EUROCARE STEERING COMMITTEE Meeting – 23 September 2019

Istituto Nazionale dei Tumori Milano (INT)

Milano, Via Venezian 1

11:00-17:00

Minutes

Attendees

- See attached list of participants and list of the Steering Committee Members

Enclosed

- Agenda
- Power point presentations

Discussion

1. Welcome and objectives of the day – *Milena Sant*
   - Welcome note and brief update about the new composition of the EUROCARE Scientific Board (Gemma Gatta and Milena Sant from INT, Roberta De Angelis and Silvia Rossi from ISS) and of the new EUROCARE Steering Committee (attached list). Aims of the meeting were to discuss the received data, country participation, problems encountered, preliminary results, publication plan and future steps.

2. EUROCARE-6 study protocol and dataset description - *Roberta De Angelis*

   - Background, aims and selection criteria of the EUROCARE-6 study protocol. Registries participation and geographical coverage (national vs regional, general vs specialized). Overall 29 countries are covered for cancers in adults (23 with national and 6 with regional registries). Timeframe of data availability (incidence and follow up) is varying from 1978 to 2014.

3. Quality control procedures and results - *Silvia Rossi*

   Quality controls were harmonized with ENCR-JRC checks. The different steps of data quality checks were described: Phase I (formal adherence to data collection protocol), Phase II (consistency between variables to check individual record validity), Phase III (standard quality indicators and preliminary results to assess completeness and quality of follow-up). Phase I checks implied multiple data transfers (2 or 3 updates for 69 CRs) to solve critical issues delaying data analysis process. The ISS platform and quality check reports were illustrated. Information on stage and treatment over 70% is available respectively for 15/19 and 13 countries for both colorectal and breast cancers. Overall, quality checks revealed satisfactory data quality for the majority of registries (major errors proportion in 2000-2013 below 1%, lost

to follow up below 2%). Incidence years with DCO proportions above 13% (EUROCARE-5 threshold) were discarded.

4. Preliminary results on cancer survival in Europe - *Gemma Gatta*

Geographical differences by country of age adjusted 5-year net survival 2010-14 were commented for the 45 cancer entities. The widest between country differences were observed for prostate and haematological malignancies (HM). Time trends of age adjusted 5-year net survival 2000-2014 for the five European regions were shown. Overall, the highest increases over time were for HM (CML, Multiple myeloma, non Hodgkin) and for kidney, prostate and colon-rectum amongst solid tumours.

5. Preliminary results on cancer prevalence in Europe and connection with iPAAC Joint Action WP7 Task 7.6 - *Roberta De Angelis*

iPAAC JA share with EUROCARE-6 the common goal to promote the delivery and use of cancer prevalence indicators in Europe. Core prevalence indicators and related methods (complete and limited duration, observed vs estimated/projected) were presented. Maximum observed disease duration by registry varies from 10 to 35 years. The relevance of completing limited duration prevalence for observed time series below 20 years was shown. Preliminary results of complete prevalence by registry, age, sex, site and duration were commented.

Highlights from the general discussion

1. *Data quality assessment*. Impact on survival estimates of using **thresholds** for the proportion of DCOs, major errors (E), censored (incomplete follow up), etc… A sensitivity analysis to assess the impact of using different thresholds was proposed

2. *Quality indicators*: DCO proportions by cancer entity should be provided to assist results interpretation

3. *Quality indicators*: Proportion of **multiple primary** tumours by registry should be included among standard quality indicators reported.

4. *Quality checks documentation*: details on the (registry-specific) procedures used to impute **dates** should be documented

5. *Quality indicators:* **completeness/reporting delay** in the registries' datasets to be reported by comparing EUROCARE-5 and EUROCARE-6 results in the same period of time (e.g. 2000-2004 or 2000-2007)

6. *Cancer entities definition*. A revision of the **solid tumours list** to present clinically relevant entities rather than broad groups (more specific, more rare) is advisable. For **haematological tumours** the new codes coming from ICDO-3 2011 revision must be included.

7. *Survival Time Trends* – the impact of using a **uniform method** of estimation (period analysis) versus a **mixed method** (cohort analysis and period analysis only in recent years) is to be assessed

8. *Survival Time trends* – the possibility of using **3-year** or annual intervals and of **modelling** time trends is to be assessed

9. *Survival estimators* – we discussed the issues related to estimating net survival for elderly patients (>75 years), especially in the long term. Individually taylored life-expectancy is hardly available in current official statistics, patients are only matched by gender, age, calendar year and area of residence (region or country). Further differences arising from socio-economic condition or comorbidity could be relevant to correctly assess the individual probability of death. Net survival estimator could amplify biases due to inappropriate life-tables at the individual level in older age groups.

10. *Prevalence estimates* – published estimates from the Nordic countries were suggested to be used for validation. Prevalence in the last year of life can be relevant for palliative care resources assessment. It must be taken into account that patients do not only die from cancer.

11. *Geographical comparisons*. Groupings based on European **Areas** (north, south, east, center) have been criticised as quite etherogenenous inside and felt not so representative. It was raised that **countries** should emerge more clearly in the results presentation. Groupings may be based on **survival ranking by country** (quartiles or quintiles) highligthing potential disparities. **Maps** with colours associated to rankings were suggested as a good solution for representing geographical variations, especially for reporting results on the web. The EUROCARE 'political' decision of not presenting rankings may have to be revised (*this should perhaps be checked with low ranking countries ?)*

12. *Conditional survival*. The importance of presenting 5-y survival conditional to surviving 1-y was stressed to comparatively assess the impact of early diagnosis.

