

What is the information availability to the cancer epidemiology data?

M Ondrusova^{1,2,3*}, D Ondrus^{1,4}, L Dusek³, J Muzik³

¹National Cancer Registry of the Slovak Republic, National Health Information Centre, ²Department of Cancer Epidemiology, Cancer Research Institute, Bratislava, Slovak Republic, ³Institute of biostatistics and analyses, Masaryk University, Brno, Czech Republic, ⁴1st Department of Oncology, Comenius University Medical School and St. Elisabeth Cancer Institute, Bratislava, Slovak Republic

Abstract

National Cancer Registry of the Slovak Republic, National Health Information Centre, would like to respond to many requests for easy and comprehensible access to the national and international data on cancer epidemiology. The working group created a new analytic web-page called "National portal on cancer epidemiology". All the data are valid, adapted for publications and quotation and the access to the web-page www.nor-sk.org is free for the wide professional public.

Keywords: Cancer, Epidemiology; Information system

Introduction

There has recently been a huge upsurge in demand for valid data on cancer epidemiology, particularly for the purposes of research effort and/or publications of experts in the fields of oncology, epidemiology, pathology, etc. The outputs released so far in regular yearly analyses of cancer incidence in the Slovak Republic, as well as in domestic and foreign publications, have often not been sufficient for the needs of the wide public. Therefore, it was decided to initiate the creation of a freely accessible information system, which would make the standard outputs of the National Cancer Registry of the Slovak Republic available to the public in an appropriate publishable form comparable to the international cancer data.

The National Cancer Registry (NCR) at the National Health Information Centre (NHIC) of the Slovak Republic (hereinafter referred to as "the NCR SR/NHIC") is a specialized and methodical centre for the registration and processing of reports on cancer

incidence. In a close cooperation with the main experts in oncology from the Slovak Ministry of Health, as well as regional experts in medical oncology, the NCR SR ensures and guarantees the completeness and high quality of data on cancer epidemiology in the Slovak Republic. All the records are maintained in an internationally unified form, and stored in the NCR SR database. The data form the background for statistical processing and analyses of onco-epidemiological situation in the Slovak Republic, as well as on the European and global level - in cooperation with international organizations (e.g. IARC WHO, ENCR). Thanks to the high reliability and quality, the data processed and published by NCR SR have been included in all international periodical publications, overviews and databases of the World Health Organization (WHO), forming a constituent part of international projects focusing on cancer epidemiology. The main objective of the project "National Portal of Cancer Epidemiology in Slovakia" (hereinafter referred to as "the NCR SR web portal", Figure 1) has been to develop an information system to support scientific analyses of cancer data registered in the NCR SR/NHIC. The system has been prepared to aggregate, analyse and present epidemiological, clinical and demographic data from the NCR SR,

*Correspondence: RNDr. Martina Ondrusova, PhD, National Cancer Registry of the Slovak Republic, National Health Information Centre, Lazaretska 26, 811 09 Bratislava, Slovak Republic. e-mail: martina.ondrusova@nczisk.sk, <http://www.nor-sk.org/>
Received: May 7, 2008 Accepted: June 8, 2008

which have been so far regularly published in special monographs or in scientific reports (Figure 2).

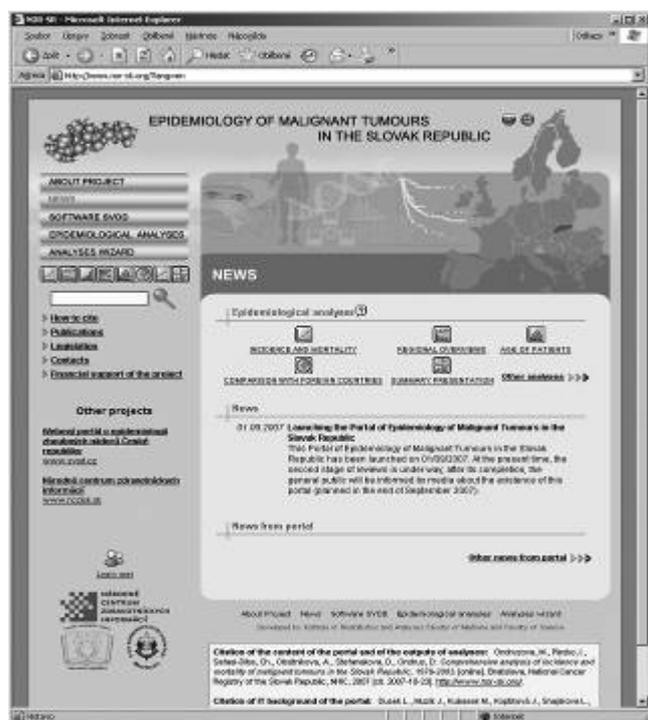


Fig 1: National Portal of Cancer Epidemiology in Slovakia.



Fig 2: Present epidemiological, clinical and demographic data from the NCR SR.

