“Measuring Effectiveness"

SNS SERVIÇO NACIONAL DE SAÚDE

RON Registo Oncológico Nacional

Ana Miranda

INFARMED, 29th November 2018

SNS SERVIÇO NACIONAL DE SAÚDE

RON Registo Oncológico Nacional

Overview of the presentation

1. Theoretical Component:

- What is the National Oncology Registry (RON)?
- What is the information collected?
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- Methodologies used?
- Comparators
- Indicators and Outcomes to be measured
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- Importance of the RON for measuring effectiveness.

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Types of registries

Hospital-based registries

- **Quick and easy access to clinical data.** Data used primarily for **administrative purposes and for monitoring performance indicators. Limitations for epidemiological purposes;**

- **Advantages:** Greater exhaustiveness, homogeneity, completeness and more frequent updates;
- Useful for foreseeing human and material resources.

Population-based registries

- **Enables statistics on the cancer cases** (incidence, prevalence, survival). Data primarily used for **epidemiological and public health purposes;**

- **Advantages:** Knowledge of the population covered;
- Useful for supporting health policy decisions.

Silva IS. *Cancer Epidemiology: Principles and Methods*. International Agency for Research on Cancer, World Health Organization. 1999. pp. 385-403.

Background

Population-based registries in Portugal

Main Goals

1. To describe the **nature and extension of** oncologic disease and to support the definition of **priorities in public health;**
2. To act as information source for various **observational studies;**
3. **To monitor and evaluate the efficacy of activities related to the control of oncologic diseases**

1) Limbert, E. A História da Registo de Cancro em Portugal: um contributo pessoal. Registo Oncológico Regional Sul, IPOLFG-EPE; Lisboa, 2008.
2) Portaria nº 35/88, de 18 de Janeiro.
3) Lei nº 53/2017, de 14 de Julho. Diário da República 135/2017. Série I.

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Innovations in the current law: practical functioning

Artigo 3.º

Registo Oncológico Nacional

1 — É obrigatório o registo na plataforma eletrónica d RON de todos os novos casos de diagnóstico de cancr por parte de todos os estabelecimentos e serviços de saúd do setor público, social e privado, independentemente d sua natureza jurídica, localizados no Continente ou na regiões autónomas, no prazo máximo de nove meses contar da data do conhecimento do diagnóstico, e a po terior atualização, no mínimo anual, do estádio da doen oncológica, das terapêuticas oncológicas usadas e do esta vital do doente.

2 — Os dados existentes nos Registos Oncológic Regionais (ROR) são integrados no RON.

3 — Os dados do denominado registo oncológico p diátrico português são integrados no RON.

4 — Os dados dos registos das regiões autónomas s integrados no RON, sem prejuízo das competências pr prias daquelas regiões na matéria.

Artigo 17.º

Financiamento e incentivos

1 — No âmbito do processo de contratualização dos cuidados de saúde que se encontra implementado no Serviço Nacional de Saúde (SNS) e nos serviços regionais de saúde, são introduzidos mecanismos de incentivo e penalização associados a uma adequada prática de registo oncológico nos termos do disposto na presente lei.

2 — Para efeitos do número anterior, no âmbito dos contratos-programa a celebrar pela Administração Central do Sistema de Saúde, I. P. (ACSS, I. P.), com os hospitais, os centros hospitalares e as unidades locais de saúde integradas no SNS e, nas regiões autónomas, entre os serviços regionais de saúde e as entidades públicas prestadoras de cuidados de saúde, as modalidades de pagamento às instituições contemplam o registo do RON na atividade realizada.

3 — Os custos relacionados com a administração do RON, em matéria de prestação de serviços relativos a sistemas de informação e comunicação, são suportados pela ACSS, I. P., no âmbito do contrato-programa anual celebrado entre este instituto público e a SPMS — Serviços Partilhados do Ministério da Saúde, E. P. E.

Artigo 22.º

Disposições finais e transitórias

1 — Os estabelecimentos e serviços do SNS e dos serviços regionais de saúde devem regularizar o registo oncológico, no prazo máximo de nove meses, de todos os doentes diagnosticados até à entrada em vigor da presente lei.

2 — Os estabelecimentos e serviços dos setores social e privado que desenvolvam atividade no diagnóstico e tratamento de doenças oncológicas ficam obrigados aos mesmos deveres de regularização dos seus registos oncológicos e respetiva integração de dados no RON.

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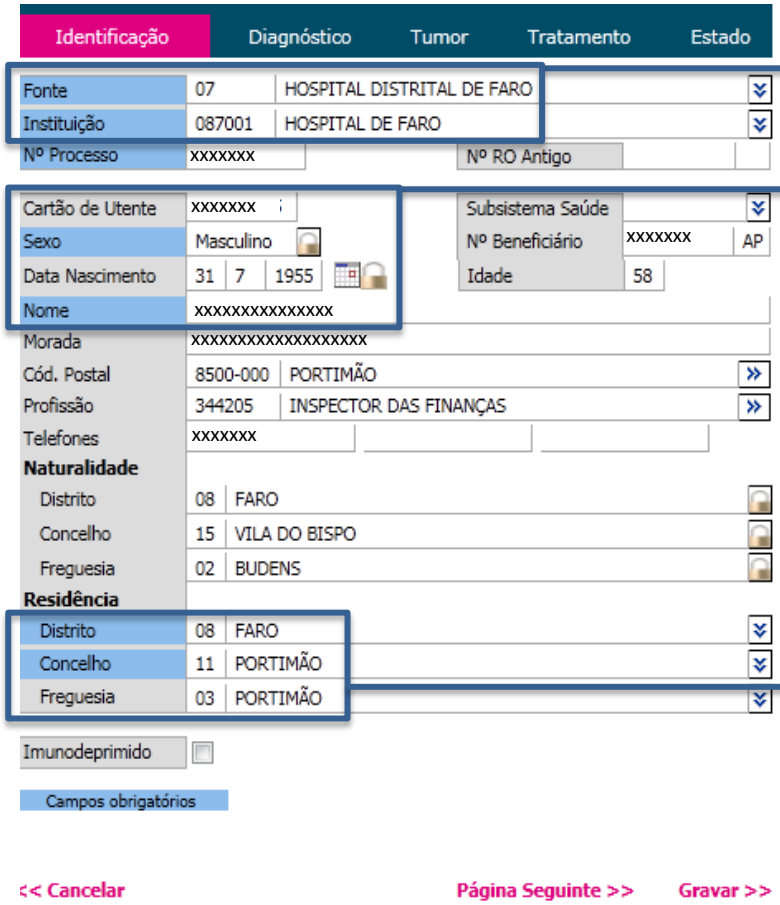
Information sources linked to RON

How is our database organized?



Institution registering the case

Identification of the citizen

Identification of the district of residence at diagnosis

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How is our database organized?

