EUROCARE STEERING COMMITTEE 18.09.2013 DRAFT MINUTES

Steering Committee (SC) Participants

Magdalena Bielska Lasota, Maja Zakelj, Renèe Otter, Marc Colonna, , Rafael Marcos Gragera, Michel Coleman, Mats Lambe, Alexandar Katalinic, Jean Faivre, Paolo Baili, Franco Berrino and the EUROCARE Scientific Direction (SD) (Riccardo Capocaccia, Roberta De Angelis, Milena Sant, Gemma Gatta)

Regrets

Jean Michel Lutz, Nadine Bossard

Auditors

The EUROCARE researchers at INT and ISS: Pamela Minicozzi, Annalisa Trama, Laura Botta, Roberto Foschi, Silvia Rossi, Silvia Francisci, Andrea Tavilla, Sandra Mallone, Daniela Pierannunzio, Camilla Amati and Simona De Santis for the EUROCARE Secretariat.

Organization

The EUROCARE **Scientific Direction (SD)** as the representative of all INT and ISS researchers involved in EUROCARE, is composed of four members, two from INT (Milena Sant and Gemma Gatta) and two from ISS (Roberta De Angelis and Riccardo Capocaccia). Franco Berrino will continue to chair the EUROCARE Steering Committee (SC), a Secretariat electronic address was created (eurocare.secretariat@istitutotumori.mi.it). The list of EUROCARE contacts was updated in collaboration with all contributing CRs and is available on the website under the title of General EUROCARE Working Group.

EUROCARE-5 Publication Plan

Authorship

Since the number of cancer registries (CRs) involved in the EUROCARE project are becoming more numerous, and the editorial rules of scientific journals always more strict, we propose the following:

1- for PHASE 1 papers, we divided the entire EUROCARE-5 Working Group (WG) in two: one for analyses of childhood cancers (Childhood WG) and one for analyses of adult cancer patients (Adult WG); the EUROCARE Steering Committee Members, the EUROCARE researchers, and technical staff at INT and ISS are going to be included in the WGs for all papers;

2-in the composition of the two WGs to be included in the different papers, the number of people from each CR will be regulated on a rotation basis. The WG will include maximum 2 representatives per CR. If more than 2 persons of the staff ought to be involved, the 2 representatives will be: the director + 1 member of staff chosen on a rotation basis, varying in different papers. This system is aimed at ensuring an homogeneous representation of colleagues across the EU while still keeping the WG to numbers that are acceptable to the editors. (The "1 member of staff" can change in the different articles: when a paper is circulated among the WG members, the director of each CR can decide whether a different name from the General WG should be included);

3- for the WGs of Phase-1 and Phase-2 papers, all CRs contributing with data eligible for survival analysis that were checked, revised, included in the common EUROCARE database and analysed. This means that for the main publications the contribution of a CR should be recognised even if its results are not reported/used in the paper because of specific inclusion criteria (DCO proportion below a given threshold, etc..);

4- For the composition of the WG for Phase-3 specific papers, the inclusion criteria should rely more closely on the specific study design. This means that, for these papers, only CRs actually contributing to the final analyses will be included in the WG.

PHASE 1 Papers

The summary papers on adult and childhood cancers have been submitted to LO and circulated to the General WG.

ACTION

1. the first revision following review is ongoing and a new draft will be submitted by the end of October

PHASE 2 Papers

EJC Monograph plan was presented. The novelty of this monograph is the clinical objective of site-specific papers included in it. Clinicians will be invited to contribute to these articles. Moreover, the Monograph will be only on adults and analyses will be centralised (at INT or ISS).

Site-specific papers were approved after the following three modifications to be checked with EJC:

- Oesophagus to be included in gastro-intestinal tract rather than in head&neck
- Gastro-intestinal tract to be split in upper (oesophagus, stomach, small intestine) and lower (colon, rectum, anus, ...) gastro-intestinal tract
- Inclusion of bladder in urological tumours.

The plan including the proposed modifications is as follows:

Main topic	
Database and Methods	
All cancers combined	
Prevalence	
Stage and treatment	
Site-specific papers including ✓ descriptive analyses, ✓ 5-year relative survival, by gender, age, country ✓ 5-year survival conditional to surviving 1 year, ✓ time-trends, ✓ incidence and mortality (when relevant for survival interpretation) **Head & Neck, larynx** **Upper gastro-intestinal tract: oesophagus + stomach + small intestine** **Lower gastro-intestinat tract : colon, rectum, anus, ..** **Liver, biliary tract, pancreas** **Skin melanoma** **Breast, female genital** **Male genital** **Urological *(bladder, kidney, ureter and other urinary organs)*** **Brain, CNS tumours** **Bone, soft tissues** **Thyroid** **Lung, Pleura** **Haematological malignancies**	

