



EUROPEAN PARTNERSHIP: ACTION AGAINST CANCER (EPAAC)

**STEERING COMMITTEE MEETING
Berlin, 21 March 2012**

WP 9: Proposal for a future European Cancer Information System

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Past Steps

- **First draft** presented and discussed at the **WP9 kick-off meeting Sept 2011**
- Amendments made according to comments:
 - including a description of already existing activities
 - providing a more structured proposal
- **Second draft** circulated in **Dec 2011, third in Jan 2012**
- Main comments received:
 - commitment from Member States
 - inclusion of clinical networks (ECCO, OECI) in the governance
 - inclusion of European and national CR networks

- **Third draft discussed on 7th February 2012 meeting with WP9 team and IARC, ENCR, JRC and EU representatives**

Aim : to constitute a editorial board for ECIS, including main research groups and institutions providing data on cancer in EU.

Issues discussed at the meeting:

- Rationale and background of the ECIS
 - need for a specific cancer information system
 - importance of a European dimension
 - permanent funding
- Main data to be included
 - data from cancer registries
 - data from other sources
- Data diffusion: possibility of a SEER-like public use database
- Information system structure: centralization/network
- Role and the programme of JRC

**Background and Rationale
of the
European cancer information
system (ECIS)**

European dimension of a cancer information system

- High variability across Europe in cancer epidemiology and cancer control activities
- Variability is an added value for research (etiology, prognosis, health services research)
- Cancer control, as part of health care system, is mostly up to member states or regions, but public health research should involve all Europe
- Importance, for both cancer research and cancer control, of a Europe-wide cancer information system
- Central role of population based cancer registries

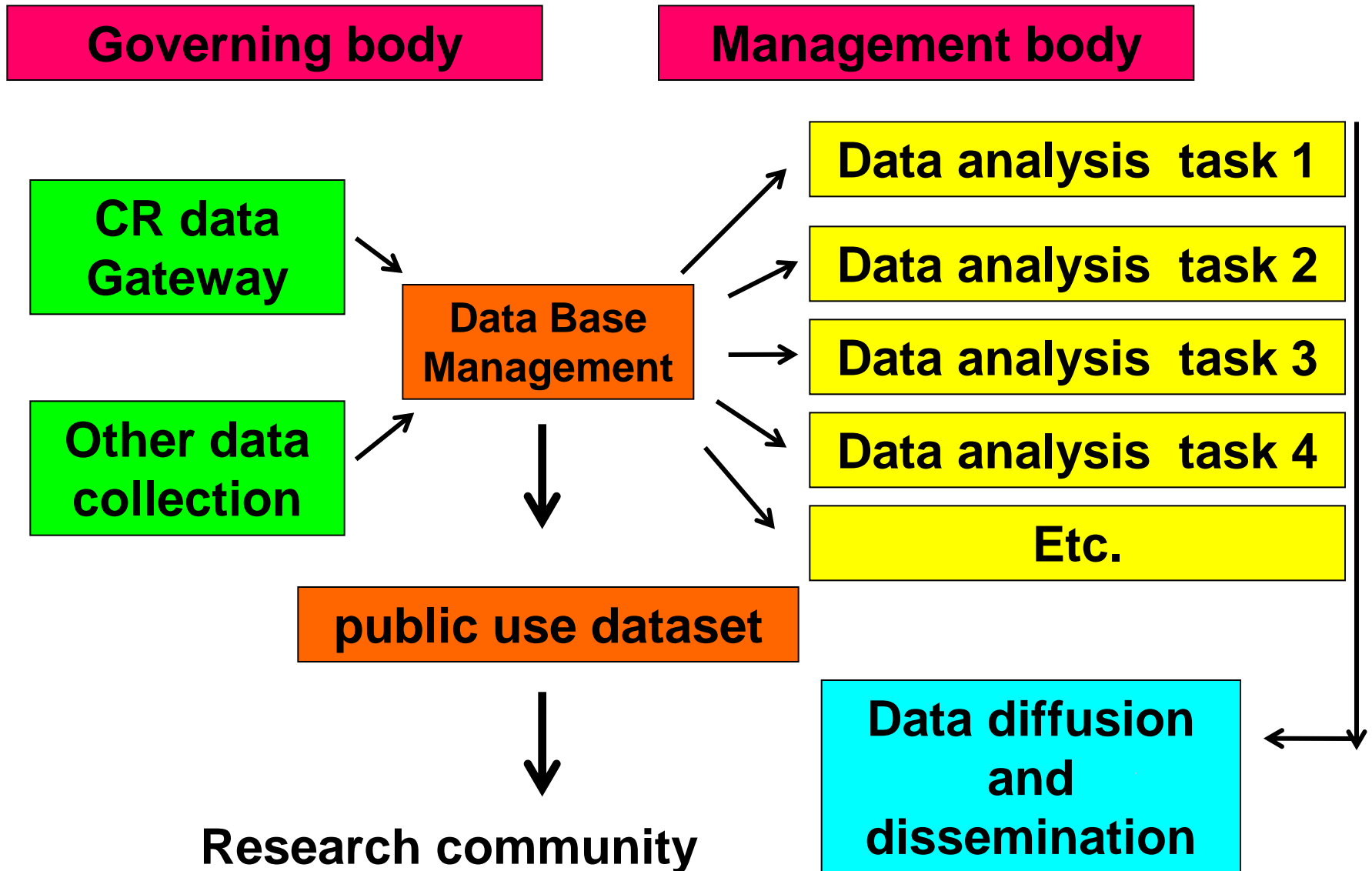
Need for a specific Information System for cancer

