



European
Commission

JRC CONFERENCE AND WORKSHOP REPORTS

Defining the roadmap towards revision of **ENCR coding standards** and **training** for cancer registries

ENCR-JRC Workshop

Emanuele Crocetti, Raquel N. Carvalho,
Tadek Dyba, Carmen Martos, Giorgia Randi,
Roisin Rooney, Lydia Voti, Alexander Katalinic
and Manola Bettio

2015



This is a publication by the Joint Research Centre, the European Commission's in-house science service. It aims to provide evidence-based scientific support to the European policy-making process. The scientific output expressed does not imply a policy position of the European Commission. Neither the European Commission nor any person acting on behalf of the Commission is responsible for the use which might be made of this publication.

Contact information

Name: Emanuele Crocetti

Address: Joint Research Centre, IHCP, Public Health Policy Support, Via Enrico Fermi 2749, TP 127, 21027 Ispra (VA), Italy

E-mail: emanuele.crocetti@ec.europa.eu

Tel.: +39 0332 78 9697

ENCR Web Site

<http://encr.eu/>

JRC Science Hub

<https://ec.europa.eu/jrc/>

JRC99783

EUR 27658 EN

ISBN 978-92-79-54205-3 (pdf)

ISBN 978-92-79-54206-0 (print)

ISSN 1831-9424 (online)

ISSN 1018-5593 (print)

doi:10.2788/419812 (online)

doi:10.2788/95370 (print)

© European Union, 2015

Reproduction is authorised provided the source is acknowledged.

All images © European Union, 2015 (unless otherwise specified)

How to cite: Emanuele Crocetti, Raquel N. Carvalho, Tadek Dyba, Carmen Martos, Giorgia Randi, Roisin Rooney, Lydia Voti, Alexander Katalinic and Manola Bettiox; Defining the roadmap towards revision of ENCR coding standards and training for cancer registries – ENCR-JRC Workshop; EUR 27658 EN; doi:10.2788/419812.



Defining the roadmap towards revision
of **ENCR coding standards**
and **training** for cancer registries

ENCR-JRC Workshop

Emanuele Crocetti, Raquel N. Carvalho,
Tadek Dyba, Carmen Martos, Giorgia Randi,
Roisin Rooney, Lydia Voti, Alexander Katalinic
and Manola Bettio

2015

Table of contents

<i>Acknowledgement</i>	4
ABSTRACT	5
1. Introduction	7
The need for action	7
The recent past and the present	8
2. Methods	11
2.1. Proposal of the ENCR-SC for a Workshop	11
2.2. Invited experts	11
2.3. Before the workshop: the questionnaire	12
2.4. Meeting: Metaplan methodology	13
3. Results	14
3.1. Recommendations	14
3.2. Training	15
3.3. Brief summary of the discussion in the Recommendation Group	16
3.4. Brief summary of the discussion in the Training Group	18
3.5. Proposals presented to the plenary session	20
4. Conclusion	21
References	22
<i>Annex I:</i> Workshop participants	23
<i>Annex II:</i> Pre-meeting questionnaire	31
<i>Annex III:</i> Workshop agenda	34

Acknowledgement

The authors would like to thank Manuel FLORENSA MOLIST for his editorial support.

ABSTRACT

The European Network of Cancer Registries (ENCR) and the Joint Research Centre (JRC) jointly support harmonising the activities of the European population-based cancer registries (CR) in providing reliable and valid data on cancer.

The process to supply valid, complete and comparable data in different European Countries, implies that CR implement common rules to define and code cancer and receive similar training. For this reason, one of the main activities of the ENCR-JRC is to provide CR staff with specific recommendations on coding along with training.

For ENCR-JRC the objective of this workshop was to collate previous and current requests from CR and provide advice on the most pressing issues relating to recommendations and training.

The workshop was planned during the ENCR Steering Committee (SC) meeting, which took place on November 2014, and JRC (the Secretariat of ENCR) was requested to organise it.

A group of experts on cancer registration was identified. This group included the ENCR-SC members, representatives from institutions and cancer research projects which collaborate with CR (*i.e.* IARC, Eurocare, Concord, Rarecare), representatives from national networks of CR, members of the Cancer Information group at the JRC, and other specialists in the field.

Prior to the workshop, an anonymous questionnaire was sent to the group of experts. Moreover, all directors and staff of CR were invited to complete the questionnaire and provide comments in order for ENCR- JRC to get a more comprehensive overview of the situation. The questionnaire invited respondents to specify the five most urgent topics, to be addressed, on both recommendations and training.

During the workshop, participants (around 30 people) were split into two groups: one to focus on recommendations and the other to focus on training. For each group a moderator facilitated the debate presented by the responses to the questionnaire, which were discussed in detail using the Metaplan method.

The results of the discussion were summarized in a final plenary section, where further clarifications were given and all the participants were involved in the discussion.

In summary, the topics to be addressed by the ENCR-SC, in relation to recommendations, either as updates of current recommendations or for new specific ones, were: Multiple primary rules; Staging; Registration/reportability criteria; Death Certificate Only cases (DCO)–Death Certificate Notified cases (DCN); Date of incidence in relation to diagnosis; ‘Complicated’ cancers (*e.g.* bladder, etc.); Haematological cancers; and coding of borderline malignancies.

The group on training suggested that all the issues that were raised (Cancer Registration; Haematological malignancies; Analysis; Stage; Quality; Multiple primaries; many on Specific cancer types; and Grading) should be addressed making available on the web high quality, reliable and training-oriented documentations. JRC offered to translate these documents, if necessary, into other European languages. For training on specific technical methodology (analysis, data quality) it was suggested that traditional face-to-face courses be provided.