ACTIONS (Strategy for contacting clinicians to be invited to contribute to the monograph article):

2. the new plan (above) is now agreed with EJC

3. first authors have been contacted for their availability;

4. the SC will receive the updated list of publications (including first authors) and are asked to provide relevant contacts within 2 weeks (clinicians and others);

5. Invite potential guest editors of the monograph, detailing rationale and purpose of the study.

PHASE 3 papers

- Pending papers Eurocare-4 Phase-3 plan discussed and approved at last plenary meeting (28/02/2012)
    a. Bielska-Lasota M. : Cervical cancer
    b. Mallone (Bastiannet resigned) : Bladder cancer

NOTE: These studies will be done by using the updated EUROCARE-5 dataset.

- Proposals discussed and approved at last plenary meeting (28/02/2013)
    a. Sant M. Recent trends of haematological malignancies survival SEE ATTACHED PROTOCOL
    b. Trama A. Survival in adolescents and young adults
    c. Arbyn M. Impact of cervical screening according to incidence, survival and cured proportion

NOTE: Although already approved, submission of the study protocols for the last two articles is still pending.

- Protocols submitted after the WG meeting (28/02/2012)

On these protocols, the following SC decisions are communicated to first authors by the EUROCARE Scientific Direction.

Siesling S Elderly breast cancer patients in Europe	The project is approved in principle, subject to the following suggestions, which should be incorporated in a revised version of the protocol: • Since dealing with elderly patients, net rather than • relative survival should be advisable (to be assessed if • there are relevant differences between the two • estimates) • Age threshold: use 65+ and 70+ definition for elderly • patients • Specify how the screening activity implemented • in each country is taken into account
Mounier M Trends of the Net Survival in Non Hodgkin Lymphoma: a population based study in Europe	The study proposal is approved
Anderson LA, Esophageal cancer survival in Europe	The two proposals are approved in principle, with a strong recommendation for applicants to work together; consider also the EJC monograph chapter on upper GI tract neoplasm
Hoelleczek B Survival of patients with oesophagus and stomach	

cancer in Europe	
Trama A, Survival and incidence trends of neuroendocrine tumours in Europe[…]	The project is approved in principle, subject to the following suggestions, which should be incorporated in a revised version of the protocol: • take care to consider the impact of changes in ICD-O classification over the 18-year period 1990-2007 proposed in the study • examine the proportion of NETs in the lung by country (also by age, sex, time, if possible) • analyse number of cases in each category by year to check registration changes
Bossard N, Relative survival indicators comparison (BETWEEN project)	The project is approved in principle, however: • take care in construction and interpretation of league tables and avoid to present survival rankings by country • clarify the intended contrast between simulation and empirical data analyses, i.e. what simulations would add to the extensive application to empirical data
Faivre J, Survival in patients with cancer in European Romance-language countries (SURCAN project)	The protocol of this project, a GRELL-EUROCARE collaboration, has been presented and illustrated directly by Jean Faivre during the SC meeting. The content has raised no critical comment from the participants and can be considered as approved by the SC. However, since it requires the provision of individual level data, the protocol will be circulated among the registries to ask for their agreement to participate with their data.
Anderson LA Myeloproliferative neoplasm survival in Europe	The project is approved in principle, subject to the following suggestions, which should be incorporated in a revised version of the protocol: • remove treatment: not available in EUROCARE database, • Ederer-2 rather than Hakulinen for expected survival • examine raw frequencies of each category of disease by single year of incidence and registry (to verify differences year by year), as a first approach to secular change in “classification and completeness of registry data” • clarify where the data will be analysed and which analytic software will be used (last sentence is not clear) • consider presentation of data for 2 periods (e.g 2000-2003 and 2004-2007) rather than attempting regression estimates of year-on-year trend

For all proposals, the SC recommended the use, whenever possible and relevant, of net survival instead of relative survival approach. A time schedule for the delivery of a first draft (after data receipt) will be agreed with all first authors.

ACTIONS:

6. first authors are informed of the above SC feedbacks, revised protocols are requested where relevant, a timeline is agreed.

7. Some authors prefer to perform the analyses locally (e.g. Bossard, Mounier, Faivre). For these papers it is necessary to ask to each registry an explicit consent to data provision.

Communication of EUROCARE 5 results

PRESS RELEASE

We are planning to collaborate with the Lancet Oncology to develop an informative press release in order to avoid mis-interpretation of the study results.
To develop the press release, EUROCARE decided to explore the availability of Anna Wagstaff (scientific journalists with long-term experience in the field). The press release should include Q &A and should be shared with CRs before circulation.

