



Co-funded by
the Health Programme
of the European Union

Survey of the activity of General Cancer Registries regarding Malignant Mesothelioma

WP 6. Activity coordinated by C. Magnani

Introduction

The survey was conducted as part of the activities of the MINE project and was aimed at gathering information on the activity of General Population Cancer Registries in respect to Malignant Mesothelioma. It was aimed at addressing the dimensions related to evaluation of cases, assessment of diagnosis, assessment of risk factors and information provided to the interested subjects. It also included a general description of the registry and of its scientific activity in respect to malignant mesothelioma.

Methods

The survey included the General Cancer Registries listed in the ENCR (European Network of Cancer Registries) as of November 20th, 2014. The ENCR database was further accessed in March 2015 in order to verify data for the registries that had not answered. For the non-responding registries a verification of the active status was carried out also with access to other databases, such as IACR or national networks of cancer registries. Documented non-active registries (defined as registries who never provided data neither published data) were cancelled from the survey base.

The survey was carried on using the MINE web site. A data collection section was included, with free access. Cancer registries were invited with a letter addressed to the Cancer registry head, according to ENCR data base or to more updated information collected during the survey. Up to 3 reminders were sent at 4 months intervals after the first invitation. Data were checked (registry name, head, address, e-mail and active status) after the first and second reminder, using literature search (published papers with affiliations) and different web databases including cancer registry data.

Results

Eighty eight registries took part in the survey, out of 121 invited. The participation in the survey was 72,7%. Table 1 summarizes participation by country. The survey included 27 out of 28 EU countries and we received answers for 25. Luxembourg could not be included because no cancer registries were listed in the ENCR data base. Switzerland was also included in the survey, even if not a EU country. Gibraltar is listed separately in the table, according to ENCR, but is not counted as a country.

Participation was lower in the countries also covered by a Mesothelioma registry, in particular France and Italy, as it was more difficult to explain to local registries that we were interested in the General Registries and not in specialized ones.

Table 1 Presents the number of registries invited and participating in the MINE survey on mesothelioma, by country.



Table 1		Answer received		Number of registries in the survey
Country	Code	y	n	
Austria	at	2	1	3
Belgium	be	1		1
Bulgaria	bg	1		1
Croatia	hr	1		1
Cyprus	cy	1		1
Czech Republic	cz	0	1	1
Estonia	ee	1		1
Finland	fi	1		1
France	fr	5	7	12
Germany	de	10	1	11
Gibraltar	gi	1		1
Hungary	hr	0	1	1
Iceland	is	1		1
Ireland	ie	1		1
Italy*	it	20	11	31
Latvia	lv	1		1
Lithuania	lt	1		1
Malta	mt	1		1
Norway	no	1		1
Poland	pl	6	3	9
Portugal	pt	4		4
Romania	ro	1		1
Slovakia	sk	1		1
Slovenia	si	1		1
Spain	es	7	6	13
Sweden	se	3		3
Switzerland	ch	10	2	12
The Netherlands	nl	1		1
United Kingdom	uk	4		4
Total		88	32	121

* One answer from a specialized mesothelioma registry

As most of the questions were in open form, the information was thoroughly revised, before and during the statistical analyses in order to check inconsistencies and to code the answers.

In addition to the general cancer registries in the EU countries some answers were received also from specialized mesothelioma registries (1, from Italy) and from non EU countries (1 each from Albania, Bosnia-Herzegovina, and Russia). The ENCR data base includes 10 registries in countries in the European region according to the UN definition but not in EU. Data provided from these registries are summarized shortly in the appendix but are not contributing to the analyses presented here.

All registries qualified as 'General Cancer Registries', with the only exception of the Mesothelioma Registry of Liguria (Italy) that is a specialized cancer registry and was not included in the analyses presented here.

Table 2 presents the population size covered by the registries included in the survey, by country. Registries with national coverage are identified ('y'). From Poland and Sweden we received answers from both 'National' and 'Local' registries. All answers are included with the same rank.

Table 2 Presents the registries that took part in the survey, by nation, national/local coverage and



population size.