The workshop highlighted that recommendations and training are interlinked and this implies that, in the future, any new recommendation should be issued together with training documentation to explain its practical application.

The technical proposals made at the workshop will help the ENCR-SC to prioritize the future supporting activities to the real needs of CR.

1. Introduction

The need for action

Population-based cancer registries (CR) provide basic information for monitoring the burden of cancer through computation and dissemination of cancer statistics. Such information is collected at individual record level, and includes data according to the type of cancer (site, morphology, etc.) and characteristics of patients (sex, age, etc.). The reliability of such information depends on their quality (Bray 2009), taking into account different dimensions: comparability, completeness, validity and timeliness (Bray 2009, Parkin 2009). In particular, comparability reflects the extent to which different CR use the same procedures, classifications and coding to define, code and report cancer cases.

The World Health Organization classifications are used in the field of cancer registration (International classification of disease, International classification of disease for oncology). Moreover, specific and necessary recommendations to complement existing classifications (*e.g.* for defining the incidence date, multiple primaries, etc.) are provided by International organizations.

In Europe, the rules are provided by the European Network of Cancer Registries (ENCR), in agreement with the International Association of Cancer Registries (IACR) and the International Agency for Research on Cancer (IARC).

Agreed recommendations are extremely important because they provide common standards for all CR. In addition, it is important to provide additional training to CR staff to enable them to understand good practices and procedures for establishing or improving cancer registration and for harmonising the registration process for collection of cancer data.

At European level, CR are networked and supported by the scientific organisation ENCR (<http://encr.eu/>), which advocates for collaboration between cancer registries, sets data collection standards and provides training for cancer registry

personnel, thus promoting homogeneous data collection and dissemination of high quality and comparable information on cancer incidence and mortality in Europe.

Established in 1989 and since then funded – among others – by the European Commission, the ENCR is currently hosted, since 2012, at the European Commission’s Joint Research Centre (JRC) in Ispra, Italy.

The recent past and the present

Since its foundation the ENCR has established expert working groups to examine specific topics, identified as potentially problematic in cancer coding. These working groups generally consisted of three to four people selected by the ENCR Steering Committee. Their task was to assess the issues, defined by the terms of reference for the working group, and make recommendations for the CR.

The first issues to be tackled were on how to code the date of incidence, bladder tumours and multiple tumours (1995), followed by recommendations for coding tumours of the CNS (1998) and basis of diagnosis (1999). Other recommendations were since issued and are all available on the ENCR web site (<http://encr.eu/index.php/activities/recommendations>) and summarised in *Table 1*. The latest recommendation available is included in the report *A proposal on data quality checks: one common procedure for European CR*, disseminated in 2014 as an outcome of the ENCR-JRC Working Group on Quality Checks.

Table 1. Previous recommendations from the ENCR.

Topics	Date	Language
Cancer data quality check harmonisation	1 st Workshop: 2 July 2013 2 nd Workshop: 15 October 2013 3 rd Workshop: 4 June 2014 Final document: December 2014	EN
New recommendations on haematological cancers	26 Feb 2014	EN
Data protection	3 May 2011 September 2012	EN

Table 1 (cont.)

Topics	Date	Language
Standard dataset	10 February 2005	EN
Incidence Date	Distributed in 1995 Revised in 1997	EN, FR, DE, SP
Multiple Primaries	Distributed in 1995 Revised in 2000 Revised in 2004	EN
Bladder Tumours	Distributed in 1995	EN, FR, DE, SP
Tumours of the Brain and Central Nervous System	Distributed in 1998	EN
Leukaemias and Lymphomas		EN
Basis of Diagnosis	Distributed in 1999	EN
Non-Melanoma Skin Cancers	Distributed in 2000	EN
Method of Detection in Relation to Screening	Distributed in 2001	EN
Confidentiality in Cancer registration	Distributed in 2002	EN, FR
Condensed TNM for Coding the Extent of Disease	Distributed in 2002	EN, FR
Structured Registry Review		EN

Recommendations may become outdated if there is substantial advancement in knowledge. This was the case for some of the earliest recommendations, which were updated and revised over time (*e.g.* new recommendations on date of incidence in 1997, updated ones for multiple primaries in 2000 and in 2004, etc.).

Besides availability, a critical issue for recommendations is their usability. Actually, the official language of the ENCR recommendations is English; while some recommendations have been translated into other European languages (French, Spanish, German), most of them were not. An additional effort to translate old and new recommendations would likely improve their usability by the CR staff.

The provision of training for CR staff has been an activity which the ENCR has carried out quite regularly over time, with about one or two course(s) per year. The issues addressed can be classified as belonging to two main groups: cancer registration methods and statistical analysis methods.

Training CR on cancer registration methods was aimed at improving the capability of CR staff in providing high quality and comparable data, while providing participants with good networking opportunities and giving them the opportunity to develop closer links with other ENCR colleagues. This type of training aimed to facilitate inter-comparative studies on specific cancer types.

Training on statistical analysis methods was aimed at ensuring that standard methods of analysis and appropriate data presentations are used in CR research and reports. The main statistical training over the years included the following: survival, geo-spatial statistical analysis, predictions and time trends.

Besides those reported above, training was also given on the use of the EURO-CIM software, on the International Classification of Disease for Oncology 3rd edition and on automated cancer registration.

