Information Network on Rare Cancers

RARECARENet

Minutes

Title meeting:	Kick-off Workshop High Resolution study meeting for Cancer Registries
Date meeting:	17th January 2014
Place of meeting:	Janssoenborch building, 8th floor Godebaldkwartier 419 3511 DT Utrecht the Netherlands
Participants:	Maarit Leinonen, Gemma Gatta, Annalisa Trama, Sabine Siesling, Jan Maarten van der Zwan, Riccardo Capocaccia, Vincent Ho, Nadia Dimitrova, Ria, Harry Comber, Lisa Licitra,

Opening and Welcome

Sabine Siesling (IKNL) welcomed the participants and invited everyone to introduce themselves and to mention the organization they represent. Also a short tour, showing the new IKNL office, was given.

Introduction objectives of the workshop

Sabine Siesling (IKNL) presented the objective of the meeting, which is to come to an agreed protocol for data collection, this to conduct the envisioned high resolution study upon identifying qualification criteria for Centres of Expertise (CoE) for rare cancers. At the end of the project this work package will come with a report identifying criteria indicating the level/quality of expertise for rare cancers management. This high resolution study is the first step to collect data supporting the indicators for Centres of Expertise for Testis tumours, Head and Neck tumours, GEP-NET and sarcomas as a sample set for CoE in Rare cancers overall.

Introduction difficulties for registering date of incidence

Vincent Ho gave a short introduction to explain the difficulties for registering the date of incidence. However we use the international guidelines for registering the date of incidence, for analysing the data some bias could have been occurred because of the difficulties for registry clerks using the correct date, this especially for the Sarcomas and NET tumour, for which a long diffuse diagnostic period can occur.

Presentations by the separate Cancer Registries :

The highlights of the presentations are described below
(the presentation will be come available on the website, www.rarecarenet.eu)

Belgium CR:

- National Coverage
- 2 Councils: General board and Scientific board
- Linked to different databases using the national number (patient ID), for example;
    - Clinical data and medical claims/reimbursement data (+drugs)
    - (SES)
    - (Geographic - statistical sector)

- The following output can be retrieved:
    - Descriptive epidemiology
    - Evaluation quality of care

Irish National cancer registry:

- National coverage however there is a difference in public and private hospitals. No difference in care between public and private, but delay is much longer. Public hospitals get the more severe patients, with complications, with high costs for chemo
- 8 public centres for Cancer, centralisation plan is not yet finalised, breast cancer is treated within the 8 centres (70%), H&N in two hospitals, etc mixed picture!
- Information is available on paper send to CR, this without using the national ID number
    - Linkage with NAW data, completeness with date of death is not 100%
    - No info on recurrence> metastasis are diagnosed often out of hospital setting, no clinical diagnosis for recurrences available
    - No imaging data, could be gathered going back to the data
    - No detail data on type of chemo or hormo treatment
    - No central histopathological database no central access
    - Co-morbidity from hospital files, but this is recorded this could be influenced by financial incentives/reimbursement (over registration)
- Data gathering for older files is costing some money due to archivation of the patients files, and these have to be retrieved in the archives

Bulgarian National Cancer Registry:

- There is a national coverage of the cancer registry including the 1 national oncological hospital, 5 university and a general hospital in every town. This is collected since the year 1952 using the handwritten pathology reports and Hospital Discharge records and death certificates.
- Progression of the disease including the metastases, recurrences and treatments have been registered since 2011.
- A module connected to the cancer information will be developed for the data collection.
- The cancer registry use the ICD 10 and therefor needs a separate ICD-O-3 field..
- Collection of in formation is active based on clinical records

Finish National Cancer Registry

- National coverage of the cancer registry from 5 university hospitals, and 20 district hospitals using passive data collection, notification by specialists, laboratories, death certificates, mass screening units. Data collection started in the year 1961.Cancer diagnosis data has been registered in a public system
- There is the use of Care Register for Health Care (HDR) by linkage, however this requires data

handling
- ICDO-3 is used however stage variable is lacking for HR studies the6th digit morphology code is not used in Finish Cancer Registry, therefor the cases should be checked.,
- Follow-up for population based public heath is high (99%) but clinical details lacking
- Permission is for data release is very strict and needs to be requested by the indivual researchers using the data, this could take some weeks (months?)

