

EUROCHIP-II
FINAL SCIENTIFIC REPORT
ANNEX 09

**REPORT OF
EUROCHIP-2 ACTION IN
GREECE**

**The population-based Hellenic Cancer Registry
Feasibility study**

July 2007

Georgios Ferentinos
geofere72@yahoo.gr

Konstantinos-Vellios Kamposioras
kambkons1@yahoo.gr

INDEX

CHAPTER 1 – CANCER REGISTRY CONCEPTS

| | |
|----------------------------------------------|-----------|
| 1.1 What is a cancer registry | 4 |
| 1.2 Objectives of the cancer registry | 5 |
| 1.3 Data to collect | 6 |
| 1.4 Sources of information | 9 |
| 1.5 Data processing and Outcomes | 11 |
| 1.6 Conclusions | 14 |

CHAPTER 2 – ACTIVITY PERFORMED IN GREECE FOR EUROCHIP-2

| | |
|-------------------------------------------------------------------------------------------|-----------|
| 2.1 Activity description | 16 |
| 2.2 Historic development of the Hellenic cancer registry | 17 |
| 2.3 Questionnaire on infirmaries and hospitalization movement | 18 |
| 2.4 Questionnaire on specialized laboratories | 20 |
| 2.5 Questionnaire on demographic data and death certificates | 21 |
| 2.6 Information collected from Hygienic District Directorate (HDD) and Prefectures | 24 |
| 2.7 Other sources of information | 31 |
| 2.8 Conclusions from the municipal registries and the death certificates | 33 |
| 2.9 Conclusions | 34 |

INTRODUCTION

EUROCHIP-2 aims to improve access to organisation and integration of information and knowledge on cancer for all EU countries, so that more effective action against cancer could be taken.

The purpose of the European Union Health Information System is to provide quality, relevant and timely data, information and knowledge in order to support public health decision-making at European, national and sub-national level. Population-based cancer registries are necessary to reach the objectives of the European Union Health Information System, as they provide uniquely important cancer information for a Member State (MS) and Europe as a whole. For the European Union Health Information System, cancer registries should be considered equal to National Institutes of Statistics, as they are the only providers of cancer data necessary for estimates of cancer incidence, survival and prevalence indicators at population level. Some MSs, including Greece, were reported to lack an organized cancer registry; hence the possibility to develop a cancer registry became a EUROCHIP priority for these EU Member States.

In the frame of the future development of a Greek cancer registry we (Georgios Ferentinos and Konstantinos - Vellios Kamposioras) participated in a two week intensive course on “Cancer registries planning and implementation” at the Reggio Emilia population- based cancer registry. Our final objective was to conduct investigation and write a report regarding the existence or non-existence of the sources of information and the feasibility of the Hellenic population-based Cancer Registry. Further steps on the research involve the desirable coordination between the Eurochip-2 project, the Greek Ministry of Health & Social Solidarity, the Hellenic Center for Diseases Control and Prevention, and the Commission for the Creation of a Cancer Registry in Greece. The activity of the feasibility study in Greece started in June 2006.

Chapter 1 - Cancer registry concepts

1.1 What is a cancer registry

The Cancer Registry (CR) is a structure that collects all the cases of neoplastic diseases taken place in a specific sanitary area or in a population geographically determined, in a continuous, systematic and nominative way. The CR has, moreover, the task to collect, appraise, verify, code, analyze and interpret all the notified cancer cases.

An important subdivision of the CR can be made between:

CR of hospital type (partial registry), when the collection consists of the patients admitted in a hospital;

CR of population type (epidemiological type), when the collection is represented by the resident population in a determined geographic area

The primary scope of *the hospital type registries* is to collect a series of information about the cases admitted into a hospital. The aim of such registries is to proceed to appraisals on the various therapies, the duration and the quality of the survival of the patients and to serve as a support for the follow-up programs of the patients. The usefulness of these registries is rather limited.

The *population type registries* (epidemiological type) have a much wider objective, since they collect all the cases of tumour taken place in the population resident in a determined geographic area, aiming at estimating the incidence of the neoplastic diseases for a site, age or other characteristics. The collection of this information is the basis of descriptive studies and represents one source of fundamental information for the formulation of aetiological epidemiological studies.

Another subdivision of the population type CR can be made between:

- *Specialized CR*, restricted to collect information either for a specific tumour in a limited population (e.g. Mesothelioma registry), or for a specific population (e.g. Registry of the Infantile Tumours)
- *Generalised CR*, which collects information about all the cancers and all the covered population in a complete way.

1.2 Objectives of the cancer registry

The objectives of CR can be generally resumed in the following activities:

(a) Sanitary programming of the territory.

