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Background and Introduction

In March 2016, Portuguese health authorities recognised a set of healthcare providers with highly specialised treatment and a concentration of knowledge and resources able to treat several rare diseases and conditions, where the majority are adult cancer reference centers for solid tumours (EURACAN). However, all actors have identified the need to establish a solid and valid continuous monitoring and assessment system of the European Reference Networks (ENR) to allow a closer follow up of the activities performed by the networks. In this work, we examine the role of a Portuguese National Cancer Registry (RON) in the support of this monitoring system.

Material and Methods

We analysed the capacity of continuous monitoring of Adult Rectal Cancer Reference Center (ARCRC) performance indicators for new rectal cancer cases diagnosed in the period 2016-2018, addressing 16 measures of performance (outcomes) through a descriptive statistical data analysis. We also evaluate the added value of (RON) in the completeness and timeliness effort of maintain a health care information database for the certification of the ERNs.

Evaluation variables of the Adult Rectal Cancer Reference Center:

Time between referencing and scheduling the consult
Time between diagnosis and complete staging
Percentage of cases discussed in multidisciplinary team meeting
Time between diagnosis and multidisciplinary team meeting
Time between diagnosis and treatment start
Number of cases with conservative sphincter surgery
Excision of mesorectum
Number of Resected glands
Surgical radicality
Definitive colostomies
Intra-hospital mortality
Anastomoses dehiscences
Unplanned reinterventions
Local recurrence
Post-operative complications
Survival

Results

From the 16 measures of performance, 56,25% were collected directly from the RON database (variables on green) and 18,75% could be available for collection from this database, if clinicians will improve the information provided in the surgery report and patient information system (variables on yellow). The remain 25% of performance indicators could be collected if the reference center provide a procedure of systematic clinical data collection to a local database (variables on red).

Conclusions

The national cancer registry can play an important role to establish the framework for evaluation of performance indicators of the majority of Adult Cancer Reference Centers.

The completeness and timeliness of cancer registries is crucial to the success of the continuous monitoring and improvement operational practices in the clinical pathway.

The surgery reports and patient's information system must be standardized in order to allow the collection of adequate information to achieve registry completeness and benchmarking. Nevertheless, Reference Centers need to implement standard prospective databases for monitoring clinical outcomes and clinical pathway performance indicators which are not covered by cancer registries data.

References

- Aviso nº 8402-O/2015 de 31 de Julho de 2015. *Diário da República*, nº 148/2015, 1º Suplemento, Série II. 2.ª série. Ministério da Saúde – Direção Geral da Saúde, Lisboa.
- European Continuous Monitoring Working Group (2019). Continuous Monitoring of ERNs. European Reference Networks. Brussels.

Fig1: Time between **Reference** and **1st ARCRC Observation** by year of diagnosis (days)

