

Insights into cancer surveillance in Central and Eastern Europe, Israel and Turkey

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VRDOLJAK E., TORDAY L., SELLA A., LEYMAN S., BAVBEK S., KHARKEVICH G., MARDIAK J., SZCZYLIK C., ZNAOR A. & WILKING N. (2015) *European Journal of Cancer Care* **24**, 99–110
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The current cancer landscape within transitional economies in central and Eastern Europe and the Mediterranean area is not particularly optimistic. Current perceptions are often based on extrapolations from other countries and regions; and hence the authors collaborated with the South Eastern Europe Oncology Group (SEEROG) to collect information on cancer registration in Central and Eastern Europe, Israel and Turkey. Healthcare authorities and specialist oncology centres in 21 countries in the region were contacted for information on cancer registries in their countries. Based on this information, the authors believe that the recording and reporting of data on cancer in the region is at an acceptable level. The authors discuss and compare institution- and population-based registries, and present opinions on elements of an 'ideal registry' based on the survey replies and comparisons with other registries. A comparison with the sources used for GLOBOCAN 2008 illustrates the need for consistent data to be communicated, published and utilised throughout the region and the oncology community. The authors conclude by considering the potential value of collaboration between health authorities across the region, as well as between the clinical and epidemiological communities, to ensure that cancer data are consistently collected, verified and made public.

Keywords: cancer epidemiology, Central and Eastern Europe, Israel, Turkey, population-based cancer registries, institution-based registries.

INTRODUCTION

Cancer remains one of the leading causes of morbidity and mortality worldwide (Ferlay *et al.* 2010a, *Cancer Incidence and Mortality Worldwide*). In addition to the

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Accepted 6 October 2013

DOI: 10.1111/ecc.12149

European Journal of Cancer Care, 2015, **24**, 99–110

Cancer Incidence in Five Continents series of monographs, which is the reference source for the international cancer incidence (International Agency for Research on Cancer 2010, *Cancer Incidence in Five Continents*), both GLOBOCAN estimates (Ferlay *et al.* 2010a, *Cancer Incidence and Mortality Worldwide*) and the WHO Cancer Mortality Database (WHO n.d., *WHO Mortality Database*) have highlighted the wide variation in incidence and mortality rates across Europe (Ferlay *et al.* 2010a, *Cancer Incidence and Mortality Worldwide*; Sant *et al.* 2009).

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Many factors may play a part in the geographical variation of cancer incidence and mortality; however, differences in cancer care account for a substantial proportion of the higher cancer mortality rates seen in some countries. There is a wide variation in the quality of cancer care both globally between developed and developing countries (International Network for Cancer Treatment and Research n.d., Cancer in Developing Countries) and within Europe between the 'old' and 'new' European Union (EU) members (Albrecht *et al.* 2008; Gouveia *et al.* 2008; Zatonski & Didkowska 2008). Cancer mortality is significantly higher in South Eastern and Eastern European countries, including the new EU countries, and it is a growing concern that the cancer problem in these states is among the worst in the region (Levi *et al.* 2004a,b; Ferlay *et al.* 2010b; La Vecchia *et al.* 2010; Znaor *et al.* 2013).

In order to provide insights into these issues, a working group of oncologists from countries within Eastern and Central Europe, Israel and Turkey collaborated with the South Eastern Europe Oncology Group (SEEROG) to conduct a comprehensive assessment of cancer registries in the region. The aim of this review was to understand better what information is available, how it is reported and interpreted, and to identify knowledge gaps that could lead to the misinterpretation of the current cancer burden in the countries evaluated. One specific goal was to establish the types of cancer registry in each country. Population-based registries record all new cases in a defined population (usually a specific geographical area such as a country or state); they focus on epidemiology, and determine cancer patterns and trends over time. Hospital-based registries have a greater emphasis on patient care and evaluation of outcomes; data may be collected by a single hospital or multiple institutions [National Cancer Institute n.d., Surveillance, Epidemiology and End Results (SEER) Training Program Cancer Registration and Surveillance Modules].

METHODS

The working group of oncologists developed the scope of the cancer registry review and the strategy for collecting information. A questionnaire was designed to ascertain what information was available from cancer registries across the region. The key aspects of information collected included: type of registry; sources of cancer data; tumour-specific data items, including cancer type and treatment; quality control and data reliability; and availability of registry data within the public domain.