Identificação | **Diagnóstico** | Tumor | Tratamento | Estado

Data Início Sintomas			
Data 1ª Observação	25	3	2014
Data 1ª Consulta	2	4	2014
Data C.D.T.			
Data Pat. Morf.	8	4	2014
Data Outros Exames	3	4	2014
Distrito	08	FARO	
Concelho	11	PORTIMÃO	
Freguesia	03	PORTIMÃO	
Diagnóstico na instituição:	☑ Sim	☐ Não	

Revisão de Lâminas

→ Date when symptoms started

→ Date of first appointment at the institution

→ Date of therapeutic decision

→ Date of anatomical-pathological evaluation

Tipo Exame	Data	Instituição	Tipo Registo	Editar	Remover
Hemoglobina (g/dl)	3-4-2014	HOSPITAL DE FARO	Processo		
Proteina C Reactiva _ PCR	3-4-2014	HOSPITAL DE FARO	Processo		
Albumina (g/dl)	3-4-2014	HOSPITAL DE FARO	Processo		
Creatinina	3-4-2014	HOSPITAL DE FARO	Processo		
T. Bioquímica/T. Imunologia	3-4-2014	HOSPITAL DE FARO	Processo		
Cálcio (Normal/Elevada)	3-4-2014	HOSPITAL DE FARO	Processo		
ß2 Microglobulina (Normal/Elevada)	3-4-2014	HOSPITAL DE FARO	Processo		
TAC	7-4-2014	HOSPITAL DE FARO	Processo		
Histologia Primário (Nº)	8-4-2014	HOSPITAL DE FARO	Processo		

→ Analytic parameters at diagnosis

→ Imagiological and anatomo-pathological evaluation

How is our database organized?

Identificação | Diagnóstico | **Tumor** | Tratamento | Estado

Topografia	C42.1	MEDULA OSSEA
Morfologia	M9732/3	MIELOMA MULTIPLO (C42.1)
Durie And Salmon		
ISS	II	ß2M<3,5mg/L, Albumina<3,5g/dL OU ß2M>=3,5mg/L<
Outra Classificacao	R-ISS - II	

Performance Status (OMS): 5 Desconhecido (Karnofsky desconhecido)

Tipo Genética/Biologia	Resposta	Resultado	Editar
KRAS	Não Avaliado	-	
Mutações do gene p53	Desconhecido	-	
t(11;14)	Desconhecido	-	
Hiperdiploidia(tetraploidia)	Desconhecido	-	
Hipodiploidia	Desconhecido	-	
Del(17p)	Desconhecido	-	
t(14;16)	Desconhecido	-	
t(4;14)	Desconhecido	-	
Trissomia 5	Desconhecido	-	
Trissomia 9	Desconhecido	-	
Trissomia 15	Desconhecido	-	

Site/location of the neoplasm

Specific histologic description of the neoplasm

Parameters for staging and prognosis

C___ ___.___

site *subsite*

Example C50.2

Breast, upper inner quadrant

___ ___ ___ ___ / ___ ___

histology *behavior grade*

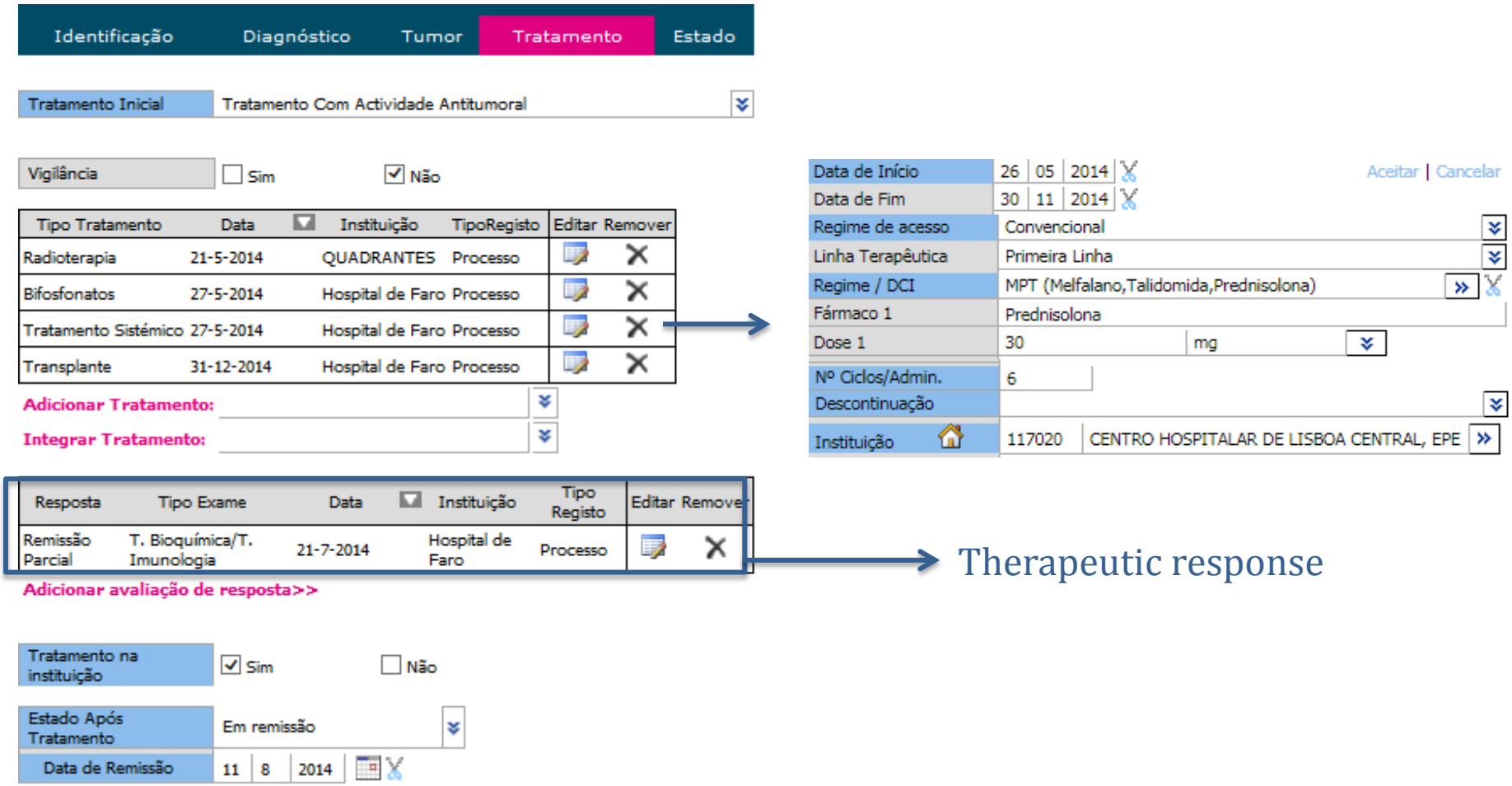
Example: well-differentiated adenocarcinoma