As with the recommendations, there is a need to increase the provision of training material in different languages.

To conclude, the ENCR has considerable experience in providing recommendations on coding and in training CR staff. Both updating recommendations and providing training should be part of an on-going process which includes continuous support for the basic needs of new CR staff. Secondly, due to the continuous improvement in cancer knowledge (*e.g.* stage, biomarkers) as well as new statistical methods (*e.g.* for net survival), the ENCR should also support CR staff who need to be updated on new or revised topics. Therefore, it would be beneficial if the ENCR keep updated with the development of knowledge and support the CR in the collection and/or reporting of new/modified variables.

2. Methods

2.1. Proposal of the ENCR-SC for a Workshop

At the ENCR SC meeting of November 12, 2014, the SC requested the ENCR Secretariat to collect suggestions from CR about their needs for both training and new/revised recommendations. Different options for the training format were evaluated, including ‘hands-on’ courses through to site visits to CR, regional meetings, or adopting a web-approach through webinars and e-learning. General topics for new recommendations were also indicated by the SC.

In this identification exercise, it was considered worthwhile to pursue a bottom up approach in the decision-making process by offering, for the first time, an opportunity for the end-users of training and recommendations to have an active role in setting the priorities of the ENCR. It was, thus, decided that the JRC would organise a workshop to brainstorm these issues and identify and specify the needs of CR staff, set priorities, set up working groups and identify workgroup members and leaders. This information could then be used by the SC to address future work on recommendations and training, by agreeing and prioritising, together with the JRC, the proposed activities given the available resources and budget.

Following this, the JRC organized on 24.11.2015 the Workshop titled ‘Defining a road map towards revision of ENCR coding standards and training for cancer registries’.

2.2. Invited experts

The experts invited to the workshop included the members of the ENCR Steering Committee, representatives from national networks of regional CR (Spain, France, Italy and Switzerland), representatives from Institutions and Projects handling CR data (IARC, Eurocare, Concord, Rarecare), experts suggested by the ENCR-SC and others who were involved in the Quality Checks project. Participants’ profiles included directors of national or regional cancer registries, CR staff, and repre-

sentatives from Institutions (IARC, INT Milan, London School of Hygiene and Tropical Medicine). The staff from the Cancer Information group of JRC's Public Health Policy Support Unit was also involved in the exercise. Overall 36 people were invited from 15 different European countries (list of participants in *Annex I*).

2.3. Before the workshop: the questionnaire

Prior to the meeting, and with the aim of gathering preliminary suggestions to help kick-off the discussion during the workshop, a short questionnaire was prepared to collect a preliminary list of topics on both recommendations and training (*Annex II*).

The questionnaire included five questions requesting each respondent to indicate the five most urgent topics to be tackled in terms of old recommendations to be updated or new ones to be issued; besides this, the sections on training requested participants to suggest the five most urgent topics for CR staff training. For each topic the respondent could suggest the name of experts to deal with each topic.

The questionnaire was created and disseminated through EU survey (<https://ec.europa.eu/eusurvey/>) on November 5, 2015, and, as well as the invited experts, it targeted ENCR-affiliated CR Directors and staff, to get a wider representation of CR needs and suggestions.

The questionnaire was designed by taking inspiration from the Delphi methodology. The Delphi method is a communication technique that aims to reach an agreement among a group of experts (Darlkey and Helmer, 1963). The method is widely used in many settings including patient registry (Cavero-Carbonell *et al.*, 2015) and cancer registry (Cuervo *et al.* 1999). Among the characteristics of the Delphi technique, the questionnaire safeguarded *anonymity* to respondents. Anonymity helps respondents to avoid the uneasiness which the presence of dominant personalities (renowned experts) may cause inhibiting the expressions of relevant needs.

The *information flow* consisted of responses to the questions by participants, who did not participate in the survey. These responses were processed and grouped together in groups of homogeneous topics. Irrelevant content was filtered out.

Finally, the responses represented the *feedback* from the experts received during the workshop.

2.4. Meeting: Metaplan methodology

At the workshop, two discussion groups were formed: one focused on training needs and the other on recommendations. The Metaplan methodology was proposed to guide the discussion in groups, having as a starting point, the outcome of the questionnaire which was presented to the participants. The Metaplan-based discussion produces a visual image of the discussed points and aims to secure a good level of interaction among participants. This is done by writing discussion points on flashcards that can be moved around and grouped according to consensus of the participants. Following this approach, discussion at the meeting led to the refinement of the proposals and their ranking based on priority, and allowed the clustering of different proposals inside broader priority groups.