13. *Results presentation*. The importance of taking the case-mix of known prognostic factors (sub-site and morphology groupings) into account was stressed and may constitute an addedd value of EUROCARE-6 publications compared to existing ones.

Publication Plan

1. *Phase-1 paper*

The following points were raised: Maximum priority to 3 main papers (adult solid, adult haematological, children), provide long term follow up results (10-y or 15-y), rare cancers should be considered (revision of the list), including morphology. We should interpret survival differences by country taking into account the Health care system and incomes (GDP).

2. *Phase-2 papers*

- the participation of registries to propose analyses and write papers is highly welcome
- Pros and Cons of publishing a monograph were discussed, editors for this task are needed
- Authorship external to ISS and INT research teams. Three options were discussed:
  i) predifined tables with core results available to authors as in EUROCARE-5

ii) authors may travel to Rome or Milan for site visits at ISS or INT (specific resources needed and to be checked)
iii) secure data sharing (this possibility is to be evaluated at the light of specific data sharing regulations)

Tentative Timing:

- End 2019: contact a high IF journal (eg LO) to explore its interest in publishing the 3 main papers
- June 2020: at least the first summary paper to be submitted within

Proposals to be conveyed to ENCR for the SC November meeting

1. Publication of survival estimates on the ECIS portal: the design of the platform to present results may go in parallel with the preparation of papers, so as to publish on paper and on the web at the same time: this proposal is to be presented to ENCR
2. How to overcome barriers for facilitating CR active participation to Phase-2 publications

List of Participants

1. Camilla Amati, Fondazione IRCCS “National Cancer Institute” , INT, Milan, Italy
2. Paolo Baili, Fondazione IRCCS “National Cancer Institute” , INT, Milan, Italy
3. Alice Bernasconi, Fondazione IRCCS “National Cancer Institute” , INT, Milan, Italy
4. Franco Berrino senior SC member and EUROCARE former chair
5. Magdalena Bielska-Lasota, Nat. Institute of Public Health - Nat. Institute of Hygiene, NIPH-NIH, Warsaw, Poland
6. Tom Borge, Norway CR, ANCR representative
7. Laura Botta, Fondazione IRCCS “National Cancer Institute” , INT, Milan, Italy
8. Riccardo Capocaccia, senior SC member and former Scientific Director
9. Roberta De Angelis, Italian National Institute of Health, Dept of Oncology (ISS), Roma Italy
10. Elena Demuru, Italian National Institute of Health, Dept of Oncology (ISS), Roma Italy
11. Anna Gavin, Northern Ireland CR, Queen's University, Belfast, UK; UKIACR representative
12. Gemma Gatta, Fondazione IRCCS “National Cancer Institute” , INT, Milan, Italy
13. Roberto Lillini, Fondazione IRCCS “National Cancer Institute” , INT, Milan, Italy
14. Rafael Marcos Gragera, Girona CR, Catalan Institute of Oncology, Spain; REDECAN representative
15. Dyfed Huws Welsh Cancer Intelligence and Surveillance Unit, Public Health Wales, UK; UKIACR representative
16. Kaire Innos, Dept Epidemiology & Biostatistics National Institute for Health Development, NIHD, Tallinn, Estonia
17. Valerie Jooste, Registre Bourguignon des Cancers Digestifs, Dijon, France; FRANCIM representative
18. Alexander Katalinic, Schleswig-Holstein CR, Lübeck Germany; GEKID, representative
19. Silvia Rossi, Italian National Institute of Health, Dept of Oncology (ISS), Roma Italy
20. Milena Sant, Fondazione IRCCS “National Cancer Institute” , INT, Milan, Italy
21. Annalisa Trama, Fondazione IRCCS “National Cancer Institute” , INT, Milan, Italy
22. Claudia Vener, Fondazione IRCCS “National Cancer Institute” , INT, Milan, Italy
23. Otto Visser National CR, IKNL, The Netherlands

Steering Committee members

1. Paolo Baili, Fondazione IRCCS "National Cancer Institute" , INT, Milan, Italy
2. Franco Berrino senior SC member and EUROCARE former chair
3. Magdalena Bielska-Lasota, Nat. Institute of Public Health - Nat. Institute of Hygiene, NIPH-NIH, Warsaw, Poland
4. Tom Borge, Norway CR, ANCR representative
5. Nadine Bossard, Centre Hospitalier Universitaire de Dijon Bourgogne, Dijon, France
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12. Alexander Katalinic, Schleswig-Holstein CR, Lübeck Germany; GEKID, representative
13. Alain Monnereau, Gironde Haematological Malignancies, Bordeaux, France; FRANCIM
14. Otto Visser National CR, IKNL, The Netherlands

The EUROCARE Scientific Directors and members of the Steering Committee are:

- Roberta De Angelis, Italian National Institute of Health, Dept of Oncology (ISS), Roma Italy
- Gemma Gatta, Fondazione IRCCS "National Cancer Institute", INT, Milan, Italy
- Silvia Rossi, Italian National Institute of Health, Dept of Oncology (ISS), Roma Italy
- Milena Sant, Fondazione IRCCS "National Cancer Institute , INT, Milan, Italy

FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI

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