M-8140 / 3 1

Tumor/cell type [adeno-] | Behavior [carcinoma] | Differentiation [well-differentiated]

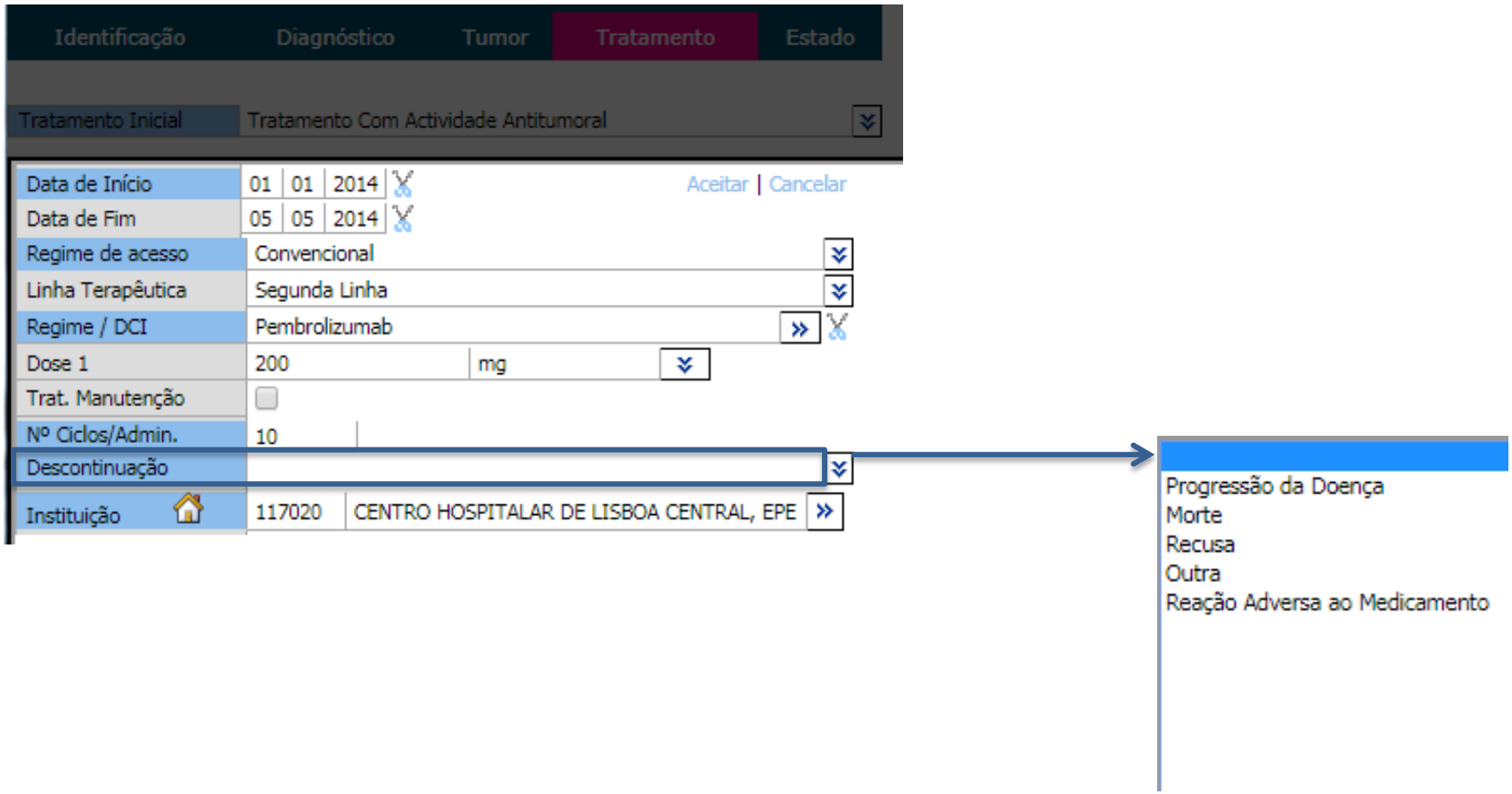
International Codification of Diseases for Oncology (ICD-O) 3rd edition 1st revision

How is our database organized?



Therapeutic response

How is our database organized?



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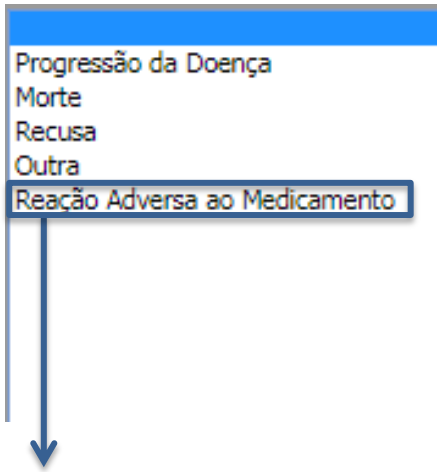