- Population based information is more available for cancer than for other diseases, due to the existence of registries and to a long tradition of epidemiological research on cancer
- Cancer has a huge impact on the population health (second cause of death in Europe)
- It requires a large amount of resources in public health, technology and research
- It is a complex disease, requiring detailed information to be studied appropriately
- **Sub-optimal use of existing cancer data has direct negative implications on public health**

Need for permanent funding

- Cancer information system as a resource for planning and evaluating of cancer control activities
- Cancer information system can become a Research Infrastructure
- Systematic updating of the included information
- Progressive inclusion of all Member States and use of new information sources as soon as they become available
- Long-term planning of the development of ECIS

Possible example of ECIS structure



Implementation of ECIS

By networking resources and experiences from existing European activities and institutions involved in cancer information and data diffusion

- Technical running of the ECIS (data input, organization, analysis and diffusion) provided by a network of European and international scientific institutions
- Data provision by cancer registries, statistical institutes, etc.:
- Government, funding, provision of rules and legitimacy: EU and Member states

Main indicators to be included in the ECIS Research groups and Institutions

- ✦ **Incidence** from population-based cancer registries centralized and regularly published by IARC.
- ✦ **Survival** collected and centralized by EUROCCARE and related projects (HAEMACARE, RARECARE).
- ✦ **Prevalence** most recent European data available from the EUROPREVAL and RARECARE projects.
- ✦ **Mortality** collected at the national level by official death certificates. Cancer mortality statistics by registry area organized and diffused by IARC.
- ✦ **High Resolution studies** clinical information collected by cancer registries (France, Italy, Spain, UK), centralised by EUROCCARE

Networking existing research activities

Incidence projections and forecasting

Finland

National estimates

Italy, France

Survival

Italy, France, Germany, UK, Finland

Cure

Italy, UK

The Joint Research Centre (JRC), as a EC institution

Hosting and Managing the central data repository

- coordinating the implementation of the future ECIS in collaboration with major stakeholders, in order to build it on the foundations already established by earlier projects and activities.
- Supporting the governance and technical coordination processes
- Taking on the responsibility of releasing the official cancer statistics in liaison and agreement with the stakeholder community.

The European Network of Cancer Registries (ENCR), as a scientific association

- Assuring and maintaining a strict connection between the ECIS activities and those of the participating cancer registries.
- Representative of the European registries
- Carrier of their scientific, technical and organizational views

International Agency for Research of Cancer (IARC)

Accreditation of cancer registries worldwide and permanent training of their personnel, providing comparable cancer information at the global level.

- continue assuring the full comparability between European and world cancer statistics.
- Research groups at IARC could be part of the Consortium according to their specific research expertise
- The terms of the collaboration of IARC to the ECIS have to be defined in the framework of the present regulations (direct agreement?).

Future actions

- Exchange of comments on the proposed structure of the ECIS (components/WPs/tasks)
- An updated version of the document was drafted and circulated before the present EPAAC SC meeting
- New version expected for internal circulation
- Organisation of meetings before the Rome Open Forum:
 - 27th March, Milano INT with JRC
 - 9th May meeting of the editorial board
- Presentation of a final WP9 proposal at the Open Forum
- Constitution of a writing committee

COMMENTS EXPECTED FROM ALL EPAAC PARTNERS

Networking the existing technical and scientific capacity

- Much less expensive
- Involving already available expertise
- More efficient in the short term
- Very quickly operational
- Active involvement of all Member States
(direct funding = modest amount)