The South Region Cancer Registry: an evaluation of its exhaustiveness in a cohort of lung cancer patients

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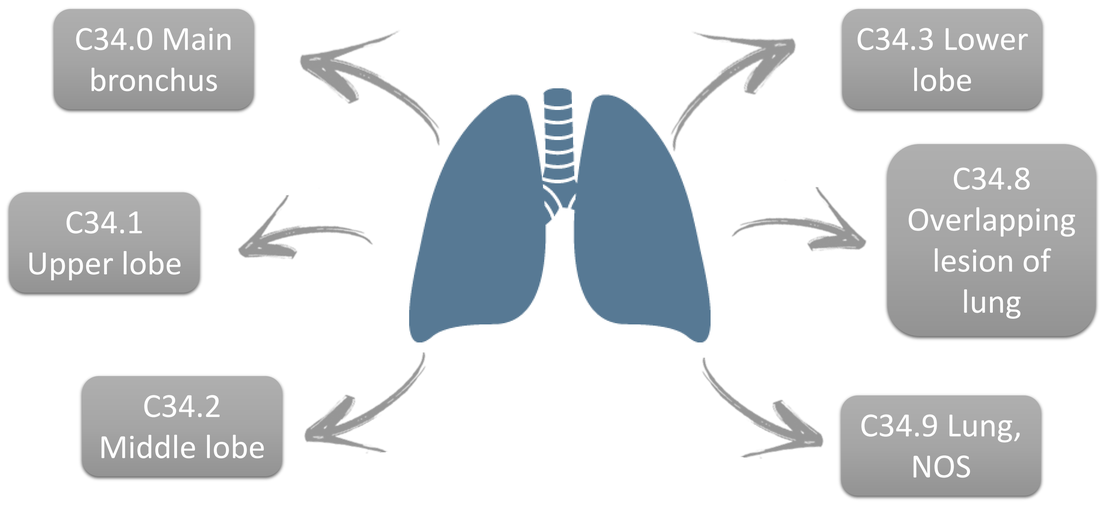
Introduction

The increasing incidence of cancer in Portugal is worrisome and may be explained by lifestyle changes, growing life expectancy, and improved early detection. The regional cancer registry for the south region exists since 1996. It was initially set up to observe and monitor the disease incidence, prevalence and survival, i.e, register all information about new cancer cases[1] . More recently, since adaptive pathways have been proposed[2], together with the creation of SiNATS [3], led to an emerging area of interest in ROR-Sul, therapeutic effectiveness monitoring. This area includes collecting high quality data to further refine the known benefit-risk ratio and to judge the therapeutic added value[4]. It is particularly important for the Portuguese health service (PHS) to evaluate the effectiveness of new high-priced medicines [5]. This study aimed to evaluate the exhaustiveness of the Registo Oncológico Regional Sul.

Materials and Methods

To assess the exhaustiveness of cancer registry in a cohort of lung cancer patients diagnosed during the year 2014 (01/01/2014 to 01/01/2015) .



High exhaustiveness	defined as missing< 1%
Medium exhaustiveness	defined as missing 1-15%
Low exhaustiveness	defined as missing>15%

Statistical Analysis: Data was analyzed using IBM SPSS software, v.24,0, comprising descriptive analysis of missing data. No ethics submission was deemed necessary.

Results

3457 patients

915 female (26,5%)

2540 male (73,5%)

Table 1. Variables considered to have a high exhaustiveness

Variable	Missing values (%)
Gender	0
Date of diagnosis	0
Date of first medical appointement	0
District	0
Stage of Disease at first diagnosis	0*
Cancer morphology	0
Cancer topography	0
Cancer differentiation	0*
Vital state	0
Date of last contact	0
Radiotherapy (type)	0

*Although no missing values exists, there are a high percentage of "Unkown" (Stage of Disease at first diagnosis -8,2% ; Cancer differentiation – 63,8%)

Table 2. Variables considered to have a medium exhaustiveness

Variable	Missing values (%)
ALK mutation	12,8
KRAS mutation	7,5
EGFR mutation	2,5
Treatment received (Immunotherapy)	7,8
Surgery (Procedure)	4,5

Table 3. Variables considered to have a low exhaustiveness

Variable	Missing values (%)
Performance Status	66,3
Treatment received (Chemotherapy)	36
Chemotherapy treatment response	44,9

Discussion and Conclusions

Cancer registry is organized to foresee compulsory variables and optional ones. As expected, the exhaustiveness of compulsory variables was near 100%. So far, treatment and mutation variables are not compulsory. However, if the cancer registry is intended to support effectiveness studies in the future, this option should be carefully considered. The low level of detail in clinical files should also be considered, in regards to treatment, where perhaps an educational investment must be made.

References

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