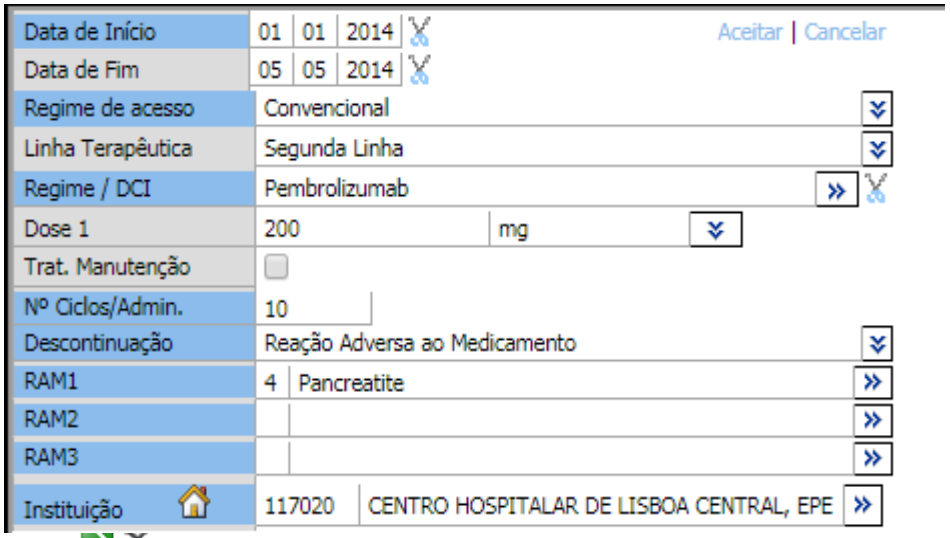

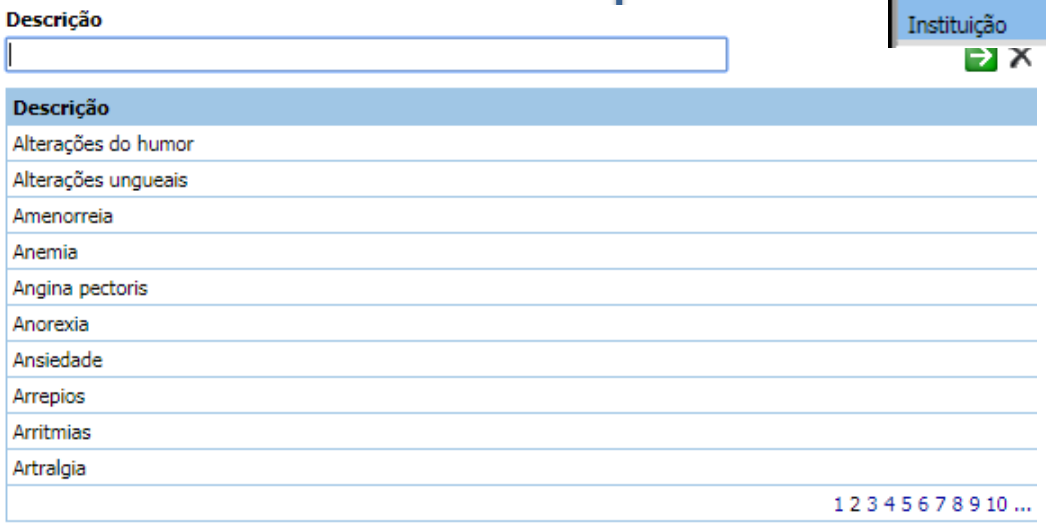

Low Level Terms, The Medical Dictionary for Regulatory Activities (MedDRA);
National Cancer Institute Common Terminology Criteria for Adverse Events (CTCAE)

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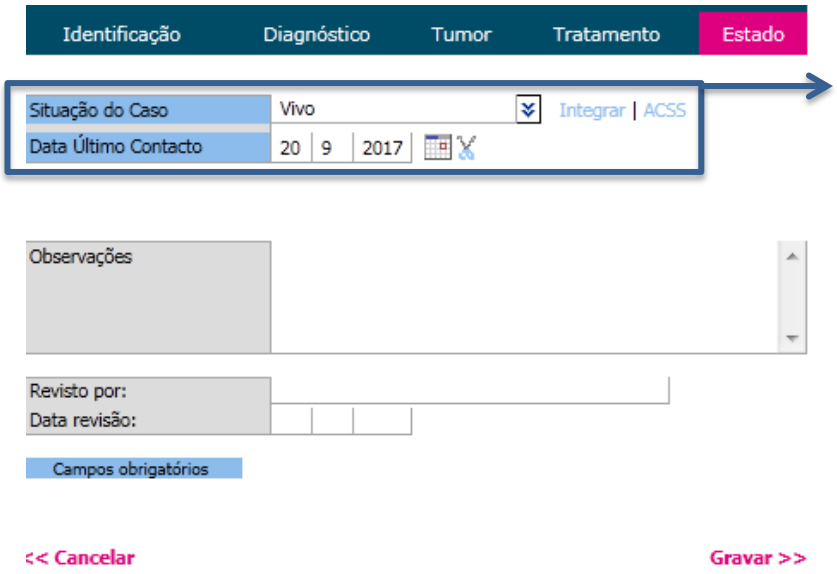

Epidemiological and pharmacoepidemiological studies

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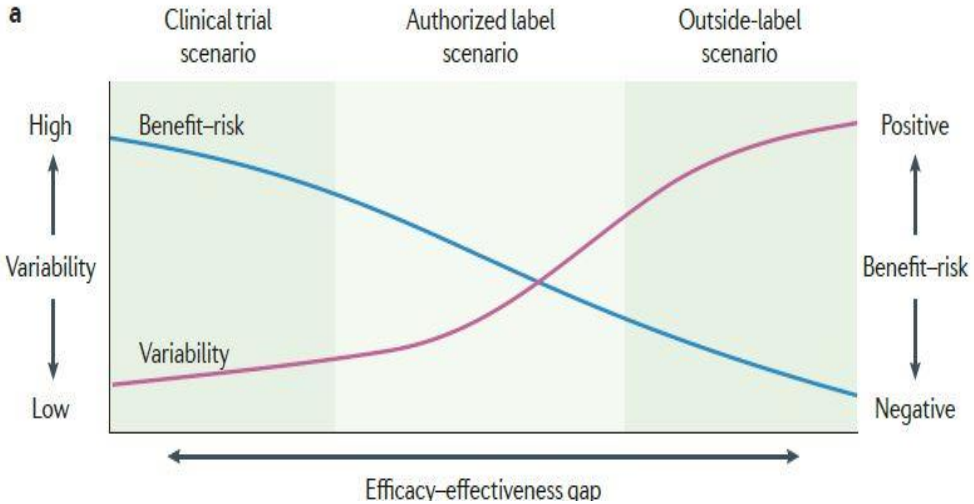
The efficacy-effectiveness gap



Randomized controlled trials	Real-world evidence studies
Experimental/ interventional trial	Observational/ non-interventional trial
Protocol-driven, compliance with Good Clinical Practice (GCP) mandatory	Usually care-driven, results derived from clinical practice
Efficacy and safety primary outcomes	Primary outcomes are long-term efficacy and safety, effectiveness and economic assessments
Narrow and restricted patient population with extensive inclusion and exclusion criteria	Wide and unrestricted patient population with few exclusions including co-morbidities
Gold standard or placebo comparators used	No comparators used or compared to standard clinical practice
Patients are randomized and blinded to treatment	No randomization or blinding
$$$$ $$$$ $$$$ High cost per patient	$$$$ $$$$ $$$$ Low cost per patient (due to large number of patients)
Internal validity	Relevant to clinical practice
Valuable to regulators	Valuable to payers
Key advantages are the randomized and controlled design and the use of gold-standard comparisons	Key advantages are the broad patient population producing more generalizable data and collection of a wide variety of real-world outcomes
Key limitations are the restricted patient population resulting in limited generalizability of the data, high cost and short timeframe	Key limitations are the non-randomized design leading to bias

Eichler *et al.* Bridging the efficacy–effectiveness gap: a regulator's perspective on addressing variability of drug response. Nature Reviews. 2011; 10:495-506

Ziemssen, T., Hillert, J., Butzkueven, H. The importance of collecting structured clinical information on multiple sclerosis. BMC Med 2016; 14:81

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Innovations in the current law: functions

Artigo 4.º

Recolha de dados

1 — Os dados recolhidos para tratamento no RON são os seguintes:

a) A identificação do nome, do sexo, da data de nascimento, da morada, do número de utente, da identificação da instituição, do número de processo clínico, da profissão e da naturalidade do doente;

b) A data e os resultados dos exames efetuados, para diagnóstico e estadiamento, que sejam relevantes para a história clínica;

c) A identificação do código da Classificação Internacional da Doença (CID), na versão em vigor à data do re no RON, correspondente à neoplasia diagnosticada;

e) A caracterização da neoplasia, não limitada à localização primária, morfologia, estadiamento, recetores, marcadores moleculares e marcadores tumorais, os dados relativos ao diagnóstico e ao estudo genético da neoplasia, quando aplicável;

f) A data do diagnóstico e do início do tratamento, bem como das várias modalidades de tratamento, como cirurgia, radioterapia e quimioterapia;

g) A caracterização de cada linha de tratamento;

h) O registo anual do estado geral do doente, o estado da neoplasia e as suas modificações, incluindo as dependentes dos tratamentos, e a melhor resposta obtida da neoplasia no fim de cada linha de tratamento;

i) A data de óbito e a causa de morte.