Key oncology centres and healthcare authorities were identified for each country and were included in the

project. These centres were selected by the authors based on their reputation and the scope of their activities. Healthcare authorities included national cancer institutes, government bodies of health information, health economics and public health agencies. Questionnaires were sent by email and regular mail to the identified participants at each oncology centre and healthcare authority included in the survey, with regular reminders to encourage replies. Data from the respondents were tabulated and reviewed by the working group to enable the results to be assessed both on an individual and on a combined level. Further contact was made with individuals, as required, to resolve any major discrepancies in descriptions of the registry data between different respondents from the same country. The main period of data collection was June to September 2011; after this period, efforts were devoted to chasing non-responders and to clarifying ambiguous or incomplete responses. The data were also compared against reference sources cited in the most recent version of the GLOBOCAN database (Ferlay *et al.* 2010a, Cancer Incidence and Mortality Worldwide).

Ethical committee approval was not required since this work did not involve human or animal subjects.

RESULTS

A total of 21 countries in Central and Eastern Europe and the eastern Mediterranean were included in the study. A total of 41 responses were received out of 77 questionnaires distributed (Table 1). Of these, 28 were received from specialist oncology centres and 13 from healthcare authorities. No responses were received from Armenia and Azerbaijan, but at least one response was received from all other countries contacted. There was no specific pattern among non-responders. In general we considered the response adequate if, after repeated reminders, at least one response was received from a key oncology centre and one from a healthcare authority, even though in some countries, such as Hungary, Romania, Croatia, Turkey and Serbia, we had identified more than five potential contributors. In Slovakia, for example, the physicians responded that one questionnaire was sufficient to reflect all their responses.

Nature of the registries

All countries who responded to the questionnaire have at least one procedure for recording cancer incidence and mortality, although the nature of the processes and the scope vary considerably (Table 2). In all countries, cancer

Table 1. List of key oncology centres or healthcare authorities by country who responded to the survey

Country	Key oncology centre (n)	Healthcare authority (n)	Respondent
Albania	1	1	Ferdinand Jorgoni, MD <i>Service of Oncology, University Hospital Centre, Tirana</i> <i>National Cancer Registry, Oncological Institute, Tirana</i> Ilir Akshia <i>Service of Oncology, University Hospital Centre, Tirana</i>
Belarus	1	–	Aleksey Okeanov, MD <i>N.N. Alexandrov National Cancer Center of Belarus, Minsk</i>
Bosnia-Herzegovina	1	–	Saša Jungić, MD <i>Clinic for Internal Oncology, Clinical Hospital Center Banja Luka</i>
Bulgaria	–	–	Bulgarian information in tables 2–4 taken from printed publication of Bulgarian national cancer registry. Information not obtained from survey replies
Croatia	3	1	Stjepko Pleština, MD, PhD <i>Department of Oncology, University Hospital Centre, Zagreb</i> Maja Drežnjak Madunić, MD <i>Clinical Hospital Centre (Klinički Bolnički Centar), Osijek</i> Eduard Vrdoljak, MD, PhD <i>Clinical Hospital Split, Center of Oncology, Split</i> Ariana Znaor, MD, PhD <i>Croatian National Cancer Registry, Croatian National Institute of Public Health, Zagreb</i>
Czech Republic	1	1	Bohuslav Melichar, MD, PhD <i>Palacký University Medical School and Teaching Hospital, Olomouc</i> Tomas Srb <i>Institute of Health Information and Statistics, Prague</i>
Estonia	–	1	Margit Magi, MD <i>Estonian Cancer Registry, National Institute for Health Development, Tallinn</i>
Hungary	1	1	Laszlo Torday, MD, PhD <i>Department of Oncotherapy, University of Szeged</i> Erzsebet Podmaniczky, MD <i>National Institute of Oncology, Budapest</i>
Israel	1	1	Avishay Sella, MD <i>Department of Oncology, Assaf Harofeh Centre</i> Micha Bar-Chana, MD <i>Israeli Cancer Registry, Jerusalem</i>
Kazakhstan	1	–	Suriya Essentayeva, MD <i>Kazakh Research Institute of Radiology and Oncology, Almaty</i>
Latvia	–	1	Anita Maurina, MD <i>Centre of Health Economics, Riga</i>
Lithuania	3	–	Alvydas Česas, MD <i>Klaipeda University Hospital, Klaipeda</i> Elona Juozaityte, PhD <i>Lithuanian University of Health Sciences, Oncology, Institute, Kaunas</i> Giedre Smailyte, MD <i>Institute of Oncology, Vilnius University, Vilnius</i>
Macedonia	2	1	Elena Kosevska, MD, PhD <i>Department for Health Promotion, Analysis and Disease Prevention, Institute for Public Health, Skopje</i> Crvenkova Simonida, MD <i>University Clinic for Radiotherapy and Oncology, Skopje</i> Petar Stefanovski, MD, PhD <i>Department of Oncology and Palliative Care, Bitola</i>
Poland	1	2	Piotr Tomczak, MD <i>University Hospital of Lord's Transfiguration, Poznan</i> Ryszard Mezyk <i>Holycross Cancer Centre (Holycross Cancer Registry), Kielce</i> Joanna Didkowska <i>Polish National Cancer Registry, Center of Oncology, Warsaw</i>

