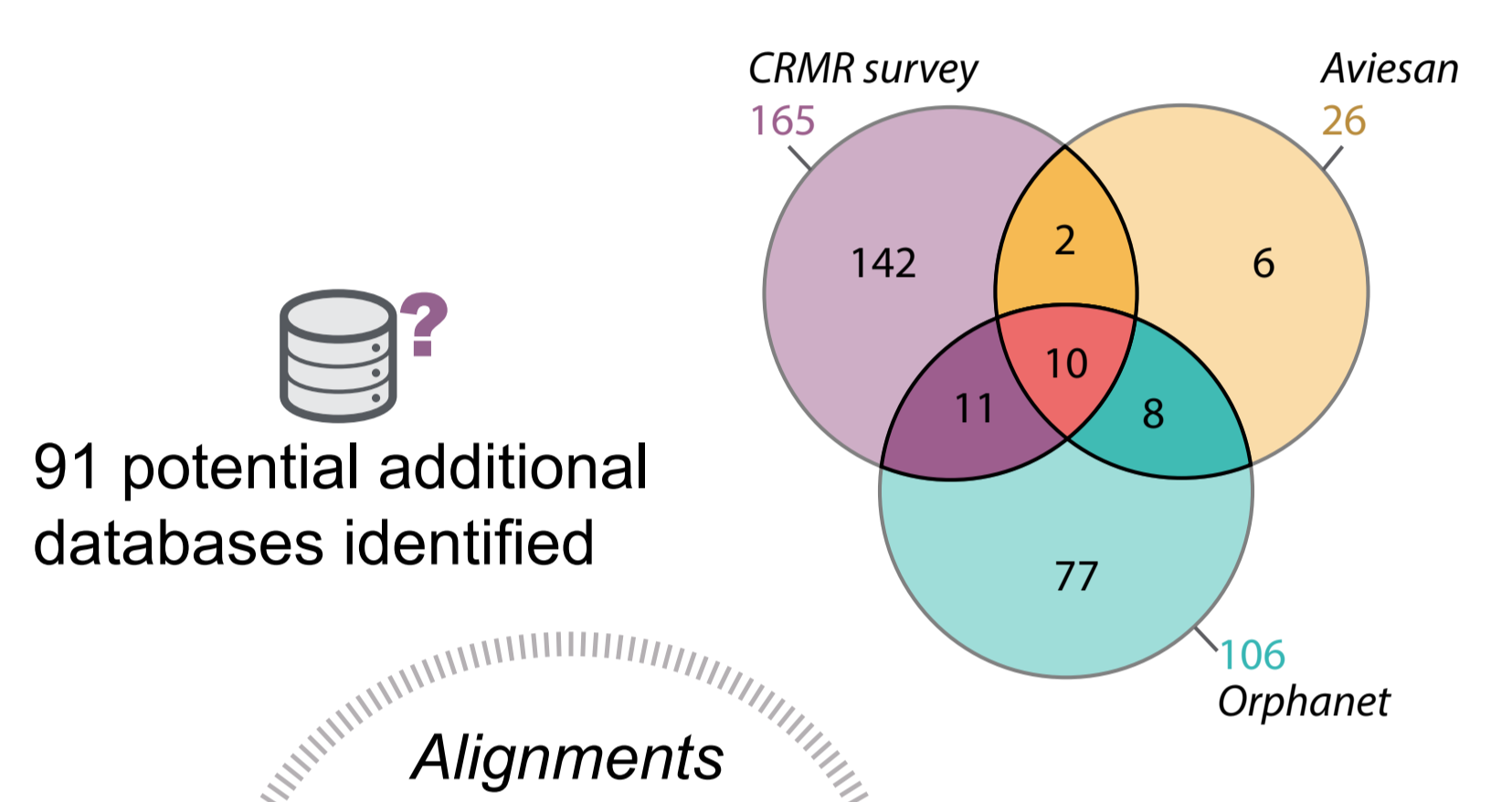
The 2 categories of French expert centres:
CRMR = reference centres (or centres of expertise)
CCMR = competences centres

234 valid answers from CRMR

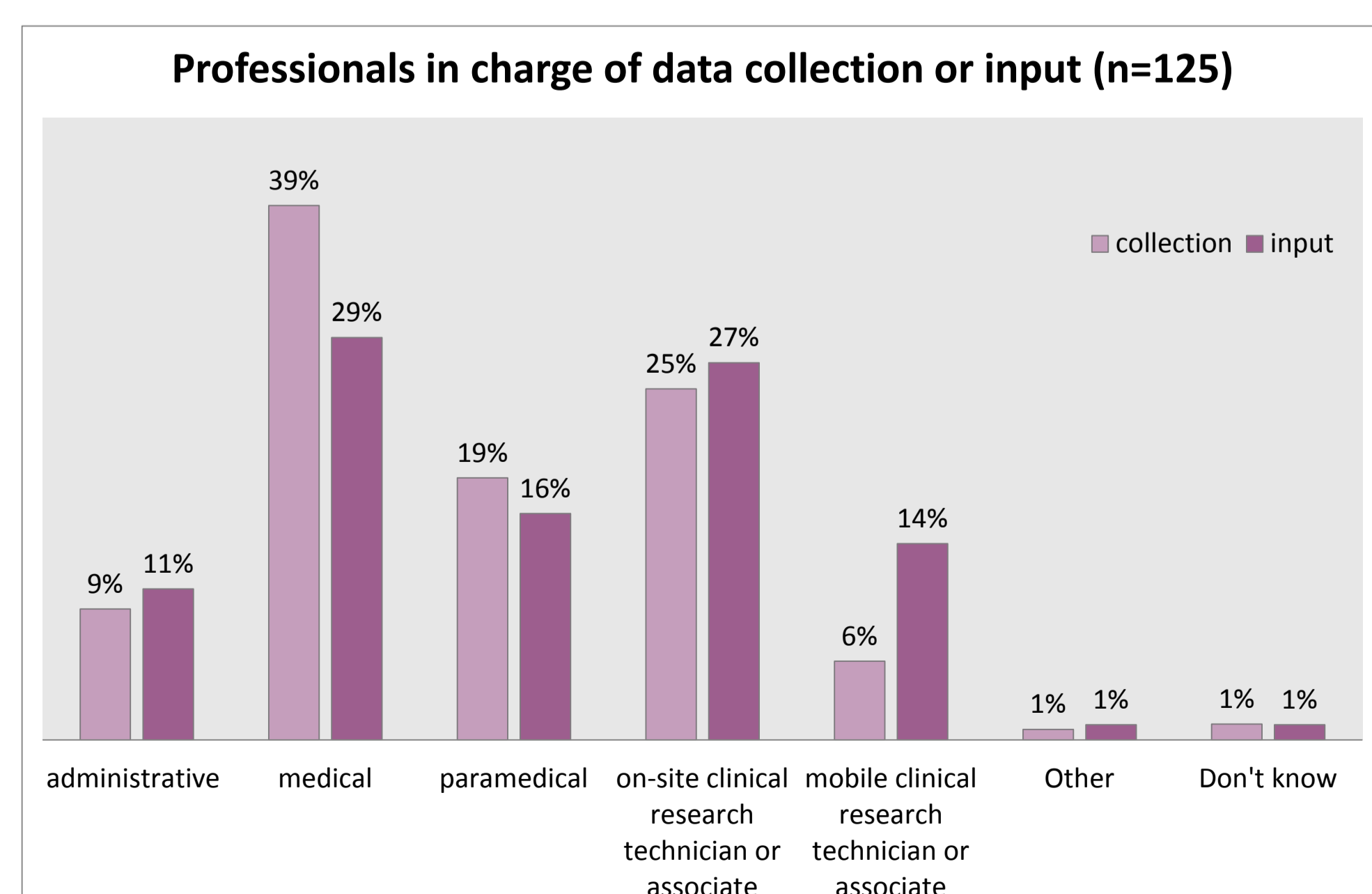
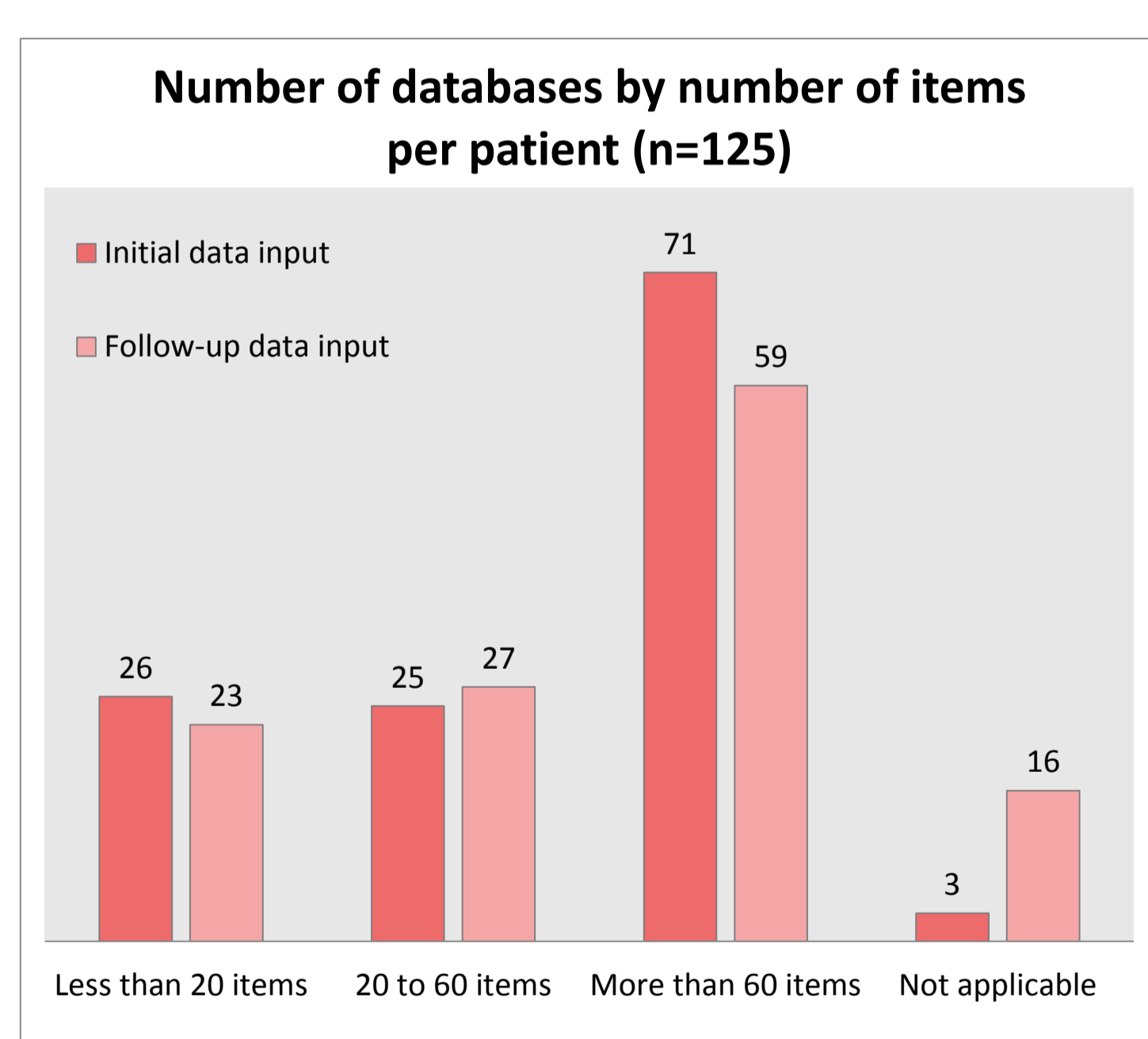
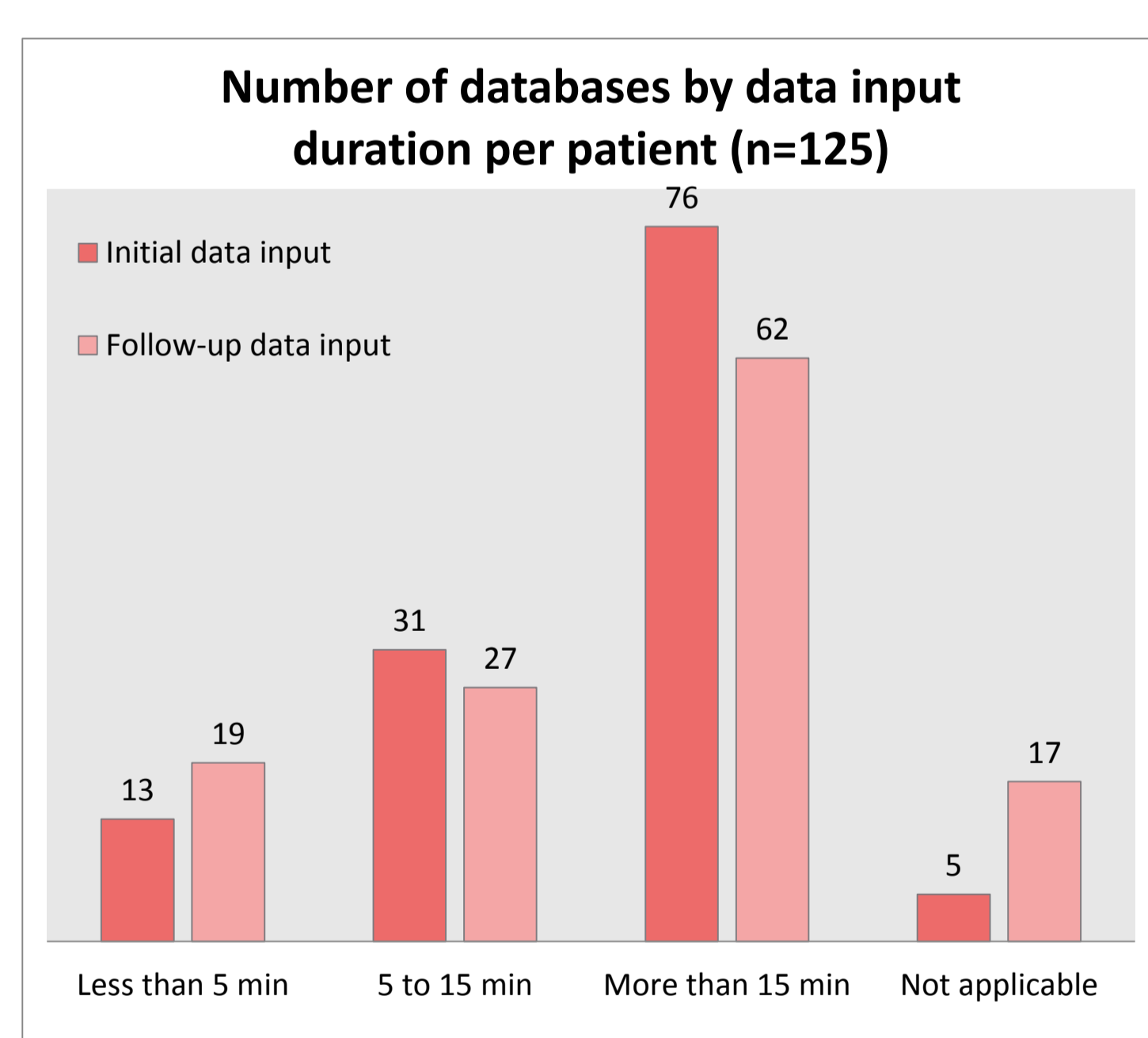
270 valid answers from CCMR

Results were aligned and completed with other censuses: Orphanet¹ and Aviesan registry portal²