Artigo 5.º

Monitorização da efetividade terapêutica

1 — Para os efeitos previstos no n.º 2 do artigo 4.º do Decreto-Lei n.º 97/2015, de 1 de junho, no que se refere à recolha de dados necessários à monitorização de efetividade da utilização de medicamentos e dispositivos médicos, podem ser ainda recolhidos dados para quantificação dos diferentes parâmetros de avaliação de resultados da utilização na prática clínica não experimental.

2 — Os registos de dados de monitorização da efetividade terapêutica devem ser efetuados no prazo indicado pelo INFARMED, I. P., para cada tipo de situação.

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Methods for measuring therapeutic effectiveness

ARTICLE IN PRESS

Original Study

Option 1

Comparative Effe
Kinase Inhibitors Ve
Treatment of Chr
Leukemia Across Ris
and Meta-Analysis

Seongseok Yun,[1,2] Nicole D.
Yang Shen,[5] Do

Abstract

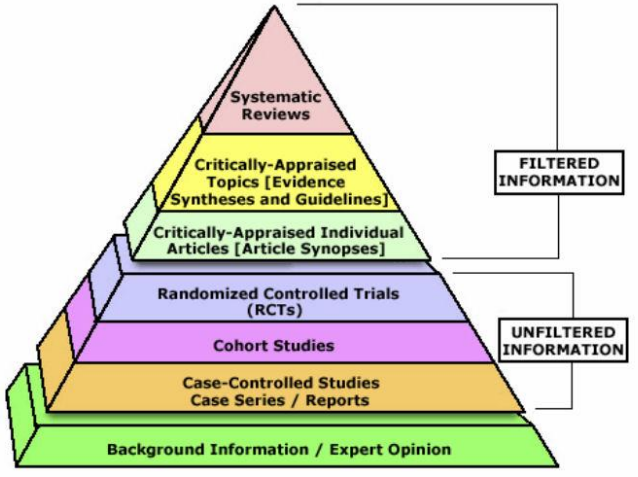
The goal of the present study was to compare the outcomes of new generation tyrosine kinase inhibitors (NG-TKIs) versus imatinib in patients with newly diagnosed chronic phase chronic myeloid leukemia and to assess the effect of the risk scores on the treatment response. NG-TKIs resulted in a greater major molecular response, and the degree of benefit from NG-TKIs on the complete cytogenetic response and major molecular response was equivalent across the risk groups.

Background: BCR-ABL1 tyrosine kinase inhibitors (TKIs) have significantly improved the survival outcomes for patients with chronic myeloid leukemia (CML). In addition to imatinib, 3 newer generation TKIs (NG-TKIs) have been approved as first-line treatment of chronic phase (CP)-CML. These have been preferably used in patients with CP-CML with a high Sokal or Hasford risk score. We performed a systematic review and meta-analysis to compare the outcomes with NG-TKIs as a category versus imatinib in patients with newly diagnosed CP-CML and to indirectly compare the efficacy of NG-TKIs among each other. Furthermore, we assessed the effect of the risk scores on the complete cytogenetic response (CCyR) and major molecular response (MMR). **Materials and Methods:** The eligible studies were limited to randomized controlled trials comparing the efficacy of first-line treatment using NG-TKIs versus imatinib in adult patients (aged $\geq$ 18 years) with CP-CML. **Results:** The differences in the CCyR, progression-free survival, and overall survival between the NG-TKIs and imatinib were not statistically significant. NG-TKI-treated patients showed a significantly greater likelihood of MMR (relative risk [RR], 0.76; 95% confidence interval, 0.63-0.91; $P = .003$) and lower likelihood of progression to an accelerated phase/blast crisis (RR, 0.37; 95% confidence interval, 0.20-0.67; $P = .001$) than did imatinib-treated patients. Nilotinib, dasatinib, and radotinib showed significantly greater CCyR rates compared with bosutinib and ponatinib. All risk groups showed statistically equivalent benefits from NG-TKIs for the CCyR and MMR. **Conclusion:** In first-line treatment, the NG-TKIs as a category showed greater effectiveness in MMR and prevention of accelerated phase/blast crisis progression. Risk stratification was not found to affect the RR of CCyR and MMR.

Methods for measuring therapeutic effectiveness

Efficacy is the extent to which an intervention does more good than harm under ideal circumstances.

Effectiveness assesses whether an intervention does more good than harm when provided under usual circumstances of healthcare practice.



Haynes B. Can it work? Does it work? Is it worth it? The testing of healthcare interventions is evolving. BMJ. 1999;319:652–653.

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Methods for measuring therapeutic effectiveness

PLOS ONE

RESEARCH ARTICLE

Comparative Effectiveness of
Targeted Therapies for Metast
Cell Carcinoma: A Systematic
Meta-Analysis of Real-World O
Studies

Daniel Y. Heng[1], James Signorovitch[2], Elyse Swallow[2], Ni
Zhong[2], Paige Qin[2], Daisy Y. Zhuo[2], Xufang Wang[3], Jinhe
Stergiopoulos[3], Christian Kollmannsberger[4]*

OPEN ACCESS

Citation: Heng DY, Signorovitch J, Swallow E, Li N, Zhong Y, et al. (2014) Comparative Effectiveness of Second-Line Targeted Therapies for Metastatic Renal Cell Carcinoma: A Systematic Review and Meta-Analysis of Real-World Observational Studies. PLoS ONE 9(12): e114264. doi:10.1371/journal.pone.0114264

Editor: Eng-Huat Tan, National Cancer Centre,

Abstract

Objective: The optimal sequencing of targeted therapies for metastatic renal cell carcinoma (mRCC) is unknown. Observational studies with a variety of designs have reported differing results. The objective of this study is to systematically summarize and interpret the published real-world evidence comparing sequential treatment for mRCC.