Table 1. *Continued*

Country	Key oncology centre (n)	Healthcare authority (n)	Respondent
Romania	3	–	Dana Lucia Stanculeanu, MD <i>Oncology Institute ‘Prof. Dr. Al. Trestioreanu’, Bucharest</i> Mircea Dediu, MD <i>Institute of Oncology, Bucharest</i> Delia Mateescu, MD <i>Queen Mary Hospital Bucharest, Bucharest</i>
Russia	2	–	Galina Kharkevich, MD, PhD <i>Federal State Budgetary Institution ‘N.N.Blokhin Russian Cancer Research Center’ under the Russian Academy of Medical Sciences, Moscow</i> Valeriy Ivanovich Chissov, MD <i>Moscow PA Gertsen Research Oncological Institute, Moscow</i>
Serbia	3	–	Ana Jovicevic, MD <i>Institute for Oncology and Radiology of Serbia, Belgrade</i> Marica Miladinov-Mikov, MD <i>Oncology Institute of Vojvodina, Sremska Kamenica</i> Jasmina Nedović, MD <i>Clinical Center Kragujevac, Kragujevac</i>
Slovakia	1	–	Jozef Mardiak, MD <i>National Cancer Institute, Bratislava</i>
Slovenia	–	2	Tina Žagar, PhD <i>Epidemiology and Cancer Registry, Institute of Oncology Ljubljana, Ljubljana</i> Maja Primic Žakelj, MD, PhD <i>Epidemiology and Cancer Registry, Head Institute of Oncology Ljubljana, Ljubljana</i>
Turkey	2	–	Mahmut Gumus, MD <i>Kartal Dr. Lutfi Kırdar Research and Training Hospital, Istanbul</i> Suayib Yalcin, MD <i>Hacettepe University Institute of Oncology, Ankara</i>
Ukraine	1	1	Yaroslav Shparyk, MD <i>Lviv Cancer Center, Lviv</i> Andrey Gaisenko, MD <i>National Cancer Institute, Kyiv</i> Zoya Fedorenko, MD <i>National Cancer Institute, Kyiv</i>
Total (41)	28	13	

cases are reported to either the national or the local authorities (Table 2). Local data are usually collected by the specialist oncology institutes which then send them to the central healthcare authority registry, if one exists.

In Russia, for example, it has been mandatory since 1953 to report all new cancer cases, and a population-based national cancer registry was initiated in 1996. Information is sourced from all healthcare institutions, including specialist oncology centres, and general health service information systems that record electronic death certification. The data are obtained annually by the two main cancer institutes (N. N. Blokhin Cancer Research Center, Moscow and PA Gertsen Oncology Research Institute, Moscow) in Russia and then sent to the national registry for registration and reporting purposes.

Poland has 16 regional cancer registries, which, according to the survey responses and the published data quality indicators, can vary in data quality. The regional statistics

are provided to the National Cancer Institute in Warsaw, which co-ordinates the work of the regional registries, although it does not produce a compiled national data set. In Kazakhstan, each oncology centre has its own registry, and the data from these are compiled by the Ministry of Health in conjunction with the Kazakh Research Institute of Radiology and Oncology but, as in Poland, not consolidated into a national cancer data set.