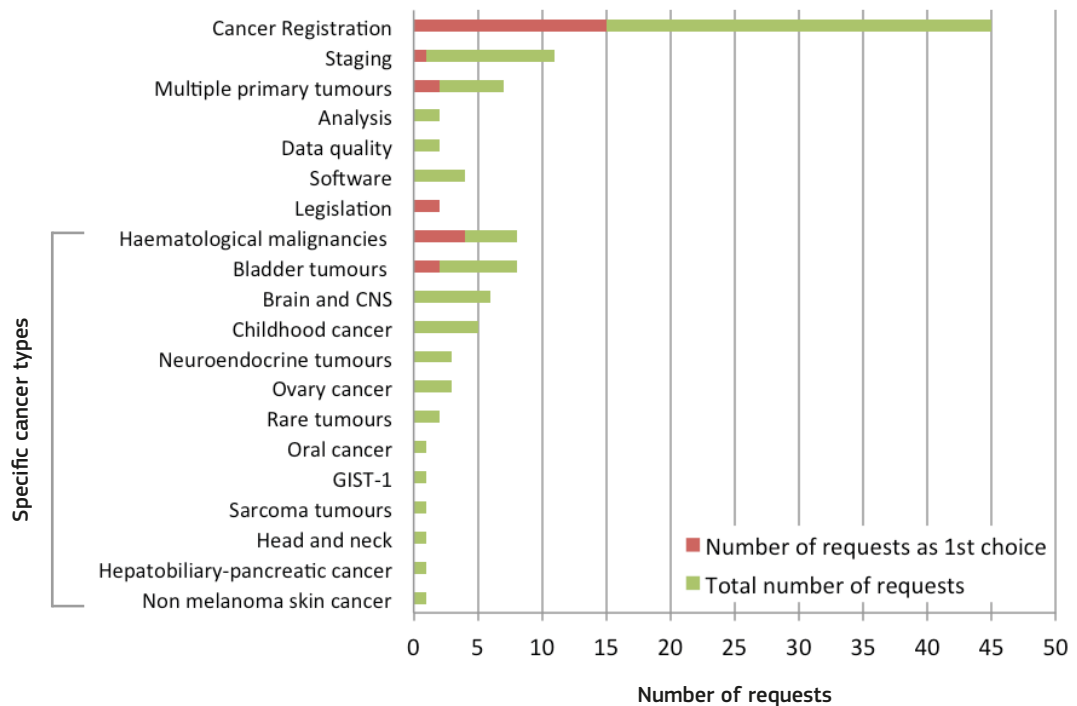
3. Results

Thirty-three people responded to the questionnaire. Among those who responded, twelve were CR staff, fifteen were CR directors and six were invited experts. JRC staff collected all the answers, and summarised them in general topics, to facilitate their presentation by the two facilitators. These were discussed in the sub/groups at the meeting.

3.1. Recommendations

As regards recommendations, 32 of the respondents indicated at least one topic of interest, 28 (97%) indicated at least two topics, 22 (69%) indicated a third and a fourth topic and 17 (53%) indicated a fifth topic for ENCR prioritisation.

Figure 1. Summary of the recommendations proposed by the questionnaire respondents.

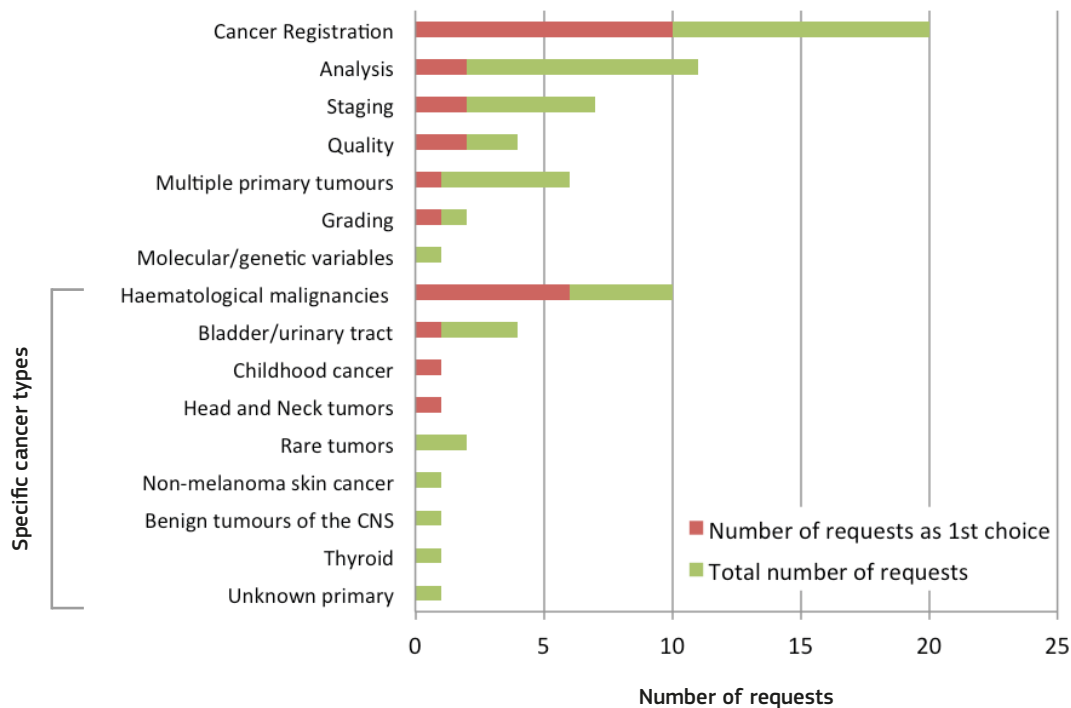


The top mentioned topics for recommendations were the following: Cancer registration (principles and methods), Staging, Haematological malignancies, Bladder tumours, coding of specific cancer types (brain and CNS; childhood cancer; neuroendocrine tumours; ovary cancer; rare tumours; oral cancer; GIST; sarcoma tumours; head and neck; hepatobiliary-pancreatic cancer; non melanoma skin cancer), Multiple primary rules, Analysis, Data quality, Software and Legislation (*Figure 1*).

3.2. Training

As regards training, 29 responders indicated at least one topic for prioritisation, 24 (83%) provided a second proposal, 17 (59%) a third, 11 (38%) a fourth and nine (31%) provided five suggestions. The most suggested topics for training were the following: Cancer Registration, Haematological malignancies, Analysis, Stage, Quality, Multiple primaries, many Specific cancer types and Grading (*Figure 2*).