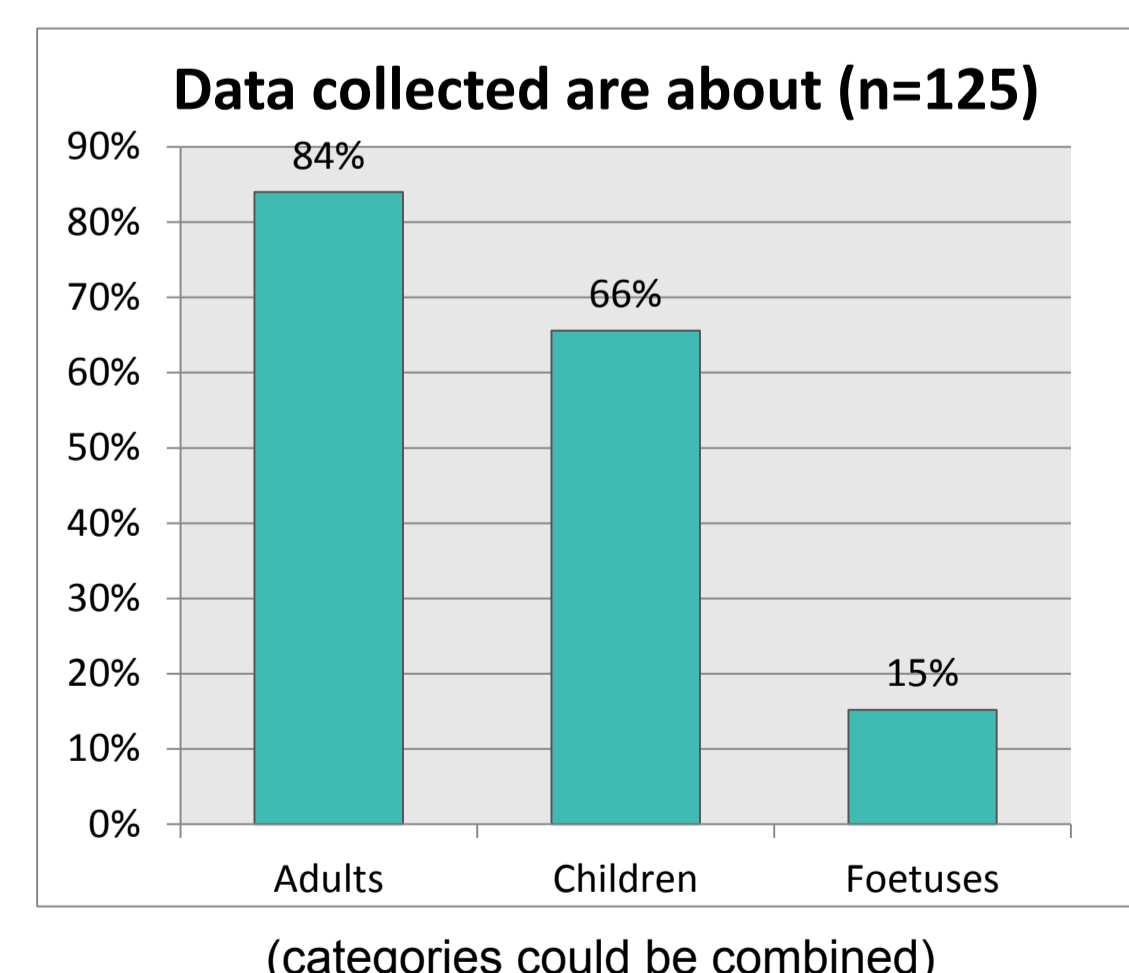
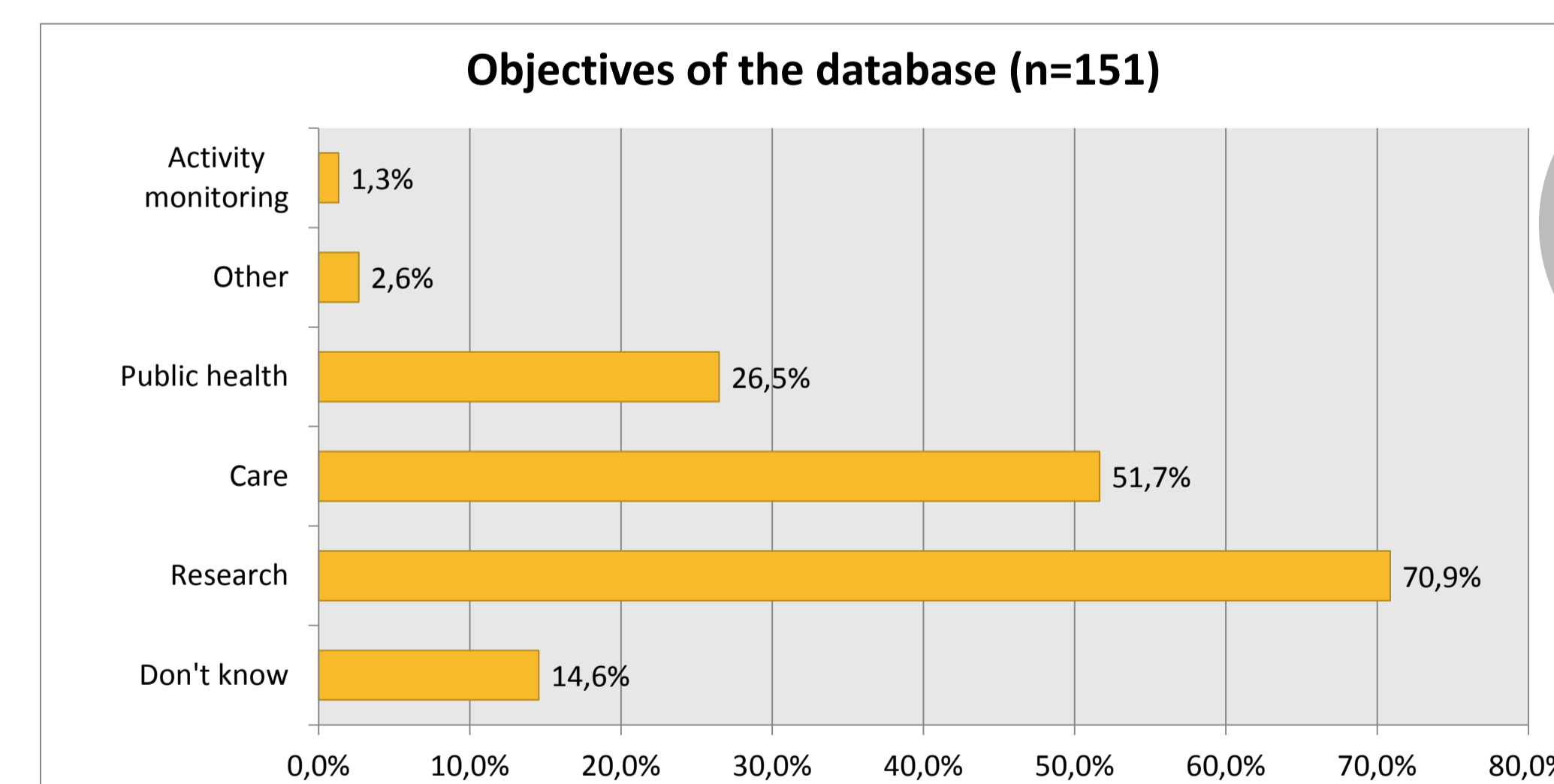
¹ <http://www.orpha.net/orphacom/cahiers/docs/GB/Registries.pdf>
² <https://epidemiologie-france.aviesan.fr/epidemiologie-france/catalogue>



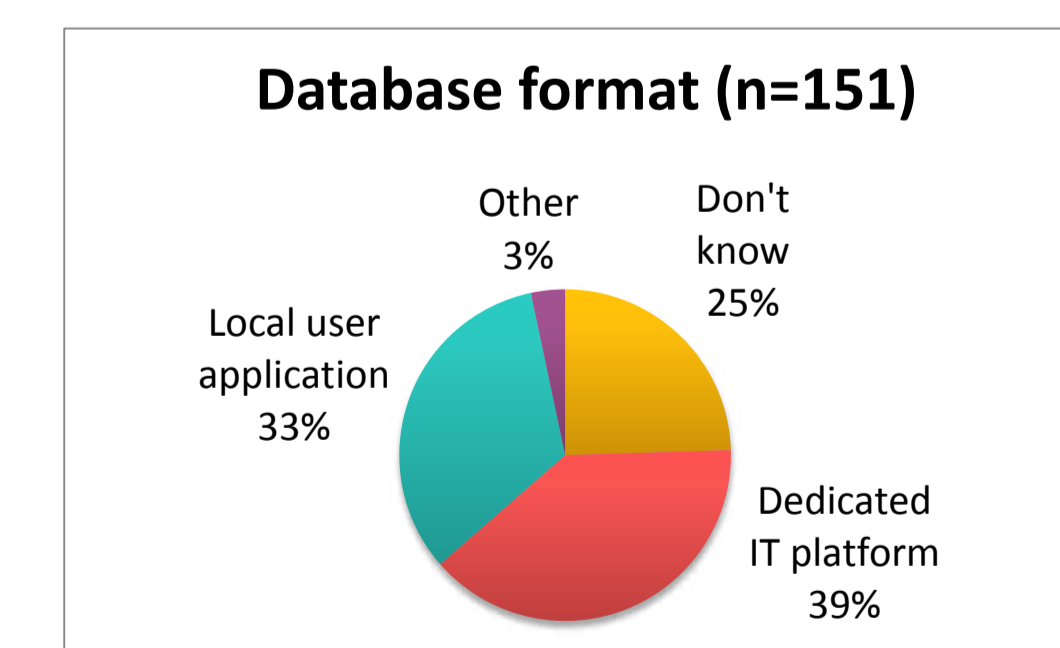
2 An important workload* Databases are usually complex (>60 items). Inputting patients data in databases is time consuming (>15 minutes per patient).