Three countries reported that they have smaller, independent registries that supplement information from national registries. In Hungary, several smaller, tumour-specific registries exist, including a hepatocellular carcinoma (HCC) and a gastrointestinal stromal tumour (GIST) registry. These registries are completely independent of the National Cancer Registry, and there is no data exchange between them (Table 2). In the Czech Republic, the national registry includes comprehensive data on all cancer types, but there are also several independent registries

Table 2. Type of country registries and comparison with source of data used by GLOBOCAN 2008 for each country

Country	Type of registry in each country					Source of data used by GLOBOCAN 2008 for each country
	Population-based	Specialist centres	National	Regional	Hospital-specific	
Albania	✓		✓		✓	National incidence modelled from estimated mortality data using incidence : mortality ratios obtained by aggregation of cancer registry data from Bulgaria and Central Serbia. Estimated mortality by sex was partitioned by site using national mortality data (including Bulgaria and Greece)
Belarus	✓		✓			National incidence rates (1978–2002) projected to 2008 population. National mortality rates for most tumour types (1989–2003) projected to 2004–2006 and applied to 2008 population
Bosnia-Herzegovina	✓		✓	✓		National incidence and mortality rates estimated as average of estimates from Albania, Macedonia, Serbia, Croatia and Slovenia
Bulgaria			✓	✓		National incidence and mortality for 2008
Croatia	✓		✓			National incidence (1998–2007) projected to 2008 population; recorded mortality rates for 2008
Czech Republic	✓		✓*			National incidence rates (1998–2007) projected to 2008 population; recorded mortality rates for 2008
Estonia	✓		✓			National incidence rates (1984–2003) projected to 2008 population; recorded mortality rates for 2008
Hungary	✓		✓†			National incidence estimated from mortality data modelled using incidence : mortality ratios obtained by aggregation of cancer registry data from Czech Republic and Slovakia; recorded mortality rates for 2008
Israel	✓		✓			National incidence rates (1983–2002) projected to 2008 population National mortality rates (1986–2005) projected to 2008 population
Kazakhstan		✓			✓	National incidence and mortality rates estimated from estimated mortality data modelled using incidence : mortality ratios obtained by aggregation of cancer registry data from South-Central Asia: India (Mumbai, Chennai, Barshi, Karunagappally) and Iran (Ardabil province)
Latvia	✓		✓			National incidence rates (1984–2003) projected to 2008 population; recorded mortality rates for 2008
Lithuania	✓		✓			National incidence rates (1986–2005) projected to 2008 population; recorded mortality rates for 2008
Macedonia	✓	✓	✓			National incidence rates estimated from mortality data modelled using incidence : mortality ratios obtained by aggregation of cancer registry data from Bulgaria and Central Serbia; for most cancers, national mortality rates (1991–2003) corrected for 8% under-reporting and projected to 2008
Poland			✓	✓	✓	National incidence rates estimated from mortality data modelled using incidence : mortality ratios obtained by aggregation of cancer registry data from four regional registries (Cracow, Kielce, Podkarpacki and Warsaw); recorded mortality rates for 2008
Romania		✓		✓	✓	National incidence rates estimated from mortality data modelled using incidence : mortality ratios obtained by aggregation of cancer registry data from Bulgaria, Slovakia and Romania (Cluj cancer registry); recorded mortality rates for 2008
Russia	✓	✓	✓	✓	✓	National incidence and mortality for 2008
Serbia	✓		✓	✓	✓	National incidence was estimated from estimated mortality data modelled using incidence : mortality ratios obtained by aggregation of cancer registry data from Serbian regional cancer registries; recorded mortality rates for 2008 corrected for 15% under-reporting
Slovakia	✓		✓			National incidence rates (1986–2005) projected to 2008 population; national mortality rates (1991–2005) projected to 2008 population
Slovenia	✓		✓		✓	National incidence rates (2000–2007) projected to 2008 population; recorded national mortality rates for 2008
Turkey	✓		✓‡			No national data available Incidence rates estimated as weighted average of those observed in Iran (Ardabil province, 2004–2006) for East and South-East regions (20% of the Turkish population); simple mean of Antalya Cancer Registry (1998–2002) and Izmir Cancer Registry (1998–2002); mortality rates estimated from incidence rates and cancer site-specific survival, estimated by GDP method§
Ukraine	✓		✓	✓		National incidence rates for 2008; mortality rates for some cancers from national data; others calculated from Ukrainian regional cancer registries

*National registry complemented by independent patient registries related to specific treatments with targeted therapies.

†In addition to the national registry a number of independent, small, tumour-specific registries exist.