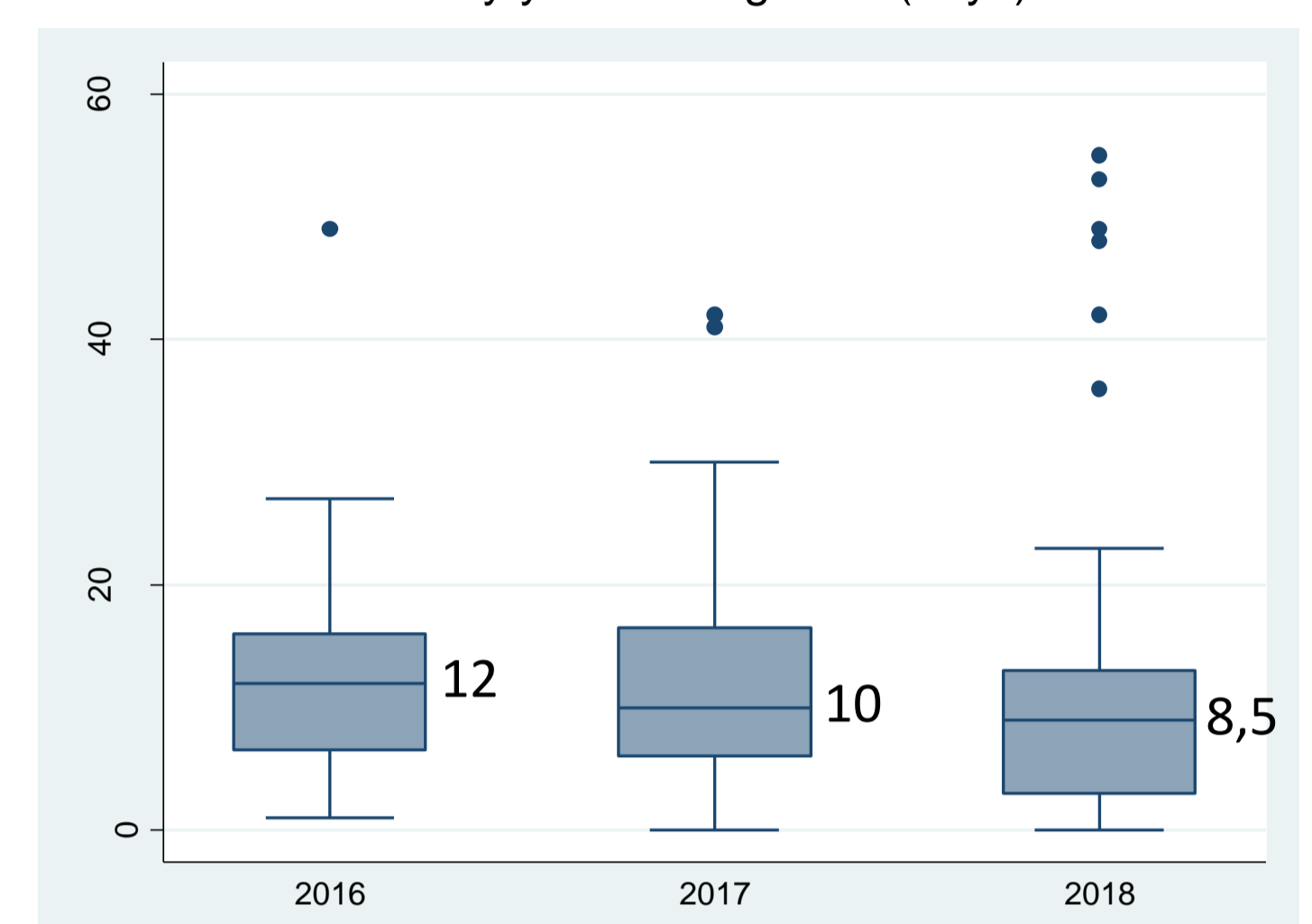


Fig. 2: Time between **Diagnosis ARCRC** and **Staging** by year of diagnosis (days)