CR could be much of a profit for the correct programming of the resources and the services on the fields mainly affecting the health status of the population. Moreover, the CR will be able to contribute to the local health services planning, supplying useful information about the positioning of industries or other unhealthy settings (e.g. rubbish dumps), the urban planning, etc.

(b) Primary and secondary prevention.

Taken into account the dimensions and the characteristics of cancer, the primary prevention will be able to address the planning of interventional activities (reclamation works, sanitary education) and the secondary prevention to support population screening.

(c) Diagnosis and therapy.

From a clinical point of view and due to survival studies, an earlier appraisal of the effectiveness of the diagnostic and therapeutic measures that can be adopted will be achieved.

Therefore, it is understood that the CR will be able to represent a useful instrument, not only for the clinician, the pathologist, the internist and the occupational physicians, but also and above all for the public health administrators, when having to plan the allocation of resources and the appraisal of the interventions.

1.3 Data to collect

Those variables currently needed for proper cancer registration in Europe will be labelled “essential” and all others supporting the monitoring role of the cancer registry will be called “optional”. It must be emphasized that the rules set out by the IACR on multiple primary cancer apply also to the European Minimum dataset. It should also be made clear, that several of the variables listed in the Optional section, cannot be meaningfully collected in many settings.

ESSENTIAL VARIABLES

THE PERSON

| Item | Comment |
|----------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Personal identification | In some countries a unique ID number, in others full name combined with date of birth & sex |
| Residence | The current residence is required |
| Date of birth | Given as day, month and year (dd/mm/yyyy) |
| Sex | Male (M) or Female (F) |
| Ethnic group | As the population mixture increases this variable importance will also increase, in order for researchers to study inequality. [May be difficult to agree in a classification applied across the whole Europe] |
| Address including postal (or zip) code | Needed for ID purpose and for geographical based studies |
| Vital status & date | It may be of value to indicate whether known or assumed (e.g. based on linkages to death certificates) (dd/mm/yyyy) |
| Date of death | Needed to study survival and follow-up (dd/mm/yyyy) |
| Last follow-up date | Needed to study follow-up (dd/mm/yyyy). Registry should indicate whether date refers to active or passive follow-up. |

THE TUMOUR

| Item | Comment |
|-----------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Incidence date | This date should be given priority as outlined by the ENCR recommendations and as indicated here A-D. (<i>Optional: In order to have comparability more dates should be collected, preferably all included in the definition</i>) |
| <i>A: Date of first histological/cytological confirmation of the tumour</i> | Date of biopsy or date of pathology report (dd/mm/yyyy) |
| <i>B: Date of first hospital admission or contact</i> | May be the date of first out-patient visit for the disease (dd/mm/yyyy) |
| <i>C: Other date of diagnosis</i> | e.g. GP visit (dd/mm/yyyy) |
| <i>D: Date of death</i> | For cases discovered at death/autopsy or unknown cases (dd/mm/yyyy) |

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece

| | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Primary tumour site | As a minimum this should be according to the ICD-O |
| Laterality | This should be recorded for all paired organs, but as a minimum for breast, eye, ovary, testicle and kidney (but observe the multiple primary rules) |
| Primary tumour histology | This should, as a minimum, be according to the ICD-O |
| Behaviour | This should, as a minimum, be according to the ICD-O |
| Basis of diagnosis | Although the most valid is recommended, it is advised to record all relevant methods used separately. The basis should follow the recommended ENCR layout into microscopic, non-microscopic, and tumour markers. |
| Stage – (condensed TNM) | Stage is needed for pan-European studies and for servicing clinicians. It is recommended to use the ENCR condensed TNM. |
| Initial therapy (i.e. initiated within 4 months from incidence date) [A clear manual on what is included should be available from the registry for all treatment items] | As a minimum, the registries should be able to present on a yes/no basis the treatment modalities used |
| <i>Surgery</i> | Any surgical procedure of curative or palliative nature |
| <i>Radiotherapy</i> | Any radiotherapy of curative or palliative nature |
| <i>Chemotherapy</i> | Any cancer chemotherapy of curative or palliative nature |
| <i>Endocrine (hormones)</i> | Exogenous therapy i.e. medication |
| Source of information | It is important to record the source of information (hospital/institution) for each diagnosis and treatment modality in order for researchers to be able to do quality control, or to collect additional information. Also this will be the registry's receipt for not inventing data. |

OPTIONAL VARIABLES

THE PERSON

| Item | Comment |
|-----------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------|
| Occupation | Since most cancer patients will be pensioned it should be the longest/last occupation if not a full occupational history is available |
| Industry | |
| Marital status | At the incidence date |
| Smoking habits at the time of diagnosis | Current, ex-smoker, non-smoker |
| Causes of death | Underlying, plus contributing (can be generated by record linkage in some places) |
| Place of death | |