‡Specific cancer centres and regional cancer working groups have additional specific disease-oriented registries.

§GDP method of estimating cancer mortality is based on the estimated relationship between cancer-specific 5-year relative survival and country-specific GDP per capita.

related to specific treatments with the new targeted therapies, such as those for renal cell carcinoma and GIST. In Turkey, specific cancer centres, such as those in Antalya and Izmir, have population-based cancer registries.

The situation in Romania is currently undergoing significant change, with the initiation of a national cancer registry anticipated in 2013. The registry will build upon experience of an existing regional registry from a specialist centre (Cluj Oncology Institute), which has undergone recent upgrades to ensure it is capable of the wider role of leadership of national cancer registration.

Sources of the cancer data

Data are obtained mostly from patients' hospital or primary care notifications and death certificates, often supplemented with pathology reports and hospital discharge data. Typically, a country's national cancer registry receives notification of every cancer case from the regional healthcare administration or the medical institution responsible for the patient. For the smaller, independent, disease-specific registries, data are provided voluntarily by the treating physicians. Thus, although these registries may be more exhaustive in their data collection due to more detailed clinical research forms being used, they are rarely able to generate reliable incidence data.

Reporting of cases is usually the responsibility of the lead oncology physician or a trained nurse. In contrast, administrators or statistics clerks undertake reporting in Serbia and Albania. However, survey responses from Israel and Romania indicated that the overall responsibility for reporting data lies with the head of the oncology institute or registry, with the assistance of administrative staff. In Russia, it is the head of the statistical department of each healthcare institution who is responsible for the reliability of these data. Polish respondents indicated that, in line with standard practice, notification of a cancer diagnosis to a regional cancer registry is actively followed up and audited by registry staff, who visit each co-operating hospital annually to complete any missing information for all cases.

Type of cancer data collected

All countries surveyed indicated that they have a basic requirement to collect data on tumour type and stage at diagnosis, with histology details to differing degrees (Table 3). The registries in almost all countries include, as a minimum, incidence rates by cancer site, sex and age group. Data for a comprehensive range of solid tumours are available from all countries, with topography coding

by the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10). A large number of countries also report survival estimates related to age and stage at diagnosis, and gender (Table 3).

Data on cancer treatment

All countries except Kazakhstan record some information on treatments, although several countries indicated that this is at a basic, minimal level (Table 3). Treatment is recorded as surgical, radiological or systemic (chemotherapy, hormone treatment, immunotherapy, targeted therapies); only the Czech Republic collects detailed information on both treatment method and intention (e.g. adjuvant or neoadjuvant).

The Czech Republic also has several specialist targeted therapy registries and listings by individual drugs and drug class (Table 3). This is likely to be the situation in other countries, but was not reported by other respondents. The targeted therapy registries are independent of the main cancer registries and are run by individual institutions. Thus, the data on them may not be as representative of the whole population as in the main cancer registry. In Russia, data on all treatment modalities, including targeted therapy, are available within the registries of the individual institutions.

Quality control of data and reliability

Most respondents stated that their registries carry out internal audits of their data. Most comply with International Agency for Research on Cancer (IARC) guidelines (International Agency for Research on Cancer 1991. Cancer Registration: Principles and Methods IARC Scientific Publication No. 95). Part of the validation process, as in Bulgaria, for example, involves analysing the extent to which the national registry conforms to international guidelines and standards for cancer registration.

Subjective opinions provided by respondents to the survey indicated that the data submitted to their registries could be more reliable.

Availability of data in the public domain

The majority of specialist oncology centres included in this study encourage physicians to publish cancer epidemiology data at national, regional or international congresses, or in journals (Table 4). The most widely used publication vehicle is government-sponsored publications in print and on the worldwide web (Table 4).