Main issues to be addressed include:

- survival does not only depend on treatment
- explain the role of overdiagnosis and screening
- low ranking countries: surveillance through cancer registries should be reinforced, results should stimulate initiatives to ameliorate health care organization, (do not shoot the messenger)
- high income countries: within-country survival disparities, for instance by socio-economical status, cannot be excluded
- financial resources to CRs is a key issue (cheapest existing public health tool) see also Deliverable 3 of EUROCOURSE's WP1, based on ENCR and EUROCHIP survey: http://www.eurocourse.org/mm_files/do_944/D1_3.pdf
- comparability issue with other publications (OECD, International Cancer Benchmarking Partnership ICBP) and with previous EUROCARE studies

ACTIONS:

8 . Lancet Oncology will lead the dissemination strategy (see action 12)
9. draft and circulate soon a press release draft among SC first and then to the registries
10. ask CRs to provide a list of press points they like us to reach with the press release

EPAAC OPEN FORUM

The possibility to include EUROCARE5 results among the topic of the EPAAC OPEN FORUM (OF) and of its press conference is now excluded. However, the OF Call for Posters is now open (till October 11th) and the submission of a Poster is considered with an extended deadline. During the SC Meeting, Maja also proposed to consider presenting the results in the ECL Annual Meeting to be held in Ljubljana on the following day to the OF.
EUROCARE5 results, will be anyway presented in EPAAC's final SC meeting to be held in Luxembourg, February 2014. This is important because all EU country representatives will attend it.

POSSIBLE HEARING AT THE EU PARLIAMENT

We are planning to organize an hearing with Members of Parliament against Cancer, possibly via the involvement of ECL, ESO, ECCO, ECPC. According to the present time schedule, a possible date for the event is foreseen early next year. We have already began taking contacts and welcome all suggestions you are willing to provide on how to structure such hearing.

In addition, any other ideas of opportunities to present the EUROCARE5 data are welcome (these include, for instance, the UICC congress 2014, the World Oncology Forum 2014, the ECCO congresses)

ACTIONS:

11. dissemination options include: EVENT with MAC at EU Parliament Brussels in December involving one representative from each country contributing to EUROCARE 5, especially Eastern European Countries, plus Brussels based organizations such as ECCO and ESMO and ESO and patient organizations, journalists, invitation to Health Commissioner Borg is being prepared). Members of Parliament Against Cancer have proposed the following dates as viable: 2, 4, 16 or 17 December (the exact date would depend on room availability)

12. coordinate with LO press office, inform LO about the forthcoming OECD issue, ask that journals are available for the EPAAC Open Forum end November 2013

PROPOSAL FOR A SHARED DATABASE

The possibility of asking EUROCARE registries to adhere to the development of a common database including individual data has been discussed in depth. The participation is on a voluntary basis and the database is to be shared only and exclusively among registries contributing with their data. A draft protocol for a shared database is now circulated to the SC for comments before it is shared to the EUROCARE WG. (The document will be sent to the CRs to explore their interest and willingness to adhere to such feasibility study).

FUTURE EVENTS AND AIMS

A EUROCARE-5 plenary WG meeting is not envisioned until 2015, because EUROCARE 6 perspectives involves a call

In 2015 (new incidence 2008- 2012).

A EUROCARE/ENCR EVENT on methodology is foreseen tentatively on January 23rd-24th 2014 possibly at the ISPRA JRC. Thank you for checking your availability already from now and for letting us know of any coinciding commitments.

A new European High Resolution study will be initiated.(2nd workshop held at JRC in Ispra on 25 and 26th September 2013. As a result, a HR protocol is circulated to CRs involved, data collection envisioned in January 2014)

OTHER BUSINESSES

Germ-cell Tumour chapter : Dr. Berrino was invited by Prof. Francisco Nogales (pathologist of the Granada Universiy) to write a chapter on the epidemiology of germ cell Europe in the book "The Pathology and Biology of Germ Cell tumours". Editors: Main Nogales FF (University of Granada), Associate Jimenez RE (Mayo Clinic, Rochester, Minn, USA) Publisher: Springer Verlag, Heidelberg, Germany
He asked the possibility to use EU-5 data to write it. The SC approved, a list of contents is annexed to these minutes which are going to circulate among the WG members, thus each CR is invited to communicate whether they have any objections within 2/3 weeks after receipt. Dr. Trama will be involved in the analyses.

US Study on Cancer Survival Gains over Time: The EUROCARE was contacted by Prof Diana P. Goldman from the Medicine and Public Policy Department at the Shaeffer Center for Health Policy& Economics of the University of Southern California, with a request for the use of EUROCARE aggregated data relatively to the research project "Valuing gains in cancer survival over time in Europe and the US" and the authorization was provided. The study analyses will be completed in December 2013 and a draft manuscript is foreseen in January 2014.