Country	Country	National	Number of registries	Population
Austria	at		2	1255881
Belgium	be	y	1	11000000
Bulgaria	bg	y	1	7304632
Croatia	hr	y	1	4255689
Cyprus	cy	y	1	862000
Estonia	ee	y	1	1300000
Finland	fi	y	1	5400000
France	fr		5	4348058
Germany	de		10	63755898
Gibraltar	gi		1	30000
Iceland	is	y	1	320000
Ireland	ie	y	1	4600000
Italy*	it		20	20619789
Latvia	lv	y	1	2013000
Lithuania	lt	y	1	3000000
Malta	mt	y	1	423282
Norway	no	y	1	5109056
Poland	pl		5	18401000
Poland	pl	y	1	38500000
Portugal	pt		4	10547549
Romania	ro		1	2700000
Slovakia	sk	y	1	5397036
Slovenia	si	y	1	2000000
Spain	es		7	7554336
Sweden	se		2	2700000
Sweden	se	y	1	9640000
Switzerland	ch		10	4554652
TheNetherlands	nl	y	1	16800000
United Kingdom	uk	y	4	22140000

Registration Period and Scientific Activity

Most registries started their activities in the 1990's, with only 16 registries starting in this century (Table 2). However, we did not notice different procedures for those registries that started their activity more recently (data not tabulated).

Table 2 Year of start of registration for the registries included in the MINE survey on Mesothelioma

Year_start	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1933	1	1.14	1	1.14
1950	1	1.14	2	2.27
1952	1	1.14	3	3.41
1953	2	2.27	5	5.68
1954	1	1.14	6	6.82
1956	1	1.14	7	7.95
1958	4	4.55	11	12.50
1960	2	2.27	13	14.77
1962	1	1.14	14	15.91



1963	2	2.27	16	18.18
1965	1	1.14	17	19.32
1968	1	1.14	18	20.45
1969	1	1.14	19	21.59
1970	1	1.14	20	22.73
1974	3	3.41	23	26.14
1976	2	2.27	25	28.41
1978	1	1.14	26	29.55
1980	3	3.41	29	32.95
1982	1	1.14	30	34.09
1984	1	1.14	31	35.23
1985	6	6.82	37	42.05
1986	3	3.41	40	45.45
1987	1	1.14	41	46.59
1988	4	4.55	45	51.14
1989	4	4.55	49	55.68
1991	1	1.14	50	56.82
1993	2	2.27	52	59.09
1994	1	1.14	53	60.23
1995	4	4.55	57	64.77
1996	3	3.41	60	68.18
1997	2	2.27	62	70.45
1998	8	9.09	70	79.55
1999	2	2.27	72	81.82
2000	1	1.14	73	82.95
2002	2	2.27	75	85.23
2003	6	6.82	81	92.05
2004	1	1.14	82	93.18
2005	1	1.14	83	94.32
2006	2	2.27	85	96.59
2008	1	1.14	86	97.73
2011	1	1.14	87	98.86
2012	1	1.14	88	100.00

ff

Seventy two of the registries (81,8%) have their data published on Cancer Incidence in Five continents, in one or more editions.

Registries were asked about the production of scientific reports on mesothelioma: Four specific reports were listed (some of them are cooperative efforts including two or more registries):

1. Lacourt A, Gramond C, Rolland P, Ducamp S, Audignon S, Astoul P et al. Occupational and non-occupational attributable risk of asbestos exposure for malignant pleural mesothelioma. Thorax. 2014;69(6):532-9.
2. Damhuis RA, Schroten C, Burgers JA. Population-based survival for malignant mesothelioma after introduction of novel chemotherapy. Eur Respir J. 2012 Jul;40(1):185-9
3. Nicita C Buzzoni C, Chellini E, et al. A comparative analysis between regional mesothelioma registries and cancer registries: results of the ReNaM-AIRTUM project Epidemiol Prev. 2014 May-Aug;38(3-4):191-9.
4. Bianchi C1, Bianchi T .Global mesothelioma epidemic: Trend and features. Indian J Occup Environ Med. 2014 May;18(2):82-8.
5. Siesling S et al. Rare thoracic cancers, including peritoneum mesothelioma. Eur J Cancer. 2012; 48: 949-60



Registration procedures

The registration procedure is based on 'Active' registration for 36 registries (40,9%) and Passive registration (notifications provided to the registry) for 52 (59,1%). The difference reflects national differences in the current procedures of cancer registration, that are not further explored but are shown in the table 3.