THE TUMOUR

| Item | Comment |
|----------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Mode of detection | Especially if screen detected as part of programme |
| Therapy details | Type of surgery Chemotherapy regimes Radiation fields – and radiation type Specification of endocrine therapy Record whether the given therapy was intended to be curative or not |
| Differentiation | As indicated in the ICD-O manual |
| Grade | For bladder tumours – grade at date of diagnosis |
| Recurrence | dd/mm/yyyy |
| Metastasis | Site of metastasis and date of diagnosis (dd/mm/yyyy) or as minimum – local, regional or distant metastasis and date of diagnosis (dd/mm/yyyy) |
| TNM – full, FIGO, Ann-Arbor etc. | If the registry has easy access to the full TNM or other stage classifications, these should be recorded |

FOLLOW-UP

| Item | Comment |
|----------------|--------------------------------------------------|
| Follow-up | Clinical follow-up information – quality of life |
| Rehabilitation | Active programme/activities should be recorded |
| Palliation | Palliative activities should be followed |

Moreover, data regarding the geographical depiction, the available health services in the covered area and the existence of an effective information network are needed.

1.4 Sources of information

Demographic data: They define the resident population covered by the registry and provide information about the population structure (age, gender, population density etc.)

The possible sources of population data are censuses, intercensal/postcensal, or any other official estimates of the population.

Pathology Laboratories: This is the main and most accurate source of information wherefrom the various reports (histological, cytological etc) are collected and stored in the data base.

Related data can be obtained from specialised laboratories involved in tissue typing such as haemolymphatic laboratories, immunocytological or cytogenetical laboratories.

Hospital Discharge Records: Hospital discharge records (computerized preferably) from all hospitals and clinics in the area covered are collected and controlled for cancer cases.

Mortality Data: The mortality data should consist of all deaths from cancer among residents of the registration area during the same period as that covered by the incidence data.

The variables required are:

1. Year of death
2. Sex
3. Age-group (0, 1-4, 5-9 ... OR 0-4, 5-9 ...) or age in years
4. Underlying cause of death by site, 3-character ICD-9 or ICD-10 code or corresponding special tabulations.
5. Ethnic group, if such information about cancer cases is available in the mortality statistics.
NB: the codes for ethnic group with a corresponding label must be given.

Other sources

They can either identify new possible cases or cross-check already existing information. These may include:

- Reports from Radiotherapy Oncology, Haematology, Pneumonology, Surgery, Dermatology Departments
- Imaging reports

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece

- One Day Clinics and Out-patient Records
- Family doctors
- Sanitary commissions for the assessment of the citizen's inability
- Competent services for the appraisal of the incapacity state, finally deciding for the right to a prosthesis (e.g. laryngeal tumours, breast tumour)
- Competent medicine services appraising the right to the exoneration from specific financial burdens (e.g. transportation tickets, pharmaceutical coverage etc.)
- Autopsy reports

Tumour Codification

Every CR must codify the tumours according to the internationally produced classifications from the World Health Organization (WHO second). The used acronym in order to indicate the edition of these classifications is: ICD, International Classification of Diseases. The tumour coding very often is published separately as ICD-O: International Classification of Diseases for Oncology.

According to the last edition of the "Cancer Incidence in Five Continents", in 2002, nearly half of the world-wide registries used ICD-O-2, while an equal percentage of approximately 14% ICD-O-1. The remaining registries were subdivided equally between the ICD-9 and ICD-10 coding.

Ideally, the reports are according to the ICD-O-3 coding system for the morphological and topological details of the tumour. Otherwise, different coding systems (e.g. SNOMED, ICD-9) are transformed to ICD-O-3 through software. Finally, if no coding system exists, a dedicated person has to check, register and codify all the information provided.

1.5 Data processing and Outcomes

Once the information is collected from the above sources it is codified, verified, and the final products are extracted (Figure 1). Detailed information is provided at the relative web pages.