Figure 2. Summary of the training topics proposed by the questionnaire respondents.



Moreover, there were nine comments regarding recommendations, and six on training. Most of them were general: translation of recommendations into different European languages, availability of reliable documentation, use of web-tools to share documents and perform training, etc.

The responses showed a certain fuzzy boundary between recommendations and training. In fact, most of the issues were mentioned in both parts of the questionnaire. The impression was that, for CR staff and experts, it was not straightforward to differentiate the rules from the guidelines and their application. This suggests that there is a need to provide specific training each time new rules (recommendations) are released.

In addition, some respondents expressed appreciation for the opportunity to provide suggestions, and highlighted a desire for more regular contact between the ENCR SC and Secretariat with the CR.

3.3. Brief summary of the discussion in the Recommendation Group

The moderator briefed the participants on the proposals captured by the survey which was conducted prior to the workshop. Each topic was written on a sheet of paper and posted on the wall. All topics were discussed, and for some topics clarifications were given. Whenever a new proposal was deemed similar to a previous one, they were clustered together on the wall. In this way some grouping started to emerge, while, on the other hand, more in-depth discussion continued on specific items.

Besides the inputs from the survey, the group members also contributed to additional proposals, either in reaction to the questionnaire's answers or following the discussion on specific themes. These new contributions were included in the appropriate clusters.

Once the responses were collated, all the sub-items were classified under a specific topic; when this was not possible, they were labelled as general/unspecified issues. One category that emerged from this process was a more generic one: that of 'coding of complicated cancers'.



Once the general topics for development, or updates of recommendations, were well defined, the participants voted in order to prioritize them.

The moderator gave each participant five green and five red strips of sticky paper. The participants were asked to vote by adding a green sticky next to the topics they considered the most urgent to be addressed, or a red sticky next to those topics they considered not so urgent.

All the votes for each topic were counted, summing up the green strips and subtracting the red ones. The final number defined the rank of the most urgent topics, *i.e.* for existing recommendation, that need an update or new recommendations that need to be developed:

Multiple primary rules (nine votes): SEER and IARC have rules but cross references are needed and comparability issue between IARC, ENCR and SEER rules need to be addressed.

Stage (seven): Comparability of different TNM versions; conversion of TNM to and from other staging systems; handling of missing data; clear distinction between clinical and pathological TNM; collection of pathologic information, etc.

Coding and registration (seven): Case reportability, Registration criteria are needed. Recommendations are needed on how information on variables should be collected.

DCO-DCN cases (seven): There are often coding problems in relation to cause of death, especially in case of a ‘suspicion of cancer’.

Date of incidence related to basis of diagnosis (six): especially in case of progression from *in situ* to invasive tumours; the increasing role of biomarkers has to be considered.

Complicated to code cases (six): *e.g.* sarcomas of the CNS; rare cancer; progression of bladder cancers; childhood cancers.

Haematological malignancies (five): they are still challenging for coding despite the availability of the HEAMACARE manual. The update of ICD-O-3 in 2011 needs also to be implemented.

Coding of borderline tumours (three).

3.4. Brief summary of the discussion in the Training Group

The main results of the questionnaire, regarding training, were presented by the group moderator. It was agreed to start discussing the training topics according to their rank, *i.e.* the highest number of requests. Therefore, the discussion focused first on cancer registration.



The moderator described the specific requests received which had been summarized under a common title, and included three main sub-topics: data process, data

analysis and data registration. The majority of the requests were for general training. The discussion considered ‘what’, *i.e.* the content of the training, and ‘how’, *i.e.* the modalities of the training to be offered. One of the topics which emerged among the agreed proposals was the need to perform a review on what was already available on the web, in order to avoid duplication of training material.

The web and web-based tools were the most suggested options for how to perform any form of training on cancer registration. The group agreed that the ENCR-SC provide documentation/materials on the different topics. The materials would be certified as ‘approved by ENCR’, specifically produced for training (simple, easy to be read and understood, with practical examples, questions and answers, etc.). This seemed a logical way to tackle almost all the specific requests, from general issues (history of cancer registration) to advanced and cancer-specific matters. Among the latter, it was considered urgent to provide training materials on how to code haematological cancers including the many specific matters (multiple primary, evolution from one tumour to another one, etc.).

According to the group, the provision of high quality training materials is the way to overcome some of the possible limits of traditional face-to-face training (limited attendance, cost for travelling and accommodation, etc.) and, on the other hand, could improve the dissemination and the harmonization of knowledge and its application in routine cancer registration with web accessibility. An important issue raised, by both the questionnaire respondents and the workshop participants, was the availability of training documentation in different EU languages (and eventually also in Russian). The JRC offered to translate training materials from English into other European languages if there is a request. Among the other topics mentioned in the questionnaire, those related to the application of a specific technical methodology (analysis, data quality). According to the group, could be better dealt with by traditional courses, provided the course materials are made available on the web and, hopefully, the course itself accessible afterwards on the web.

After a long and fruitful discussion, the group agreed on a series of points to be presented to the plenary meeting before agreeing the final points for the ENCR-SC.

3.5. Proposals presented to the plenary session

In the final plenary meeting, the moderator of each of the two groups presented a summary of the results of the questionnaire related to the groups' specific section (recommendations and training), and summarized the work within each group to reach an agreement on the most urgent topics to be addressed.