The NCR SR web portal processes mainly epidemiological data on patients registered in the NCR SR. Anonymized and validated data from 1978 to the present day are available in the registry, which is a uniquely representative dataset, at the European level at least (the database currently contains nearly 500.000 records from the period 1978-2003). The epidemiological trends were processed with relevant demographic data about the population of interest.

The project initiation has been driven by the effort to make these representative and valuable data available to a broad spectrum of interested individuals. The project is based on the presumption that general information about cancer epidemiology and related population risks should be freely available. In this way, the user gets a direct and unique access to complex information from available resources, which can be further used in subsequent analyses and interpretations.

The launch of the NCR SR web portal has provided a free access to all standard data on cancer epidemiology registered in the NCR SR/NHIC, thus ensuring that both professional and lay public in the Slovak Republic and abroad can get relevant information about cancer incidence and diagnosis.

Here is an overview of information service at the NCR SR web portal:

1. News: regularly updated information on recent developments in population risk assessment and cancer epidemiology.
2. Interactive analyses: freely available software tools, allowing a direct examination of trends in cancer epidemiology.
3. Repors: commented outputs and presentations, prepared by leading experts in the field.

The information service of the NCR SR web portal will be further improved, taking into consideration the users' remarks as well. At present, an opposition procedure is under way, in cooperation with experts in oncology and pathology. The data can be analysed according to basic demographic characteristics and diagnostic information, and also sorted by region or time. The system is ready for automatic updates of epidemiological data once a year at minimum as soon as the data are validated within the NCR SR/NHIC. Future objectives involve the extension of the information service over the population risk assessment, in relation to available data on environmental conditions in the Slovak Republic. The presented version of the NCR SR web portal makes available standard epidemiological data from the NCR SR, which can only be

used in conformity with the Copyright Act. Any reproduction, copying, editing, publication or further distribution is strictly forbidden without the appropriate citation of the source.^{1,2} All services of the portal are freely available.

Technical solution to the web portal

The web portal is run on two computers: a database server with aggregated data from the NCR SR and other data sources (OS Linux with database control system MySQL v.4.0), and a web server with user interface (OS Linux supporting the PHP scripting modules), thereby guaranteeing the physical separation of the database server from the internet. The technical solution involves a secured backup of the processed data and scripts, ensuring a quick recovery of necessary data after a possible system breakdown. Technical requirements for the use of the web portal include a computer connected to internet and a web browser supporting HTML 4.01 and JavaScript.²

Main benefits of the NCR SR web portal

1. The NCR SR web portal spares your time

The web portal NCR SR makes available standard data from the NCR SR database in an aggregated form, providing end results of analyses and graphical outputs.

2. The NCR SR web portal is fully automated

The software enables users to perform automatic analyses even to those without mathematical background, as the communication tools offer a simple selection of analyzed items.

3. The NCR SR web portal is a comprehensible and graphically-oriented tool

The web portal contains an independent graphic module with more than 30 types of graphic outputs. All the results of analyses are directly visualized in the form of a graph.

4. The NCR SR web portal is a full-fledged information source

The system provides its users with all data inputs needed for a comprehensive analysis of population risks related to cancer formation, i.e. aggregated epidemiological data as well as demographic population data.

The following analytical tools are available:

INCIDENCE AND MORTALITY

Time trends in cancer incidence and mortality in the Slovak Republic (Figure 3).



Fig 3: Time trends in cancer incidence and mortality in the Slovak Republic.

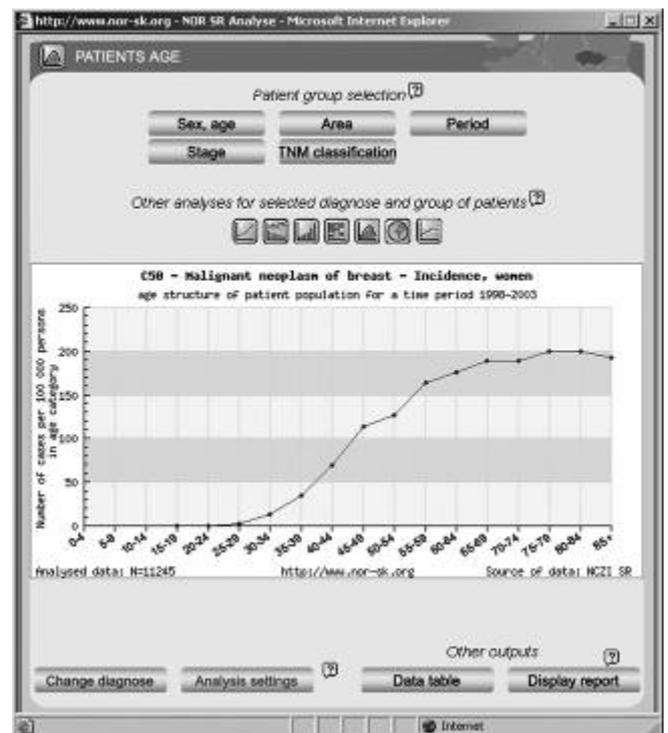


Fig 4: Age structure of living and deceased cancer patients.