Table 3 Presents the number of registries using active or passive registration, by country.

Country	Active	Passive	Total
at	2	0	2
be	0	1	1
bg	0	1	1
ch	4	6	10
cy	1	0	1
de	0	10	10
ee	0	1	1
es	3	4	7
fi	0	1	1
fr	4	1	5
gi	0	1	1
hr	0	1	1
ie	1	0	1
is	0	1	1
it	15	5	20
lt	0	1	1
lv	1	0	1
mt	0	1	1
nl	0	1	1
no	0	1	1
pl	2	4	6
pt	2	2	4
ro	0	1	1
se	1	2	3
si	0	1	1
sk	0	1	1
uk	0	4	4
Total	36	52	88

Active registration was carried on using different sources, as current practices for cancer registries. The sources most often used were:

Source	N	%
Clinical records	30	
Pathology records	30	



Co-funded by
the Health Programme
of the European Union

Death records	17	
Imaging records	1	
Palliative care records	1	
Radiotherapy records	3	
Health insurance records	4	

Two registries mentioned the access to Hospital based cancer registry data and 2 (both in Italy) the access to the mesothelioma registry data.

As for passive registration, the sources reported were:

Source	N	%
Clinical records	20	
Pathology records	44	
Death records	21	
Hospital admissions and discharge records	27	
General Practitioners	14	

Several registries nowadays use hospital admissions and discharge files as a preliminary tool to select the information that must be examined, and therefore the criteria of selection of relevant codes is of special importance. We observed that 4 registries reported the use of the C45 code (mesothelioma) but did not mention the C39 code (pleural malignancy). This selection criterion is a possible cause for the loss of mesothelioma cases.

As for diagnostic criteria, 85 registries out of 88 follow the IACR criteria.

All registries include histology and histology with immunohistochemistry as valid diagnostic bases for mesothelioma. 66 include also cytology with immunohistochemistry and 56 just cytology. Imaging is accepted as a diagnostic base by 48 registries.

Additional clinical information are collected by 82 registries (93,2%). Stage is recorded by 56, therapy by 41 and survival by 74.

In 71 registries (80,7%) mesothelioma cases are evaluated as all the other tumor types, without special evaluation. Special evaluation is reported by 15 registries: in 14 instances by internal staff and in 1 by external experts. Answer was missing for 1 registry. Histology / cytology specimens of MM cases are revised systematically in 6 registries: in 4 with panel verification (2: all cases, 1: selection and 1: missing answer) and in 2 by a single expert (1 for all cases and 1 no answer on the selection criteria). Two registries reported that the revision is prompted by the need to fulfill the rules for the compensation of cases and not because of the registration in the database.

Evaluation of exposure and information provided to subjects



Co-funded by
the Health Programme
of the European Union

Information on exposure does not receive special attention by general cancer registries: only 12 reported that exposure is collected and only 2 mentioned that questionnaire interviews are used. Eight used the information from clinical records, either as the unique source or in addition to the occupation reported in the death certificate. One registry mentioned the compensation claims as source of information. Information on exposure is evaluated by an expert in 3 registries.

If we exclude the countries served by a specialized mesothelioma registry (Germany, France, Italy, The Netherlands and the United Kingdom), collection of information on exposure was reported by 5 registries only, all using clinical record or clinical record plus death certificate as the source of data. Those registries are located in Switzerland (4 registries), Cyprus and Malta.

Only 2 registries (1 in France and 1 in Norway) inform cases of MM about the causes of the disease and of the right of compensation. Two registries (1 in Italy and 1 in Norway) notify MM cases to the compensation board. We also collected free comments on these topics: 6 registries claimed that informing patients or compensation boards is not a duty of cancer registries and that it is a duty of clinicians or of the special registries on mesothelioma.