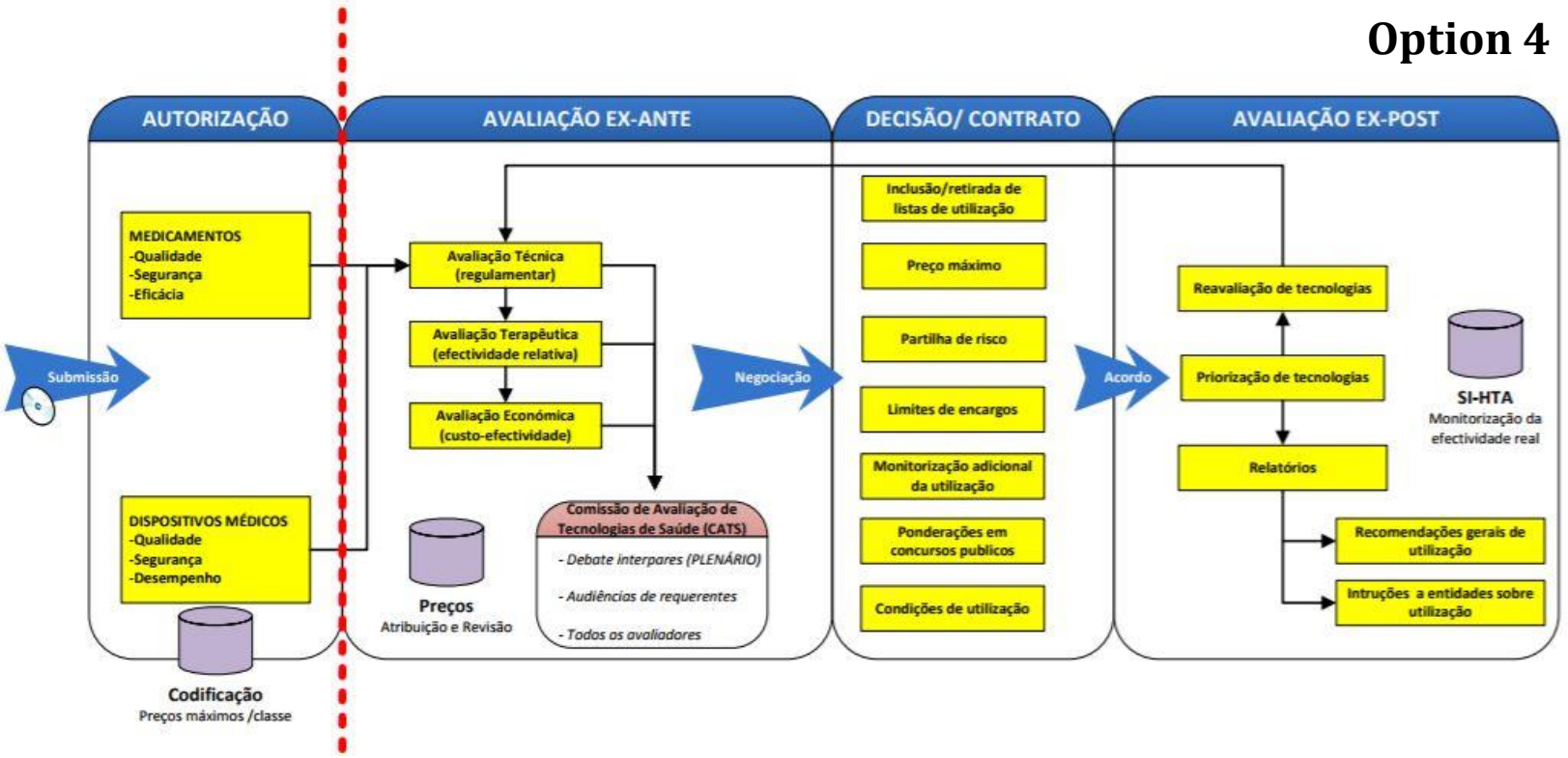
Methods: A search was conducted in Medline and Embase (2009–2013), and conference proceedings from American Society of Clinical Oncology (ASCO), ASCO Genitourinary Cancers Symposium (ASCO-GU), and European Society for Medical Oncology (ESMO) (2011–2013). We systematically reviewed observational studies comparing second-line mRCC treatment with mammalian target of rapamycin inhibitors (mTORi) versus vascular endothelial growth factor (VEGF) tyrosine kinase inhibitors (TKI). Studies were evaluated for 1) use of a retrospective cohort design after initiation of second-line therapy, 2) adjustment for patient characteristics, and 3) use of data from multiple centers. Meta-analyses were conducted for comparisons of overall survival (OS) and progression-free survival (PFS).

Results: Ten studies reported OS and exhibited significant heterogeneity in estimated second-line treatment effects (I^2=68%; P=0.001). Four of these were adjusted, multicenter, retrospective cohort studies, and these showed no evidence

Option 2

Methods for measuring therapeutic effectiveness

Option 4



Ex post evaluations are used throughout the European Commission to assess whether a specific intervention was justified and whether it worked (or is working) as expected in achieving its objectives and why.

INFARMED, SINATS

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Outcomes

Outcome	Abr.	Definition	Variables needed
Global survival	OS	Time from diagnosis until death from any cause	Date of diagnosis Date of death Date of last known contact
Overall survival	OS	Time from treatment initiation until death from any cause	Date of treatment initiation Date of death Date of last known contact
Progression-free survival	PFS	Time from treatment initiation until disease progression or death	Date of treatment initiation Date of disease progression Date of death Date of last known contact
Objective Response Rate	ORR	Proportion of patients with reduction in tumor burden of a predefined amount	Therapeutic response