TIME TRENDS

Changes in trends in cancer incidence and mortality over time (growth index and year-on-year changes).

AGE OF PATIENTS

Age structure of living and deceased cancer patients (Figure 4).

REGIONAL OVERVIEWS

Comparison of cancer incidence and mortality in individual regions of the Slovak Republic (Figure 5)

COMPARATIVE ANALYSES

Time trends in epidemiological parameters in individual regions of the Slovak Republic in comparison to reference standards.

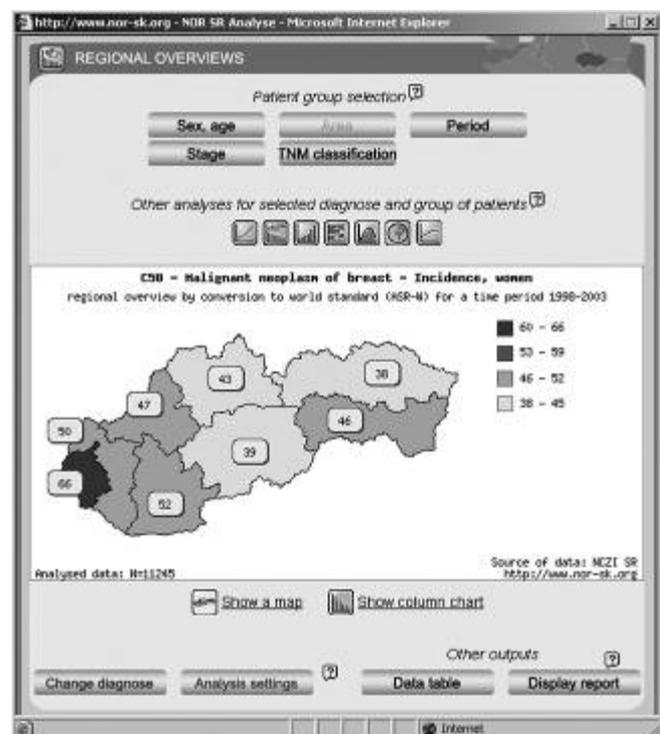


Fig 5: Comparison of cancer incidence and mortality in individual regions of the Slovak Republic.

CLINICAL STAGES

Time trends in distribution of clinical stages (Figure 6).

COMPARISON WITH FOREIGN COUNTRIES

Comparison of cancer epidemiology in the Slovak Republic and worldwide (source: IARC - GLOBOCAN 2002).

SUMMARY PRESENTATION

Comprehensive presentations of basic analyses for individual diagnoses.

The authors of the project believe in a widespread use of these freely available data as provided by the NCR SR web portal.

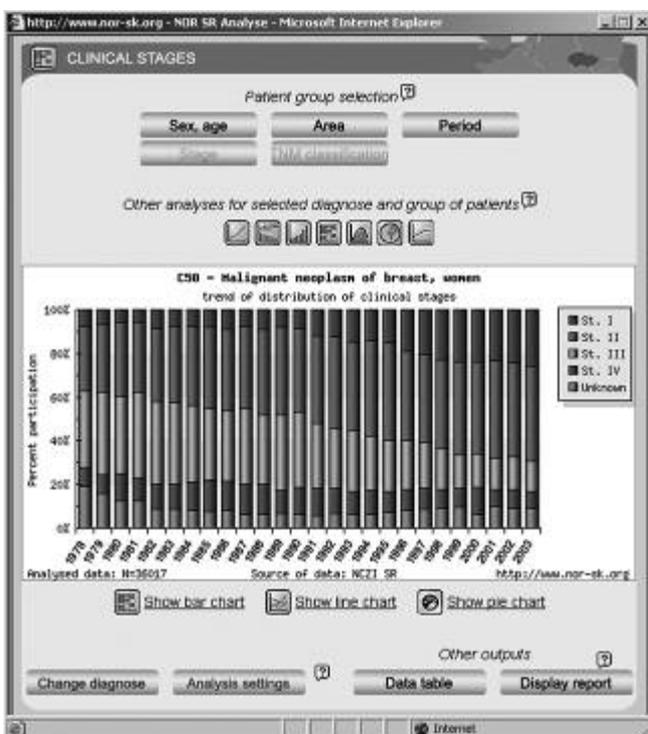


Fig 6: Time trends in distribution of clinical stages.

References

- 1 Ondrusova M, Plesko I, Safaei-Diba Ch, Obsitnikova A, Stefanakova D, Ondrus D. Complex analysis of cancer incidence and mortality in the Slovak Republic, 1978-2003. Bratislava, NCR SR, NHIC, 2007; (online), <http://www.nor-sk.org>
- 2 Dusek L, Muzik J, Kubasek M, Koptikova J, Snajdrova L, Ondrusova M. National portal of Cancer Epidemiology in Slovakia. Masaryk University, Brno, 2007.