Sixty eight registries showed interest in receiving more information and in accessing to information as reported in the MINE website. Information of interest were mainly of the clinical and diagnostic domain (rules of registration, information on survival and on long survival, organization and location of excellence centres). Only 4 cases listed an interest in information on exposure and on the causes of mesothelioma in workers and in the general population.

Discussion and conclusion

This survey enquired the current practices in data identification, registration and use of individual information in the Population based Cancer Registries active in the EU. The survey was completed by 72,7% of registries, that was over the target set in the project. The survey provided information from all EU countries as well as from Switzerland.

Procedures used for mesothelioma followed the standard rules adopted by the registries, with only a minority of the registries deciding to adopt special procedures for the verification of the cases. When adopted these procedures were based on the use of internal resources, however.

Only few registries investigated exposure and even fewer transferred this information to the interested subjects. Information aimed at compensation was considered not a duty of registry in its ordinary activity.

The survey will be completed with a revision of current activity of the mesothelioma registries set up in some countries.



Co-funded by
the Health Programme
of the European Union

Annex 1:

Answer to the survey			
Country	yes	not	Total
Albania	1		1
Belarus		1	1
Bosnia and Herzegovina	1	1	2
Moldova		1	1
Russia	1	2	3
Serbia		2	2
Ukraine		1	1
Totale complessivo	3	8	11



Co-funded by
the Health Programme
of the European Union

Annex 2 Acknowledgements

We are indebted to the registrars that took part in the survey:

Country	Name	Official_name_registry
al	Ferdinand Jorgoni	Interhospital Cancer Registry
at	Willi Oberaigner	Cancer Registry of Tyrol/Austria
at	Zorica Jukic	Carinthian Cancer Registry
ba	Zivana Gavric	The Cancer Registry Republic of Srpska
be	Kris Henau & Michael Roskamp	Belgian Cancer Registry
bg	Zdravka Valerianova	Bulgarian National Cancer Registry
ch	Fabio Levi	Cancer Registry of Jura
ch	Fabio Levi	Cancer Registry of Neuchâtel
ch	Fabio Levi	Cancer Registry of Vaud
ch	Dehler, Silvia	Cancer Registry Zurich and Zug
ch	Bertrand Camey	Registre des Tumeurs du Canton de Fribourg
ch	Anne Schmidt	Krebsregister Thurgau
ch	S. Mohsen Mousavi	Krebsregister beider Basel
ch	Andrea Bordoni	Ticino Cancer Registry
ch	Massimo Usel	Geneva Cancer Registry
ch	Konzelmann Isabelle	Valais Cancer Registry
cy	Pavlos Pavlou	Cyprus Cancer Registry
de	Sabine Luttmann	Bremen Cancer Registry
de	Alexander Katalinic	Cancer Registry of Schleswig-Holstein
de	Joachim Kieschke	Epidemiologisches Krebsregister Niedersachsen
de	Meike Ressing	Cancer Registry Rhineland-Palatinate
de	Martin Meyer	Bevölkerungsbezogenes Krebsregister Bayern
de	Bernd Holleczeck	Saarland Cancer Registry
de	Heidinger, Oliver	Epidemiologisches Krebsregister des Landes Nordrhein-Westfalen
de	Alice Nennecke	Hamburg Cancer Registry
de	Silke Hermann	Krebsregister Baden-Württemberg
de	Gabriele Schubert-Fritschle	Munich Cancer Registry
ee	Margit Magi	Estonian Cancer Registry
es	Rafael Marcos-Gragera	Girona Cancer Registry
es	Maria Ramos Monserrat	Registre de càncer de Mallorca
es	Manuel Errezola	BASQUE COUNTRY CANCER REGISTRY
es	Jaume Galceran	Registre de Càncer de Tarragona
es	Josefina Perucha González	Registro de Cáncer de La Rioja
es	J.Ramón Quirós	Registro de Tumores del Principado de Asturias
es	Araceli Alemán	Registro Poblacional de la Comunidad autónoma de Canarias
fi	Nea Malila	Finnish Cancer Registry
fr	F. Molinie	Loire-Atlantique and Vendee cancer registry
fr	Nathalie Leone	Registre Général des Cancers en Région Limousin
fr	Brigitte Tretarre	Registre des Tumeurs de l'Hérault
fr	Emilie Marrer	Haut-Rhin Cancer Registry
fr	P. Grosclaude	Registre des Cancers du Tarn
gi	Rachelle Asquez	Gibraltar Cancer Registry
hr	Mario Sekerija	Croatian National Cancer Registry
ie	Harry Comber	National Cancer Registry
is	Jón G. Jónasson	Icelandic Cancer registry
it	Gemma Gola	Cancer Registry of Como province
it	Francesco Cuccaro	Cancer Registry of ASL BT - Section of Cancer Registry of Puglia
it	Francesco Vitale	Palermo Province Cancer Registry
it	Diego Serraino	Friuli Venezia Giulia Cancer Registry
it	Adele Caldarella	Cancer Registry of Tuscany
it	Silvia Patriarca	Piedmont Cancer Registry
it	Rosario Tumino	Registro Tumori della Provincia di Ragusa
it	Valerio Gennaro	Registro Mesoteloma della Liguria (COR Liguria del RENAM)
it	Mariangela Autelitano	Cancer Registry of Milan
it	Silvano Piffer	Trento Cancer Registry
it	Stefano Ferretti	Registro tumori Area Vasta Emilia Centrale
it	Giovanna Tagliabue	Lombardy Cancer Registry , Varese Province (LCR)
it	Lucia Mangone	Registro Tumori Reggiano
it	Michele Magoni	Registro Tumori dell'ASL di Brescia
it	Giovanni Marazza	Registro Tumori di Lodi
it	Fabio Falcini	Registro Tumori della Romagna
it	Mario Usala	Registro Tumori di Nuoro
it	Luigina Ada Bonelli	Ligurian Cancer Registry
it	Mario Fusco	Cancer Registry Campania Region c/o ASL Napoli 3 south