3 Characterisation of the databases* Over 70% of inventoried databases were created for research purposes, and over 50% for care purposes (objectives could be combined)



Usually 100 to 500 patients / database
50% nominative databases



The lack of interoperability of electronic patient records in hospitals with external data entry points adds to the burden by multiplying data entries.

Overall time dedicated to data entry is very difficult to estimate given the information collected, however, the rough estimation made for CRMR declared databases, only for data input, is 766 person-months.

* Analysed on CRMR answers only

Conclusion

This study should help making French RD stakeholders more aware of the current situation in hospitals even if it only presents a partial view of the situation in France. It should catalyse the establishment of national strategies to better address the needs of RD centres, by creating new specific databases or adapting existing ones. However, the large number of identified databases underlines the **importance of simplifying data collection and limiting multiple entries by favouring interoperability**. Interoperability tools, such as a national RD patient identifier (IdMR), are offered by the BNDMR but do not cover all the needs. Pooling databases and resources would be interesting between centres, care units or hospitals in order to factorise the costs of such collections. Indeed, the proliferation of databases is an obstacle to their effective implementation and use over the long term (data collection, quality control, analysis). Maintaining them is also challenging and expensive. Finally, the large number of diseases and the highly specialised field of RD requires specific tools that could be share between centres. Connecting HIS and complementary data collections could reduce the workload of the teams by limiting multiple inputs and improve the identification of patients, based on hospital centralised registration. This study must now allow the RD health networks specific working groups to define a roadmap (converge, harmonise and consolidate) in order to get prepared for future ERNs.