Registries are typically updated at least once per year, but it can take up to 2 years to analyse the data fully;

Table 3. Type of cancer data collected in registries

Country	Information available				Pathology reports/histology data	Information by gender	Treatment: S = surgery; R = radiotherapy; ST = systemic treatment
	Incidence rates	Mortality/survival rates (1-year, 5-year, 10-year survival)	Stage at diagnosis (TNM)	Survival by age and stage			
Albania	✓	✓	✓		✓	✓	S; R; ST
Belarus	✓	✓	✓	✓	✓	✓	S; R; ST
Bosnia-Herzegovina	✓		✓*		✓	✓	Individual drug treatments listed
Bulgaria	✓				✓	✓	No data provided
Croatia	✓	✓	✓		✓	✓	None
Czech Republic	✓	✓	✓	✓	✓	✓	S; R; ST
							S; R; ST
							Treatments further categorised as adjuvant or neoadjuvant, and listed by drug class and individual drugs
Estonia	✓					✓	Additional, independent, specialist targeted therapy registries
Hungary	✓	✓‡	✓	✓‡	✓+	✓	S; R; ST
Israel	✓	✓	✓§	✓	✓	✓	S; R; ST
Kazakhstan	✓	✓	✓	✓	✓	✓	S; R; ST
Latvia	✓	✓	✓	✓	✓	✓	None
Lithuania	✓	✓	✓	✓	✓	✓	S; R; ST
							Additional listing of symptomatic therapies
							None
							Listed as patient received/did not receive treatment
Macedonia	✓	✓	✓	✓	✓	✓	S; R; ST
Poland	✓	✓	✓	✓	✓	✓	S; R; ST
Romania	✓	✓	✓	✓	✓	✓	S; R; ST
Russia	✓	✓¶	✓	✓	✓	✓	S; R; ST
Serbia	✓	✓	✓	✓	✓	✓	Treatment data only available within individual institutions
Slovakia	✓	✓	✓	✓	✓	✓	S; R; ST
Slovenia	✓	✓	✓*	✓	✓	✓	Limited treatment information
							S; R; ST
							Basic treatment information only
Turkey	✓		✓	✓	✓	✓	S; R; ST
Ukraine	✓	✓¶	✓	✓	✓	✓	S; R; ST

* Alternative stage ranking used.

† Histology data only.

‡ Indirect data collection.

§ Summary stage according to SEER.

¶ 1-year mortality data available only.

Note: These data are subject to change.

Table 4. Publication of cancer registry data

Country	Sources of information				Other information available
	Conference abstracts	Other unpublished data	Data from individual hospitals	Information on websites	
Albania	✓	✓	✓		Only presented at country medical events relating to individual cancer sites covered
Belarus	✓		✓	✓	Published as national registry document Scientific articles published in the Oncological Journal – a quarterly journal of the Belarusian Society of Oncologists
Bosnia-Herzegovina				✓	Health Condition of Population of Bosnia – government publication
Bulgaria	✓	✓	✓	✓	Bulgarian National Cancer Registry published in print
Croatia	✓		✓	✓	Annual published bulletins from Croatian National Cancer Registry and Croatian National Institute of Public Health
Czech Republic	✓	✓	✓	✓	Annual publications from Czech Republic Institute of Health Information and Statistics in collaboration with the National Cancer Registry
Estonia	✓		✓	✓	Some publication in Estonian and international journals Information submitted to international cancer survey websites
Hungary	✓	✓	✓	✓	Data published annually in Yearbook of National Statistics Office
Israel	✓		✓	✓	Peer review publications on MEDLINE National data for breast/CRC cancer screening by Dr Rennert Gad
Kazakhstan			✓		Statistical compilation prepared by Ministry of Health and Kazakh Research Institute of Radiology and Oncology
Latvia	✓	✓	✓	✓	Cancer Data Registry published annually by Centre for Health Economics
Lithuania	✓	✓	✓	✓	Publications in international and Lithuanian medical journals, often combined with data from other Baltic countries
Macedonia	✓	✓	✓	✓	Publication 'Cancer registry' 1995–2007, Institute for Public Health, Skopje, Macedonia. No recent data due to legal issues over patient information
Poland	✓	✓	✓	✓	No data published by regional cancer registries
Romania	✓	✓	✓	✓	Data available from individual regional registries (e.g. Cluj Regional Cancer Registry) but these are not published regularly
Russia	✓	✓	✓	✓	Reports published by the two cancer institutes: Hercin Institute – Malignant diseases in Russia (morbidity and mortality); Blokhin Centre – Cancer statistics in Russia and CIS states
Serbia	✓	✓	✓	✓	National population registry: for central Serbia 1998–2008 published online
Slovakia	✓	✓	✓	✓	Annual reports published by National Institute of Oncology
Slovenia	✓	✓	✓	✓	Annual reports published. All other publications are published at the end of the annual reports
Turkey	✓	✓	✓	✓	Cancer Control in Turkey (published book of Ministry of Health) Individual oncology centres may publish data online
Ukraine	✓	✓	✓	✓	Published annually online by National Cancer Registry

Note: These data are subject to change.

hence publication is often around 2 years behind the current date.

