EUROPEAN PARTNERSHIP ACTION AGAINST CANCER (EPAAC)

STEERING COMMITTEE MEETING

Luxembourg, 23 January 2014

Reporting from WP9 on Health information: collection and analysis of comparable data in EU

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WP9 leader, INT Milan, Italy
WP-9 MAIN ASSOCIATED/COLLABORATING PARTNERS

- INT – Fondazione IRCCS “Istituto Nazionale Tumori” – Italy
- ISS – Istituto Superiore di Sanità – Italy
- IARC – International Agency for Research on Cancer
- ENCR – European Network of Cancer Registries
- JRC – Joint Research Center
- OECD – Organisation for Economic Co-operation & Development
- INRC – Istituto Nazionale Ricerca sul Cancro – Italy
- ERI3 INSERM – France
- IKNO – Integraal Kankercentrum Noord-Oost - The Netherlands
- IOL – Institute of Oncology Ljubljana – Slovenia
WP-9 OBJECTIVES

- Map sources of cancer data
- Harmonization of cancer burden indicators
- Cancer Survivorship
- Socio-economic indicators and cancer
- Statistical methods

OTHER WP9 ACTIVITIES

- Cancer survival data update
- EPAAC Book Chapter 6
Map sources of cancer data

- Activity performed during the first year of the project
- Starting point: EUROCHIP-1 cancer indicator list
- Main sources:
  - Cancer Registries
  - EUROSTAT
  - HIS/HES
  - Screening registries
  - etc
- Basis for discussion of objective nr 2
Note: at the date of press, the Hellenic cancer registry had just completed its first year of operation and national coverage has not yet been reached.
Harmonization of cancer burden indicators (1)

Formal agreement between ISS and IARC to update the ECO, with data on survival and prevalence provided by EUROCARE

- 1st hypothesis: HEIDI but not technically possible
- Data on incidence, mortality, survival and prevalence
- Agreement to include in ECO cancer burden indicators with common definitions of
  - Cancer site: 45 cancer site groupings provided by EUROCARE will be adopted
  - Period: around 2008
  - Geographical areas: countries, national pools of registries, and single registries
Other initiatives for the same objective

- Workshops organized by JRC between EPAAC, ENCR, EUROCARE to harmonise quality checks of cancer registry data requested for incidence and survival

- Need to harmonize cancer registry data requested by different projects and institutions: possible launch of a common call for data (to compute incidence, survival and prevalence)
ECIS is defined as a *public health and research* infrastructure functionally connecting all institutions, people, procedures and resources producing meaningful information from cancer data and working within a common framework of concepts, methods, structures and technical standards.

**MAIN CHARACTERISTICS**

- One access point for data retrieval
- Network-based data analysis and data quality control
- Operating as a research infrastructure for cancer community at large
- Funded on a sustained basis
In 2012 the Joint Research Centre (JRC) was identified to establish, and support an ECIS, and to coordinate its further development.

JRC will work in close collaboration with all the major stakeholders, including the European Network of Cancer Registries (ENCR), the International Agency for Research of Cancer (IARC), other networks of European scientific institutions (such as those involved in EUROCARE) to define the best effective options on all major ECIS functions:

**DATA QUALITY CONTROL - ANALYSIS - DIFFUSION - DISSEMINATION**
Harmonization of cancer burden indicators (2)

European Cancer Information System (ECIS) document


WORKSHOP

TOWARDS A EUROPEAN CANCER INFORMATION SYSTEM,
Overview of Cancer Information System in Europe and Strategies for the Future

Organised by the European Parliament’s Policy Department A-Economy & Science for the Committee on the Environment, Public Health & Food Safety (ENVI) Health Working Group

to be hosted by MEPs Alojz PETERLE and Glenis WILLMOTT with the participation of
High resolution studies

Strengths and achievements of past HR studies

- Registries proved able to collect HR data allowing generalized (population-based) conclusions:
  - Variation in stage at diagnosis explained most survival variations for breast, colorectal and stomach cancer;
  - Treatment was a major survival determinant for testicular cancer;

**BUT**

- Long time interval between data collection, quality checks, statistical analyses and publication of results
- Published papers describe the past not the current situation
- Very expensive to carry out
Two workshops at JRC in 2013 on the new HR project

Study protocol agreed and circulated to all EUROCARE and ENCR Cancer Registries for:

- breast
- colorectal
- lung
- lymphoma
- melanoma
**MAIN AIMS of the new HR studies:**

- To investigate and compare **patterns of care** and adhesion to **clinical guidelines** across countries, regions, groups of patients
- To **set the basis for updating follow-up** (linkage with EUROCARE)