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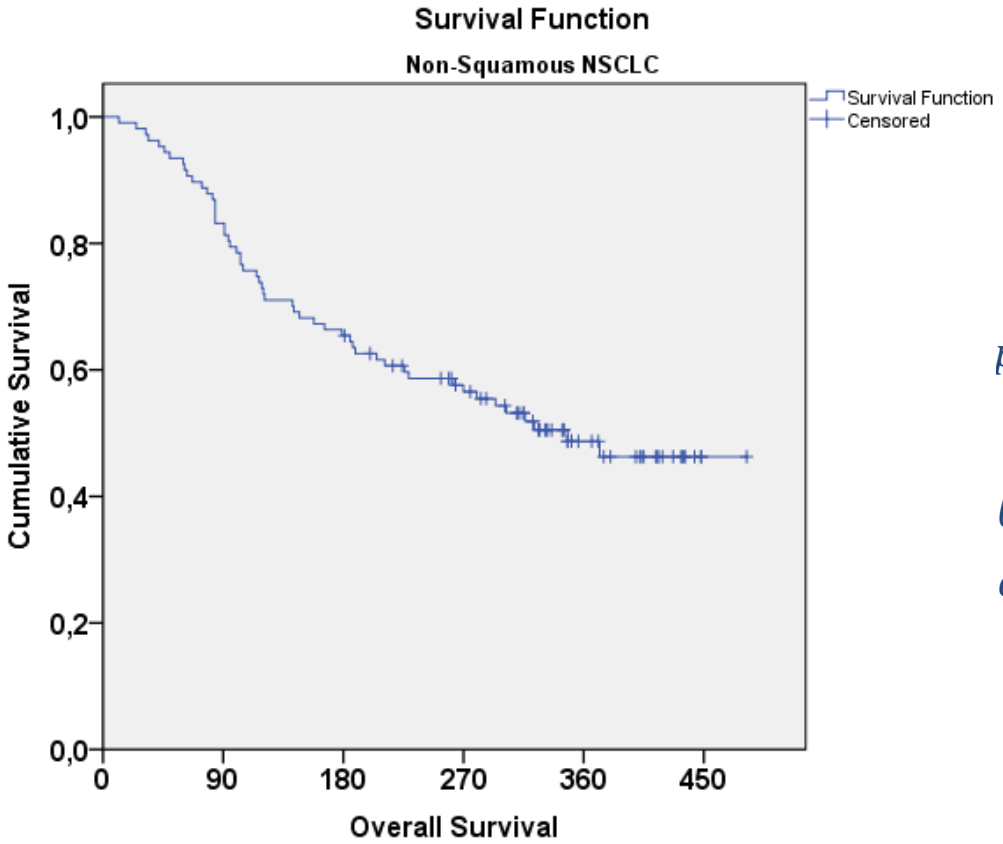
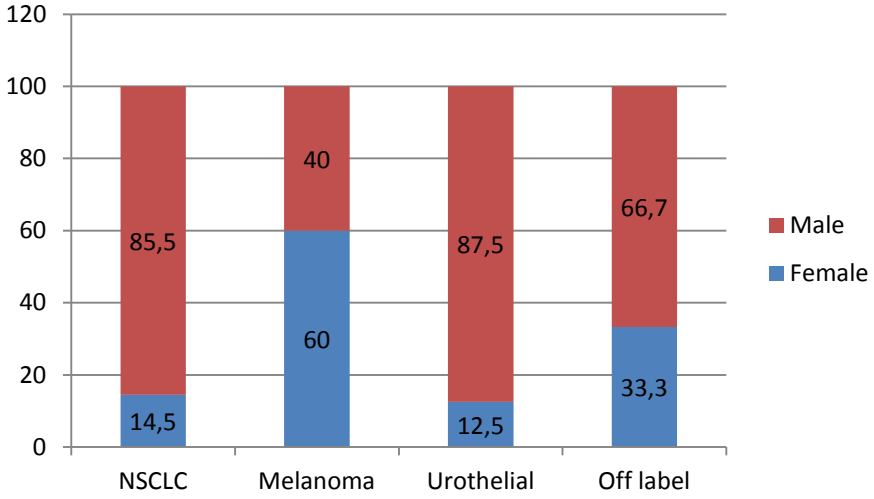
Examples of studies undertaken

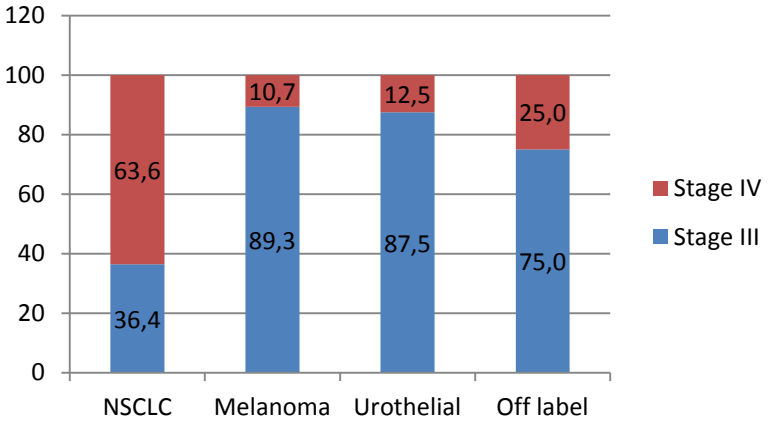


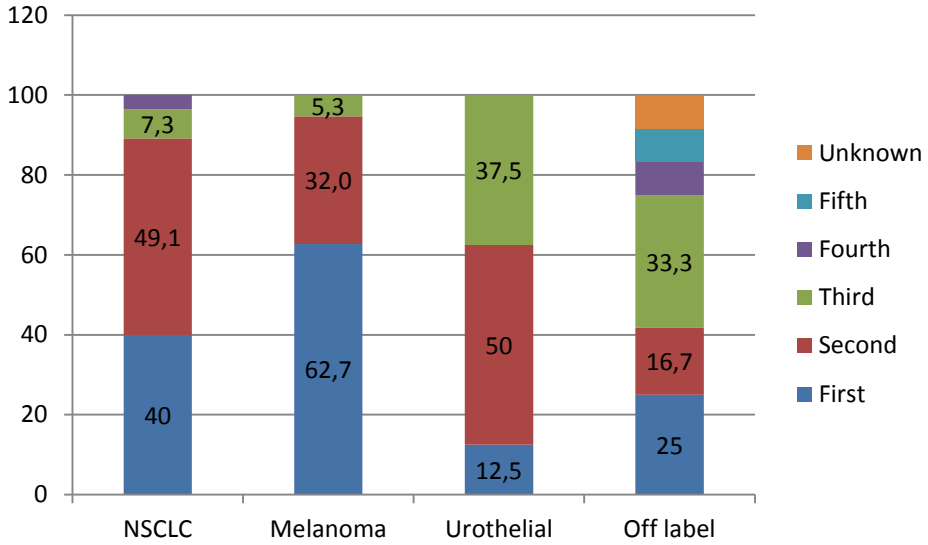
*Median **Overall survival** among exposed patients was **11.4 months**, slighly inferior to that reported in published clinical trials (**12.2 months**). However, the characteristics of patients in our sample indicate they had a **worse prognosis**.*

Borghaei et al. N Engl J Med 2015;373:1627-39.
Costa et al. The cancer registry as an ally in monitoring treatment effectiveness. Revista Portuguesa de Pneumologia 2018. In press

Examples of studies undertaken







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RON Registo Oncológico Nacional

Overview of the presentation

1. Theoretical Component:

- What is the National Oncology Register (RON)?
- What is the information collected?
- What is the purpose of measuring effectiveness?
- Methodologies used?
- Comparators
- Indicators and Outcomes to be measured
- Particularities and difficulties in effectiveness monitoring in oncology
- Importance of the RON for measuring effectiveness

2. Practical cases

3. Discussion

In Sumary

SITUATION BEFORE RON PORTAL

- **DATA**

> **Poor Quality** (accuracy and completeness)

> **Not Updated** (low accessibility and sharing between agents)

Not enough contribute to clinical practice and knowledge progress

Practical cases

NEW RON PORTAL – Main Goals

TO INNOVATE

- Innovate Methodology on Registry Philosophy
- Innovate Technologically the existing Regional Computerized Registry Platform (dated from the 1990's)