DISCUSSION

Data available

Epidemiological information is at the core of knowledge in medicine, especially in the field of cancer, and there is an expectation that improvements in the data available will have a positive influence on the ability to target resources effectively (Levi *et al.* 2001, 2003, 2004b; Parkin *et al.* 2001; Antunes *et al.* 2003; Boyle *et al.* 2003; Janssens *et al.* 2003; Quinn *et al.* 2003; Boyle 2004; Znaor & Bray 2012). It is anticipated that using all available knowledge could enhance the success and enable monitoring and evaluation of cancer prevention and treatment in the transitional countries discussed here compared with the original 15 EU countries (Boyle *et al.* 2003).

Based on the information collected, the authors believe that the recording and reporting of data on cancers is at an acceptable level in most countries across the region. The authors agree that all cancer registries throughout the region should comply with international standards and guidelines provided by the European Network of Cancer Registries and the International Association of Cancer Registries (IACR) (European Network of Cancer Registries n.d.; International Agency for Research on Cancer 1991, Cancer Registration: Principles and Methods IARC Scientific Publication No. 95; International Association of Cancer Registries n.d., Resources for Cancer Registration). Ideally, this would also be combined with treatment data, which would allow for ongoing assessment of the real impact of newer, more expensive cancer therapies.

Higher incidence rates compared with neighbouring countries should encourage authorities to explore risk factors responsible for these variations; higher mortality rates in South Eastern compared with North Western European countries (Znaor *et al.* 2013) should lead to evaluation of possible causes and a review of cancer management and treatment, as well as the implementation of screening programmes.

Awareness of the quality of reported mortality and incidence data is critical for reliable interpretation of the data and subsequent decisions. A round-table or consensus meeting where representatives of health authorities, cancer registries and key oncology centres would debate and comment on their national data, and have the opportunity to exchange information with neighbouring countries, could contribute to informed decision-making and eventually lead to measures improving the overall quality of the information. Ideally, dedicated staff would be

available to collect and analyse cancer information but economic constraints may inhibit this. Involving the pharmaceutical industry in such a process on a national, regional or European level may ease the economic burden.

Types of registry

A further consideration is whether it is necessary to have both institution-specific and national/regional population-based cancer registries. This might seem to be duplication, but there are theoretical reasons for having both types of registries. National population-based registries capture and present key epidemiological data such as mortality and incidence rates. Institution-based registries, typically from specialist centres, are more likely to include detailed case information including tumour size, grade, molecular markers present, treatments and clinical outcomes, which can provide valuable insights into local cancer patterns and treatment successes. The authors believe that a complementary system has many advantages, as well as some inherent risks if not executed properly.

One option to capitalise on the value of institution-based data collection and at the same time avoid the inherent risks of duplication of effort would be to collect data only at an institutional level, with selected data, carefully predefined by specific rules, transferred to a central registry. An alternative would be to submit all primary cancer data directly to a central registry, with a possibility for linkage with cancer treatment data in the future.

Comparison of country registries with the GLOBOCAN 2008 data sources

At least one registry from each country that responded to the survey either contributes data to, or is a member of, the IACR (International Association of Cancer Registries n.d.). GLOBOCAN cancer incidence estimates are available for all countries and are based on the most recent data available at the IARC, on information publically available on the internet or directly from local sources (Ferlay *et al.* 2010a, Cancer Incidence and Mortality Worldwide). The incidence data used must fulfil certain standards, and pass quality checks both locally and by the IACR. If such data are not available, other sources are used to estimate incidence, as described in the GLOBOCAN methods (Ferlay *et al.* 2010a, Cancer Incidence and Mortality Worldwide). Inconsistencies were therefore observed between some source data used by GLOBOCAN and the information that survey respondents indicated was available in their countries (Table 2).