As regards recommendations, either as updates of already available recommendations or for new specific ones, the rank of the most urgent matters was:

- 1) Multiple primaries.
- 2) Staging.
- 3) Registration criteria.
- 4) DCO–DCI.
- 5) Data of incidence/base of diagnosis.
- 6) 'Complicated cases'.
- 7) Haematological malignancies.
- 8) Coding borderline malignancies.

As regards the group on training, the summary message to the participants was:

- 1) A proposal to move from traditional face-to-face courses to the production of official documentation of high quality, reliable, training-oriented, with simple messages and easy to be understood by all the members of CR staff, bearing in mind what is already available, and making it available on the web.
- 2) The training portfolio should be built up stepwise, by focusing the initial efforts on producing training material on basic issues of cancer registration, and later by including more advanced training material on issues mentioned in the questionnaire's responses, including general matters and cancer-site specific (*e.g.* Haematological malignancies), and specific topics (*e.g.* Multiple primaries).
- 3) Consider the translation of training material into different languages upon request.
- 4) Consider traditional courses for addressing data analysis/data quality evaluation but making the documentation used/presented in the course and possibly, the record of the course, available on the web.

During the plenary session there were several questions put to the two moderators, with requests for clarifications and comments.

4 . Conclusion

The proposal made by the two groups will be forwarded to the ENCR-SC as a list of suggestions representing the requests from the CR perspective. Cancer registration is an activity that requires harmonization of data collection, coding and reporting, in order to produce reliable and comparable data. Recommendations and training are invaluable tools for CR to achieve high quality performance in the data recording process. From the responses to the questionnaire, and from the discussion within the two groups, ‘recommendations’ and ‘training’ did not appear to be completely separated topics; on the contrary, most of the issues appeared as priorities in both groups. Therefore, it was concluded that, in the future, any new recommendation should be issued together with training material, to explain its practical application.

Given that cancer registry activity is a continuous process, with periodic turnover of the CR staff, the need to continuously offer basic training was assessed. Moreover, there are traditionally ‘difficult’ matters (*e.g.* haematological tumours, multiple primaries, etc.) which still need to be clarified, including specific training on how to apply recommendations.

Furthermore, European CR staff includes expert professionals who may need more advanced training. Therefore, the recommendation and the training should be customized to different levels.

The web will increase the availability of recommendations and training documentation/materials among CR, at all levels.

Finally, CR are strictly linked to the clinical world. Therefore, the updating of recommendations, and the offer of training, have to be considered an ongoing process alongside continuous development of knowledge in the cancer domain, with the aim of extending rules and procedures to new topics which currently are essential for clinicians for the correct cancer diagnosis and definition (*e.g.* imaging, biomarkers).

References

- BRAY F, PARKIN DM (2009). Evaluation of data quality in the cancer registry: Principles and methods. Part I: Comparability, validity and timeliness. *European Journal of Cancer*, 45(5), 747-755, <http://dx.doi.org/10.1016/j.ejca.2008.11.032>.
- PARKIN DM, BRAY F (2009). Evaluation of data quality in the cancer registry: principles and methods. Part II: Completeness. *European Journal of Cancer*, 45(5), 756-764, <http://dx.doi.org/10.1016/j.ejca.2008.11.033>.
- MARTOS C, CROCETTI E, VISSER O, ROUS B *et al.* (2014). *A proposal on cancer data quality checks: one common procedure for European cancer registries* (Version 1.0). JRC Technical Report, ISBN 978-92-79-44675, ISSN 1831-9424.
- DARLKEY N, HELMER O (1963). An experimental application of the Delphi method to the use of experts. *Management Science*, 9(3):458-467.
- CAVERO-CARBONELL C, GRAS-COLOMER E, Guaita-Calatrava R, López-Briones C, Amorós R, Abaitua I, Posada M, Zurriaga O (2015). Consensus on the criteria needed for creating a rare-disease patient registry. A Delphi study. *J. Publ. Health*. doi:10.1093/pubmed/fdv099.
- Cuervo LG, Roca S, Rodríguez MN, Stein J, Izquierdo J, Trujillo A, Mora M (1999). Evaluation of institutional cancer registries in Colombia. *Rev Panam Salud Pública*, 6(3):202-206.

Annex I: Workshop participants

Members of the ENCR Steering Committee



Alexander KATALINIC

Institut für Sozialmedizin und Epidemiologie
Institut für Krebs epidemiologie e.V., Universität Lübeck
Universitätsklinikum Schleswig-Holstein, Campus Lübeck
Germany



Harry COMBER

Director of the National Cancer Registry Ireland



Carlotta BUZZONI

Coordinamento Statistico/S.C. Epidemiologia Clinica
Istituto per lo Studio e la Prevenzione Oncologica
Italy



Anna MIRANDA

Representative of the Groupe pour Epidémiologie et l'Enregistrement du Cancer dans les Pays de Langue Latine (GRELL)

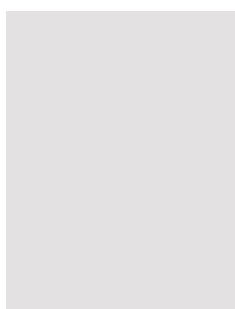
Instituto Português de Oncologia de Francisco Gentil
Centro Regional de Lisboa
Portugal



Andrea BORDONI

Representative of the International Association of Cancer Registries (IACR)

Ticino Cancer Registry
Cantonal Institute of Pathology
Switzerland



Jacques FERLAY (replacing Freddy Bray)