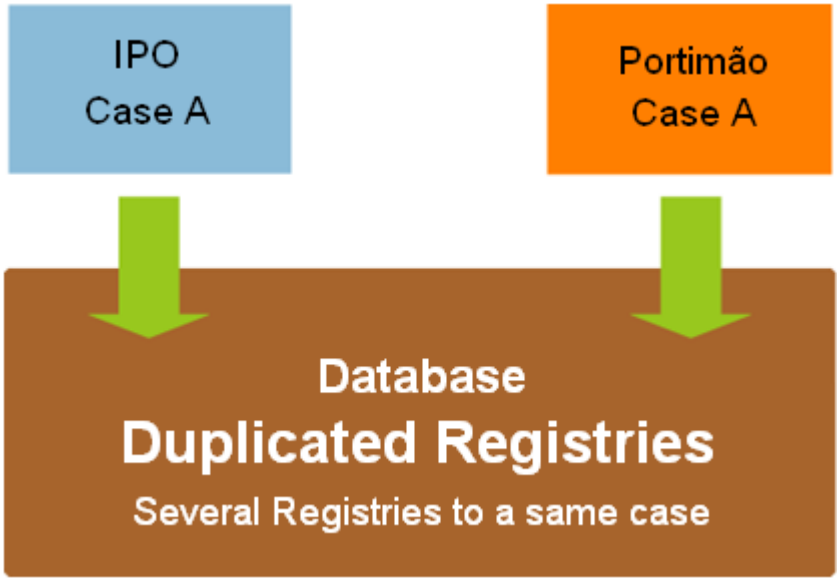
IMPROVE

- To create an Information Support System to Cancer Health Care Management, to Every Day Clinical Practice and to Cancer Epidemiological Research
  - > Improve Information Sharing
  - > Improve Interaction and Comunication between agents

Practical cases

NEW RON PORTAL – Innovating Registry Methodology

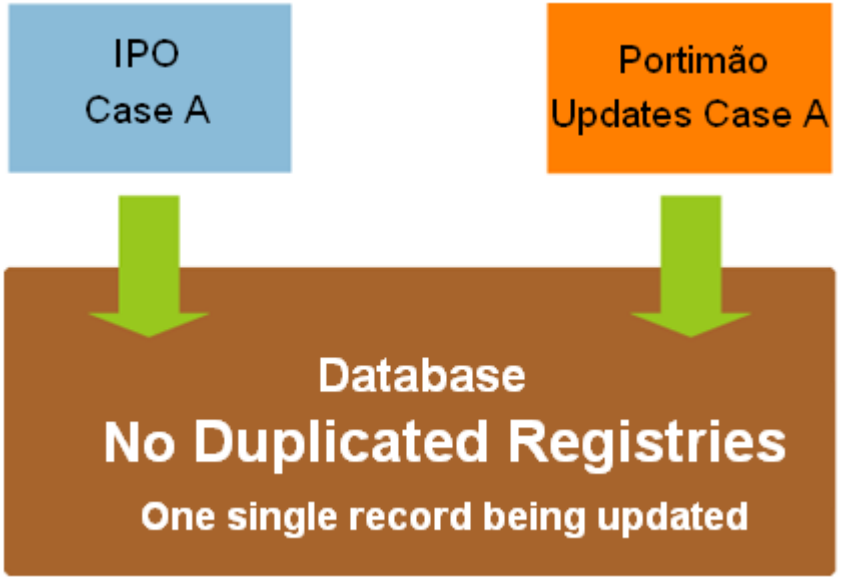
On The Old Registry Method : Data Source oriented



Practical cases

NEW RON PORTAL – Innovating Registry Methodology

On The New RON Portal : Tumor and Patient oriented



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Practical cases

NEW RON PORTAL –

Improving Information Sharing

Cancer Registry Data Base built by integration of multiple local Data Bases

Better Data Quality

More Updated Information

Bigger Functionality and Use

Quicker Information Access

Optimized Communication between Agents

Database

Using Integration

Of different databases

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Practical cases

NEW RON PORTAL –

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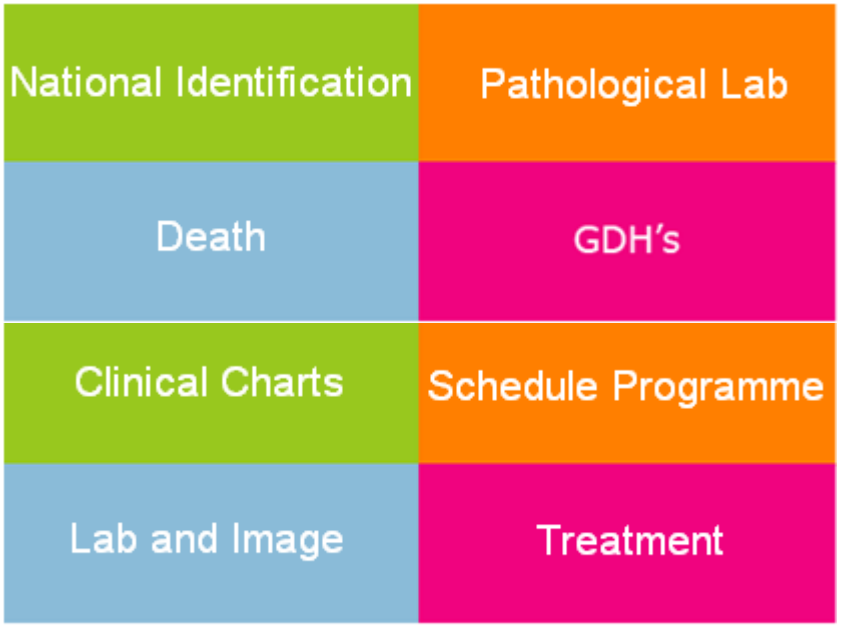

Practical cases

PORTAL RON - http://ron.min-saude.pt

First Step – Create an Account

Second Step - Log In

Click on Registry

You can:

-Search and consult on **RON** and on **RNU Data Base**, by patient, by case or by institution;

- Edit, change, update and delete cases on **RON Data Base**

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Practical cases

Data “manager” cancer registry profile:

- Medical doctors
- Biologists
- Pharmaceuticals
- Psychologists
- Social workers
- Administrative staff

- ❖ According to different data access
- ❖ Signed confidentiality document

Practical cases

Indicators- developped in conjunction with Diferent Actors

- New cases - Incidence
- Time between diagnosis / treatment
- Stage
- Global Survival
- Survival till progression

  - Hospital/Population based

Practical cases

Data availability

- National Health Administration
- National Statistics Institute
- Regional Health Administration
- Hospital Administration
- Mutidisciplinary teams and Units
- Specific Population/Hospital Based Studies Researchers

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Thank You for the invitation and forYour atenttion

Ana Miranda