Suggestions for the future use of cancer registry data in oncology

The authors believe that the future role of a cancer registry will expand beyond a focus on epidemiology. A registry should be multi-purpose, and include reliable data on treatments and outcomes for cancer patients, including survival data, as well as survivorship data. In addition to the well-established uses of cancer registries in epidemiological research and as the key tool for evaluation and monitoring of preventive programmes in the population, they could include disease-specific outcomes, enable evaluation of different treatment modalities (such as radiation therapy, surgical and medical treatments) and generate data on healthcare resource utilisation, which can be used in developing cost-effectiveness models. For example, data from the British Columbia Cancer Agency have been used in cost-effectiveness analyses for imatinib and trastuzumab (Mabasa *et al.* 2008; Hedden *et al.* 2012). Registry databases could be used to identify potential patients for inclusion in clinical trials, as well providing a tool to identify subsets of patients who do or do not benefit from specific treatments. For example, an analysis of the Surveillance, Epidemiology and End Results (SEER) database showed that the benefits of adjuvant radiation for gastric cancer were stage-dependent (Coburn *et al.* 2008).

Treatment- or drug-specific registries have been set up in other therapeutic areas when novel drugs have been introduced, such as anti-tumour necrosis factor- α treatment registries in the field of rheumatoid arthritis (Hetland 2005; Tubach *et al.* 2005; Watson *et al.* 2005; Neovius *et al.* 2011), but in oncology, few drug- or cancer type-specific registries exist. Newly introduced, personalised treatments, such as targeted agents for renal cell carcinoma and non-small cell lung cancer, and immune system activators for melanoma, represent important investments for health authorities and as yet little is known of their clinical impact. Specific drug- or cancer-type registries, ideally at a national level, would be a valuable source of information to monitor the clinical benefit of these novel treatments, and assist in assessing the advantages of reimbursing these drugs. For certain very rare types of cancer, or cancers with specific driver mutations (which may be the future of oncology), it will probably be necessary to organise regional or global registries in order to manage these patients better and to facilitate research on these populations.

The comprehensive nature of the information that can be obtained through a national cancer registry is illustrated by a model from the Nordic countries. Typically, all inhabitants of these countries have a national personal identification number through which their entry to

healthcare registries for various diseases can be aligned with comprehensive data on all aspects of healthcare relating to the condition. The RENal COMPARison (RENCOMP) study in Sweden, for example, used data from the National Cancer Register, National Patient Register and the Swedish Prescribed Drug Register (from 2005 onwards) to assess trends in treatment and survival of renal cell carcinoma. They showed, on a national level, that the introduction of tyrosine kinase inhibitors was associated with improved overall survival of patients with metastatic renal cell carcinoma (Harmenberg *et al.* 2012).

Communication of registry data

Collecting and analysing the data is one part of the process, but communication of the information is equally important. One of the widest areas of inter-country variation revealed by this survey is the publication and availability of data from both population-based and institutional registries. If the true, complementary value of population-based and institution-based registries is to be realised, then wider publication and publicity should be actively encouraged.

Effective communication is an important responsibility for all institutions, national and global bodies to ensure that data are truly representative for each country and cancer sub-specialty. In situations such as those outlined here, it is understandable that medical specialists may be confused as to what to consider as a true representation of their country's cancer burden. To this effect, the GLOBOCAN website does contain a cautionary note that the data it represents may not always correspond to recorded data which are now becoming available (Ferlay *et al.* 2010a, Cancer Incidence and Mortality Worldwide).

It must be acknowledged that a questionnaire-based survey has some weaknesses which limit the conclusions that can be drawn. For example, the response rate was considerably lower from healthcare authorities than from oncology institutions and the quality of the data was not further validated. Detailed and structured interviews with key physicians and healthcare authority leaders, as well as involving the cancer registry community to follow up on survey responses, and provision of data quality indicators rather than isolated checks of inconsistencies, could provide further insights.

CONCLUSION

Individual country health authorities should encourage cancer registration and base their decisions for cancer healthcare on robust, nationally owned and up-to-date epidemiological data. The potential value of collaboration

between health authorities across the region to ensure that their data are consistently collected, verified and made public should be explored.

ACKNOWLEDGEMENTS

The authors thank all of the respondents who contributed their information to the survey which formed the basis of this manuscript. They also thank Tonkica Boban for her assistance in collecting responses.

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DISCLOSURE

The authors designed the survey and analysed the data. Editorial support in the form of collation of survey responses, preparation of draft outline and manuscript first draft, assembling tables and figures and collating author comments was provided by Mark Edmondson and Christine Drewienkiewicz (Choice Healthcare Solutions, London, UK) and was funded by Pfizer Oncology. The study was sponsored by Pfizer.

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