Co-funded by
the Health Programme
of the European Union

it	Giuseppa Candela	Trapani Cancer registry
it	Adriano Giacomini	Registro Tumori Piemonte, Province di Biella e Vercelli
lt	Giedre Smailyte	Lithuanian Cancer Registry
lv	Elina Liepina	Latvian Cancer Register
mt	Dominic Agius	Malta National Cancer Registry
nl	Ronald Damhuis	Netherlands Cancer Registry
no	Kristina Kjaerheim	Cancer Registry of Norway, inst. of population-based cancer research
pl	Maciej Trojanowski	Greater Poland Cancer Registry
pl	Andrzej Tukiendorf	Silesia Cancer Registry
pl	Kamila Kepska	Lower Silesian Cancer Registry
pl	Monika Gradalska-Lampart	Department of Epidemiology and Podkarpackie Cancer Registry
pl	Maria Zwierko	Warsaw Cancer Registry
pl	Urszula Wojciechowska	Polish National Cancer Registry
pt	Gonzalo Forjaz de Lacerda	Registo Oncologico Regional dos Azores (Azores Cancer Registry)
pt	Ana Miranda	ROR-Sul - Registo Oncológico Regional Sul
pt	Joana Bastos	Registo Oncológico Regional do Centro (ROR-Centro)
pt	Maria José Bento	Registo Oncológico Regional do Norte
ro	Daniela Coza	Cluj Regional Cancer Registry
ru	V. M Merabishvili	Population-based Cancer Registry of St. Petersburg
se	Erik Holmberg	Regional Cancer Register Western Sweden
se	Shiva Ayoubi	The Swedish Cancer registry
se	Johan Rosell	Swedish Cancer Registry
si	Maja Primic Akelj	Cancer Registry of Republic of Slovenia
sk	Chakameh Safaei Diba	National Cancer Registry of Slovakia
uk	David Brewster	Scottish Cancer Registry
uk	Deirdre Fitzpatrick	N.Ireland Cancer Registry
uk	Joy McRae	Welsh Cancer Intelligence & Surveillance Unit
uk	Karen Linklater	National Cancer Registration Service (London)