Representative of the International Agency for Research on Cancer (IARC)

France



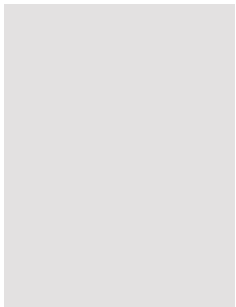
Nadia DIMITROVA

MD, PhD, has been an epidemiologist at the Bulgarian National Cancer Registry since 2007 and during the period 2010-2013 she was its Director



María Dolores CHIRLAQUE

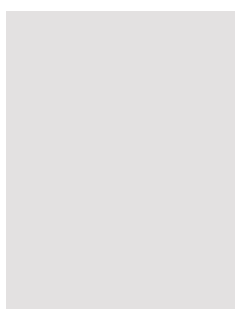
MD, Specialist in Preventive Medicine and Public Health
Coordinator of Murcia Cancer Registry
Professor in Murcia University, Department of Health
and Social Sciences
Member of REDECAN (Spanish Network of Cancer
Registries)



Hans STORM

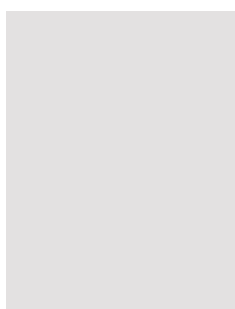
Representative of the Association of the Nordic cancer
registries (ANCR)
(Unable to attend)

Invited participants



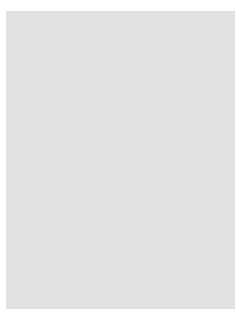
Milena SANT

Analytical Epidemiology and Health Impact Unit
Department of Preventive and Predictive Medicine
Fondazione IRCCS Istituto Nazionale dei Tumori
Via Venezian 1, 20133, Milan, Italy



Annalisa TRAMA

Assessment epidemiology Unit
Department of Preventive and Predictive Medicine
Fondazione IRCCS Istituto Nazionale dei Tumori
Via Venezian 1, 20133, Milan, Italy



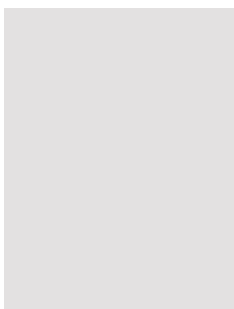
Gerda ENGHOLM

Documentation & Quality
Danish Cancer Society
Strandboulevarden 49
DK-2100 Copenhagen Ø, Denmark



Brian Rous

Consultant Histopathologist based in Cambridge and adviser of the National Cancer Registration Service, England, on the classification of tumours and staging. Senior Visiting Scientist at IARC and member of the ICD-O committee which is responsible for the maintenance and development of ICD-O



Otto VISSER

Department of Registration
Netherlands Comprehensive Cancer Organization
Utrecht, The Netherlands



Maja PRIMIC ZAKELY

MD, DSc, Specialist in epidemiology and in public health and doctor of cancer epidemiology at the Institute of Oncology Ljubljana, Slovenia, and Head of the Epidemiology and Cancer Registry Unit, consisting of Cancer Registry of Republic of Slovenia, Epidemiology Service, and Screening Service



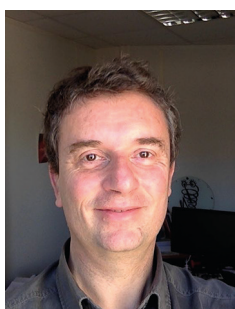
Miriam HOLZMANN

Data manager at the Cancer Registry Schleswig-Holstein, Germany, responsible for abstracting, coding, checking, conversion and analysis of the medical data



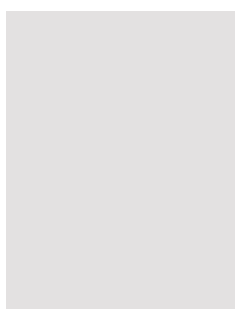
Meike RESSING

MD, MSc, since 2010 Research Fellow at Registry Office, Cancer Registry Rhineland-Palatinate, University Medical Centre Mainz, Germany



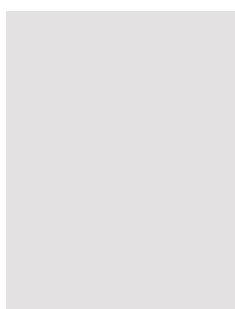
Alain MONNEREAU

MD, PhD, Hospital Practitioner and Scientific Director of the Hematological Malignancies registry of Gironde, President of the French Network of Cancer Registries (Francim) and member of the French Association of Epidemiologists, the ENCR and the NCI-supported International Lymphoma Epidemiology Consortium where he chaired the Environmental, occupational and lifestyle working group



Gemma OSCA GELIS

Epidemiology Unit and Girona Cancer Registry
Oncology Coordination Plan
Department of Health
Autonomous Government of Catalonia
Catalan Institute of Oncology
Girona Biomedical Research Institute IdIBGi
Spain



Sally VERNON

Head of Quality and Analysis
National Cancer Registration Service–Eastern Branch Office
Public Health England
Unit C–Magog Court, Shelford Bottom, Cambridge, UK



Elisabeth VAN EYCKEN

Director of the Belgian Cancer Registry
Radiation Oncologist and Physician Expert
Health Data Management. Member of the International
TNM Core Group, UICC, Geneva