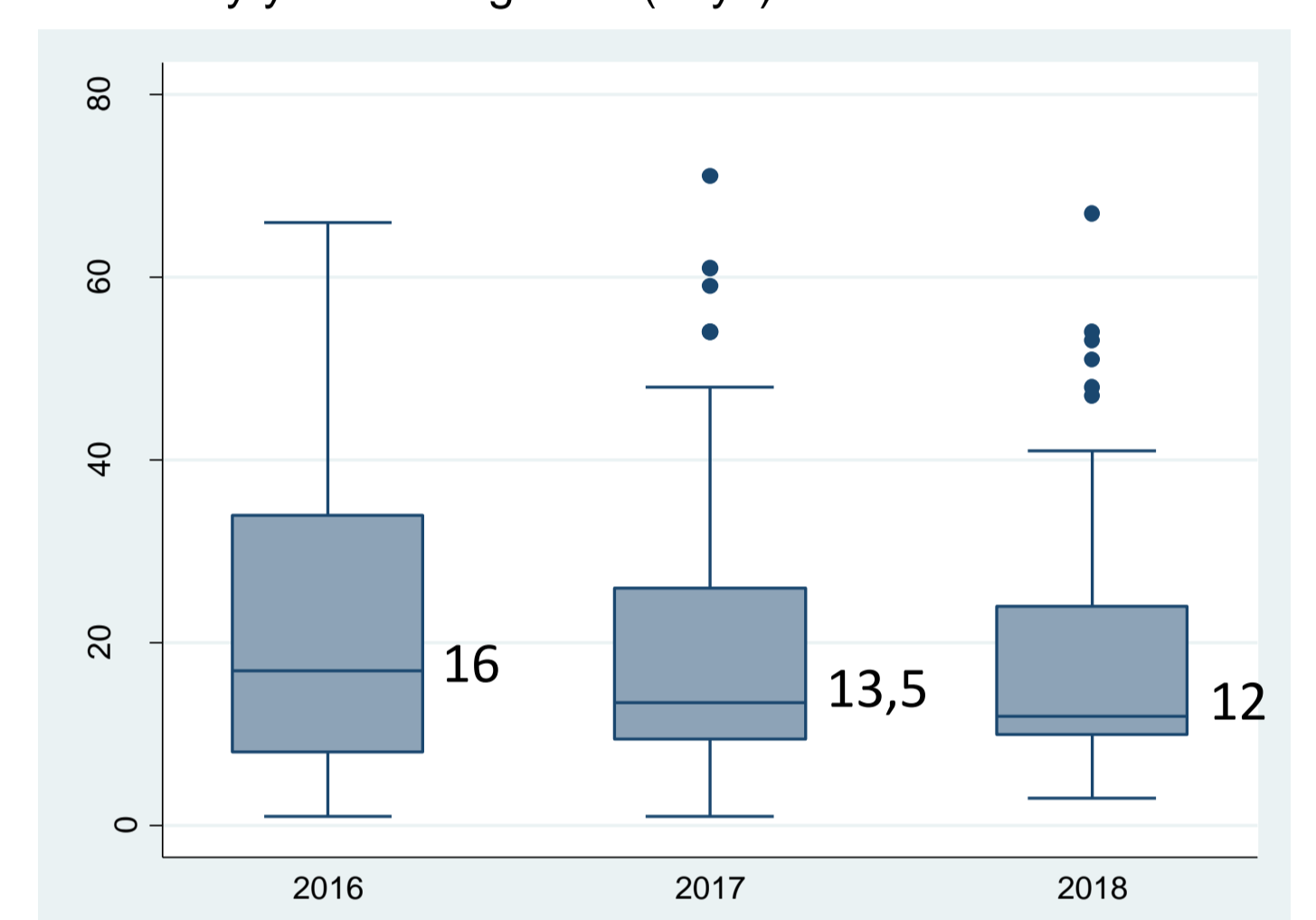


Fig. 3: **Surgical radicality** proportional distribution by year of diagnosis

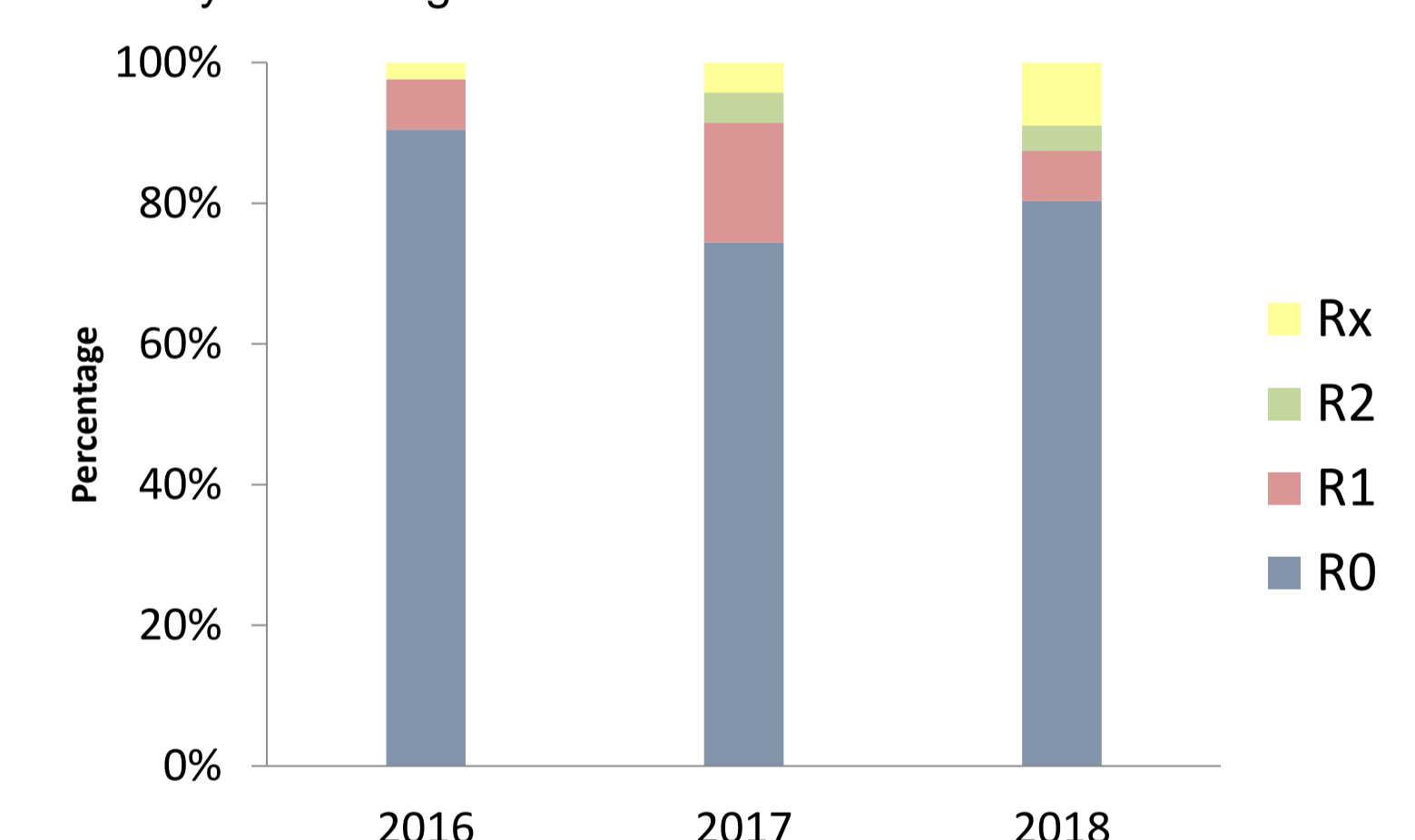


Fig. 4: **Overall survival** of the cohort 2016-2018 rectum cancer patients, by stage (months)