Presentation number of cases to include for the HR-study
Riccardo Capoccacia gave a short presentation with the different options upon the period of data inclusion. The following points were raised by Riccardo to be discussed:
- Do we want to analyse indicators per hospital
- Can we group the hospitals?
- Do we want to use survival analyses for evaluating the indicators?
- Do we need the same number of cases for each cancer type?

The following outcome is the result of the discussion:
- ➔ Descriptive aim, not testing hypothesis
- ➔ We do not know what we can expect on the variance of the indicators
  - National level number can be low number per hospital (statistical unit)
  - Main aim is quality of care on not outcome, but these are related of course. The question is which are the characteristics that would ensure a better outcome: high volume or other (correcting) factors, so outcome should be included in the data > NB statistical correlation versus individual hospitals, no focus only on volume> the probability will increase of being better quality, not for sure.
  - Look at distribution between hospitals within countries
  - Country is not relevant in first place! Really important data is difficult to retrieve, reasons for absence of data is very important
  - Absolute number are most important> incidence is too low
- ➔ All registries try to collect as much data as possible for the period 2009-2010
- ➔ Analyse per country and compare the hospitals, due to different health care systems

12:45 A lunch was provided

Afternoon discussion on the data collection protocol:

General comments:
- Aim of the study: indicators back to the experts> treatment according to guidelines. If many hospitals do not score on this indicator there is potential for improvement. Even if there is a low score on some indicators we still have to conclude that this information. Volume of the hospital is not the main focus! Look at the criteria. The aim is not to compare countries
- Before analysing the data we will test whether data is available. Correct for differences between countries in case we have hospitals as the entity of analysis.
- Comparability between countries is difficult! Other study? Can these indicators explain differences in survival between countries?

- Hospitals have to be anonymous in all cases!
- Collect the indicators and define the feasibility of the gathering and the value of the indicators--> possible criteria to define aim of this WP
- Orphanet: list of hospitals per country for certain tumours; provide the criteria to Orphanet
- Organise conferences where hospital representatives are invited, discussion for centres of expertise

Tumour specific comments:

Clinical information that suggests a different TNM than the clinicians do, the CR has to decide upon this!

GEP-NET:
- ICR: anything that is not hormonal therapy is coded as chemotherapy, this includes targeted therapy need to go back to files to separate them = effort do we need this distinction, clinician
- Belgium: trails could be not included
- Belgium: start date radiotherapy is not collected but the end date

Sarcomas
- review, critical for collection and interpretation, going back to the records is necessary
- if TNM is available then it is enough no need to go back to the data file, otherwise code superficial / or five items from Annalisa,

Testis
- Bulgaria: S marker after one month available which is probably the lowest value, so take this value
- Bulgaria: should ask all hospitals for their normal values for serum markers

Head and Neck
- All CR pattern of invasion should be searched for in the report by all CR, so too much work?! Only for surgical patient 10% sample taken ?? or choose subsite? Sample 50 patients with surgery
- Ireland retrieves smoking status, is only important for survival
- Other CR have to go back to the files

Actions for CR:
- Make lists per tumour for type of hospital, centralisation
- Guideline availability and send in this guideline to us
- Ask permission to Privacy Committee (NCR) or THL (FCR)
- Educate the registrars
- Harry will discuss the budget
- Vital status will be updated if possible at the end of the study registration period and even later so keep the ID numbers of the included patients
- After data collection: make a list how difficult it was to obtain the data on review for sarcomas and other items/tumours
- Nadia: ask normal values for serum markers for testicular cancer will be asked in teh hospital in Sophia cancer hospital

Actions WP5:

- A more specific list of drugs needed, chemotherapy, targeted, hormonal therapy et cif it is not on the list the drug is not included , in case of questions contact Otto.
- Vital status and last date will be added in the protocol
- Remark in protocol: No information available': is to be descided upon by the CR, or not able to read the principle document; if thing did not happen it is not written in the file, but it should be coded as not performed, in case there is enough information
- JM ask clinicians: need for separation of chemo and targeted?
- Include cTNM and pTNM in GEP-NET, TNM edition 7
- Extent of disease if TNM is not available: GEP-NET
- JM add extra item: residual disease yes/no
- Annalisa: discuss list with clinicians on treatment wheter group chemo and targeted therapy
- Otto: codebook for sarcomas grading
- JM: do not use 0, code starting with 1
- List factors influencing prognosis (smoking oropharynx).
- JM : adapt the ACCESS data tool ,version problem and 0 not applicable, gender issue and ID should not be free text; adaptation due to the changes, drop down menu's? Italy and Finland will use this, dose of medication for testicular cancers
- Maarit will send the protocol for data secure sending, Belgium will have to use possible a different tool
- Slovenian Cancer Registry will be informed and invited to join the HR study with the updated protocol

Timeline:

- Changes discussed today in protocols and ACCESS database
- Ask permission to data protection board
- Start collecting data already

List of Decisions:

1. ENCR rules are used for definition of incidence date
2. Define centres in which there are centralisation of oncology for all rare cancers, but specific for these 4 cancers
3. Definitive morphology code: based on largest specimen and most specific code (sarcomas)
4. Focus on most recent years 2009-2010, information on outcome alsof or these early years> data gathering on the vital status at end of project period, so we have latest available information on vital status
5. Vital status will be added in the protocol at time of gathering the extra items, at a later moment this date might be updated if possible> CR should keep the ID number of the included patients for updates later
6. In all cases hospitals have to remain anonymous
7. Volume is not the focus but the criteria/indicators are focussed on
8. Specific coding questions to Otto Visser: O.visser@iknl.nl
9. Use the codes from the coding guidelines as much as possible so make an conversion or otherwise send an algorithm with the database to us
10. Use the most specific codes! Recode 8446 for Nets
11. 'No information available': is to be decided upon by the CR, or not able to read the principle

document; if thing did not happen it is not written in the file, but it should be coded as not performed, in case there is enough information

12. GEP-NET: extent of disease if no TNM is available
13. Sarcomas: give the grading as given by the pathologist in case of Coindre/Trojani not available
14. The CR will be asked how difficult it was to retrieve data on reviews for e.g. sarcomas
15. Sarcomas: residual disease coded as R0, R1, R2 if possible, extra item will be made: residual disease yes/no
16. If TNM is available no construction data is needed, (TNM should be based on depth,
17. TNM is allowed to be changed in case the clinicians have an other TNM than what is generated from the files, CR has to decide upon this
18. Otto makes a coding list for grade examples for sarcomas
19. Indicator 12 sarcomas: pathological report complete if TNM is there so to be generated out of the database
20. If the value of the Serum marker is unknown then code X.
21. We do not have information on actions during the active surveillance time for testicular cancers, do we generate this item from the data and do not collect the item 'active surveillance' as separate items
22. Recurrence after 9 months and within two years
23. Do not use 0 but start all options with 1
24. H&N: C14.0 and C14.8 not included, very rare and no use to gather data on them
25. Whole project: only include only histological verified tumours
26. H&N: 50 randomly selected patients surgically treated will be checked by all CR for the pattern of invasiveness,
27. HPV only for oropharynx, limited numbers 2009-2011, very view case with positive HPV, but it is important for the outcome, good prognostic criteria/indicators could be different, smoking status, age stratification could be solution since age is related to HPV. Smoking is not related to the indicators> but involves prognosis>only oropharynx: to be decided upon next week
28. To define items for survival!! next week?? Needed to validate the indicators
29. We will use the data protection tool of Finland CR, in case CR do not have an own data protection tool
30. Database cannot be send to all participants for other projects or research questions
31. Budget: Italy has other financial support; each CR has received about 10,000.- , with half for travel, money for the staff was allocated for the data gathering personnel, Ireland might not use this money
32. ICR will make random ID number
33. How may patients the criteria are met and in which hospitals: "80% of the criteria are not met within cancer in five countries", "100 cases how many meet criteria, which hospitals meet these criteria"
34. Focus on descriptive
35. 2008/9-2010 starting from the tumour sites with low number to the highest number
36. CR decides on what years; most recent year preferably
37. CR decides on what cancer types> starting with the least incident cases, depends on feasibility
38. Before 7 February CR makes clear which year and which tumours and which items