**Specific CHARACTERISTICS of the new HR studies:**

- Data as recent as possible since 2011
- “Prospective” recruitment, during current registration activity

40 cancer registries from 17 countries involved in the new HR study

Data collection started 1st January 2014
INFORMATION ON CANCER SURVIVORSHIP

• Starting point: EUROCHIP-3 cancer rehabilitation indicator list
• Indicators of rehabilitation success (ex: return to work, quality of life...) -> questionnaire to randomly selected samples of patients from population-based CRs
• These indicators must be adjusted for cancer characteristics at diagnosis

• High Resolution samples can be population-based cohorts of cancer patients on which various outcome studies can be performed
CONNECTIONS WITH OTHER WPs

High Resolution and WP-8 Pilot 2

- Adequate methodology to internationally evaluate survival differences and adherence to guidelines at population level
- Implementation of same methodology also with hospital-registry data
- Data collection and organization also useful for other outcome research areas (QoL, health-economy studies)

WP-9 as “Information System” for other WPs

- WP-5 in occasion of Rome Open Forum
- WP-7 for work on multidisciplinary
- WP-10 for cancer plan indicators
THE EPAAC BOOK CHAPTER 6

INCLUDES

• Mapping of data sources
• Status of cancer indicator availability
• ECIS document

SINTHETISES

Key agreements in EPAAC among cancer data providers (IARC, ENCR, JRC, EUROCARE, etc)
DISSEMINATION OF CANCER SURVIVAL UPDATE

EUROCARE-5 latest results (adults, childhood)

The Lancet Oncology vol 15, 2014

MAC Roundtable

“Key Determinants of Inequalities in Cancer Survival across Europe”
(European Parliament, 05.12.2013)
Public health research conducted on the basis of population-based disease registries should not be impeded through the new proposal on the General Data Protection Regulation.

Ad hoc-studies are needed to investigate survival inequalities.

To reduce the childhood cancer survival gap in Europe, twinning programmes should be promoted.

New studies are necessary to address emerging issues related to the management of elderly patients and of survivorship.

To ensure good clinical cancer care is important to follow evidence-based clinical guidelines covering the whole patient pathway.
Difficulties in analyses of social inequalities in health:
- No gold standard of deprivation
- Multiplicity of deprivation indices

Using deprivation indices based on:
- a shared mode of construction
- a shared concept of relative deprivation
- the same database (same questionnaire)
could overcome the lack of comparability and appropriateness

European versions of EDI were constructed for
- France, UK, Portugal, Spain, Italy
Socio-economic indicators and cancer (1)

The most deprived

The least deprived

EDI

[-23.052,-3.492)
[-3.492,-1.850)
[-1.850,-0.706)
[-0.706,0.450)
[0.450,1.747)
[1.747,3.512)
[3.512,34.909]
During the first year it was decided that cancer cost data for international databases should follow the same methodology used in OECD System of Health Accounts framework (SHA).

OECD expenditures by disease (including cancer) shortly available on-line for an expanded set of OECD countries under different health service settings and by age and gender (where available).
• Ecological models between socio-economic health-related technology & resources variables and EUROCARE-5 cancer survival rates
• These models have been applied to national areas covered by CRs for these sites:
  • NHL - M+F
  • Colon-Rectum - M+F
  • Melanoma - M & F
  • Breast - F
  • Corpus uteri - F
  • Prostate – M
Analyses on survival, incidence and patterns of care data were presented and discussed in several meetings throughout EPAAC.

Final WP9 Meeting with major experts in population based cancer data analyses:

“State of Art of Methods for Analysing Population-Based Cancer Data”
22-23 January 2014 at the EC-JRC
AIMS

Statistical methods for descriptive analysis of population-based cancer data have considerably progressed, also due to the increasing availability of cancer registries data. These methodological advances should be systematically applied, when possible and appropriate, to descriptive epidemiology and current reporting of cancer data.

Objective of this Meeting is to review the present status of statistical methods for the analysis of population-based data discussing possible applications of different methods and trying to point out:

- which of them are sufficiently standardized to be applied for current data reporting (push a button approach);
- which are also well defined and applicable to epidemiological research, but need careful analysis for each specific application;
- which still need methodological research.

Another point will be a review of available software for the different methods, as an important prerequisite for their wide use outside the specialist groups.

Each session will be made of a 10 minutes introduction illustrating the session layout, a series of presentation of about 15 minutes each, and a general floor discussion chaired by a Discussant, who will propose the main discussion topics emerged from the presentations.
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