Eva STELIAROVA

Msc, PhD, Scientist at the International Agency for Research
on Cancer (IARC) of the WHO. She was the leading author
of the European Cancer Observatory website



Henna DEGERLUND

Medical coder at the Finnish Cancer Registry.
Genetic counsellor, teacher and researcher at Department
of Medical Genetics in University of Helsinki



Christine LEUTOLD

Foundation National Institute for Cancer Epidemiology
and Registration (NICER), University of Zurich

Cancer Information group at the JRC

Manola BETTIO

Raquel CARVALHO

Emanuele CROCETTI

Tadek DYBA

Carmen MARTOS

Nicholas NICHOLSON

Giorgia RANDI

Roisin ROONEY

Lydia VOTI

Invited and unable to attend

Freddy BRAY

Agency for Research on Cancer (IARC), France

Hans STORM

Danish Cancer Society

Claudia ALLEMANI

London School of Hygiene and Tropical Medicine

Anna GAVIN

Northern Ireland cancer registry

Antonio RUSSO

Osservatorio epidemiologico e registri specializzati, ASL Milano 1, Italy

Euro PUKKALA

Finnish Cancer Registry

Annex II: Pre-meeting questionnaire

Introduction

The JRC is organizing on 24th of November an ENCR-JRC Workshop titled ‘Defining the road map towards revision of ENCR coding standards and training plan for cancer registries’.

The workshop is targeted at selected experts from the cancer registry community, and will be organized as a brainstorming session to discuss and evaluate the priorities both in terms of recommendations (identifying the ones needing an update or new topics to be tackled) and training courses to be planned.

Prior to the meeting, the short questionnaire you will find hereafter is finalized to gather preliminary suggestions and activate discussion, and is offered to you as an opportunity to express your registry’s needs and requests. Please try to be as detailed as possible, to clearly identify and customize cancer registries’ needs.

Any suggestions provided would be highly appreciated, and will be considered as proposals for discussion at the workshop. The outcome of the meeting will be a list of priorities to be addressed, that will constitute the basis for the ENCR SC to draft a roadmap for the revision of ENCR coding standards and a training plan for cancer registries.

A. Recommendations

A1. What are in your opinion **the most urgent topics** to be tackled as regards **ENCR recommendations**?

Please specify up to 5 topics (either old recommendations to be updated, or proposals for new issues to be addressed) and try to be as detailed as you can in your proposals/suggestions.

A1_1

A1_2

A1_3

A1_4

A1_5

- A2.** Could you please suggest **the most suitable expert** that should be involved in the work on each topic you mentioned before, and why?

Name of the expert Reason for involvement

On topic A1_1

On topic A1_2

On topic A1_3

On topic A1_4

On topic A1_5

- A3.** Do you have any other suggestions regarding **other experts** (maximum 2-3 names) to be involved for each topic?

Name of other experts Reason for involvement

On topic A1_1

On topic A1_2

On topic A1_3

On topic A1_4

On topic A1_5

B. Training

- B1.** What are in your opinion the most urgent topics to be tackled as regards ENCR training for cancer registries?

Please specify up to 5 topics and try to be as detailed as you can in your proposals/suggestions.

Usually training courses are given in English; please specify if you deem it necessary for specific training to be given in a different language.

B1_1

B1_2

B1_3

B1_4

B1_5

- B2.** Could you please suggest **the most suitable expert** that should give training on each topic you mentioned before, and why?

Name of the expert Reason for involvement

On topic B1_1

On topic B1_2

On topic B1_3

On topic B1_4

On topic B1_5

- B3.** Do you have any other suggestions regarding **other experts** (maximum 2-3 names) to be involved in the faculty of each training course listed above?

Name of the expert Reason for involvement

On topic B1_1

On topic B1_2

On topic B1_3

On topic B1_4

On topic B1_5

Additional comments

Do you have any other comment/proposal for recommendations for cancer registries?

Do you have any other comment/proposal for training for cancer registries?

Annex III: Workshop agenda

- 09:30** Kick-off plenary meeting
- Welcome and general introduction (JRC - MB)
 - Tour de table to introduce meeting participants (All)
 - Aims of the workshop, methodology and expected outcome (ENCR - AK)
- 10:00-12:30** Groups meetings
- 12:30-13:30** *Lunch*
- 13:30-14:30** Groups meetings
- 14:30-16:30** Final plenary meeting
- Presentation of the proposals from each group
 - General discussion
 - Roadmap for future ENCR training and recommendations activities and closing remarks (ENCR - AK)

Europe Direct is a service to help you find answers to your questions about the European Union
Free phone number (*): 00 800 6 7 8 9 10 11

(*): Certain mobile telephone operators do not allow access to 00 800 numbers or these calls may be billed.

A great deal of additional information on the European Union is available on the Internet.
It can be accessed through the Europa server <http://europa.eu>

How to obtain EU publications

Our publications are available from EU Bookshop (http://publications.europa.eu/howto/index_en.htm),
where you can place an order with the sales agent of your choice.

The Publications Office has a worldwide network of sales agents.
You can obtain their contact details by sending a fax to (352) 29 29-42758.

JRC Mission

As the Commission's in-house science service, the Joint Research Centre's mission is to provide EU policies with independent, evidence-based scientific and technical support throughout the whole policy cycle.

Working in close cooperation with policy Directorates-General, the JRC addresses key societal challenges while stimulating innovation through developing new methods, tools and standards, and sharing its know-how with the Member States, the scientific community and international partners.

*Serving society
Stimulating innovation
Supporting legislation*