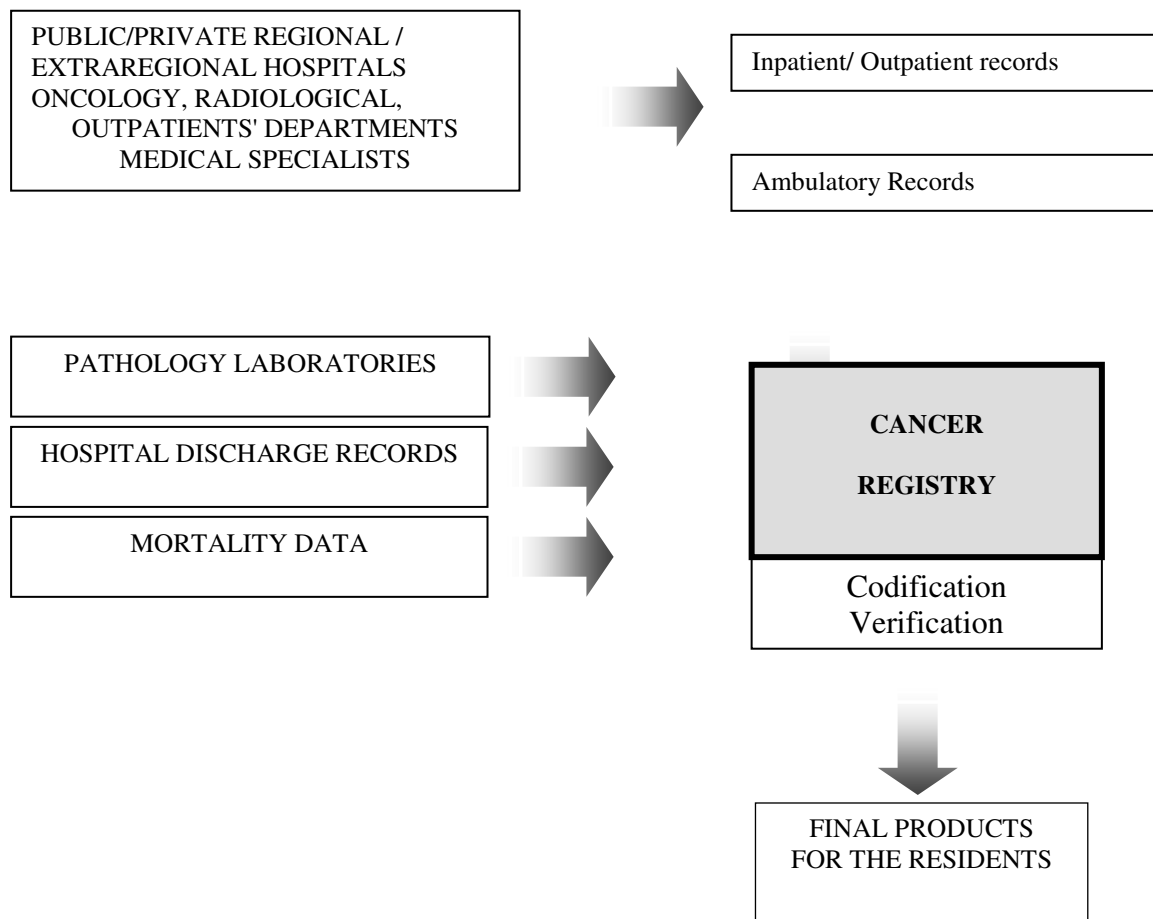


Figure 1: Flow of information in a CR

Products of a CR

A CR has to produce annually data regarding:

- Incidence (crude and age-specific)
- Survival
- Prevalence
- Mortality (crude and age-specific)
- Standardised incidence/mortality rate
- Cumulative Risks
- Mortality/incidence ratio
- Estimations of time-trends
- Estimations of cancer specific sites
- Estimations of specific geographic area
- Geographical comparisons (regional, national, worldwide)
- DCO. ‘Death certificate only’ (DCO) indicates those cancer cases for which no other information than a death certificate mentioning cancer could be obtained. This must not be confused with the cases first notified by a death certificate (death certificate notification - DCN).

Quality indicators

The whole CR operation is evaluated by the following indicators

In the first place...

- Percentage of microscopically verified cases (histology and cytology).
- Percentage of cases known from Death Certificate Only (DCO)
- The Mortality/Incidence ratio

Moreover...

- Percentage of cases with unspecified sites
- Percentage of cases with unspecified morphology
- Change in annual standardized incidence rate
- Change in annual Mortality/Incidence ratio

Human and Material Resources

For the right operation of a CR both personnel and appropriate equipments are necessary. From organizational point of view, it should be kept in mind that the organisation of a modern and efficient Registry would need a director/coordinator, medical advisors, statistician, information technology engineer, registrars and secretary. The total number of the personnel depends on the existence of automated sources and internal procedures, the personnel experience and the dispersion of the information sources. More specifically the total number of registrars may be estimated as 1 person per 1000 new cancers (*Jensen et al. 1991*) or 1 person per 250.000.

Material resources include premises in order to record in safe way documents of the registry and the necessary equipments for the precise operation of the CR. This embraces a reasonable number of computers for the normal operation of recording and analysis of the data, updated manuals containing the coded information (ICD-O) for the recording and codification of the diseases and all disposable materials. Finally, the cost estimation depends also on the dimensions of the covered area, the amount of the information to be collected, the quality level of the information sources and the automation degree of the area.

Privacy, Confidentiality and Ethical Code

The privacy requirement for operation of the CR derives from various legal sources, some of recent definition. Every country has its own legislation regarding these issues. However, already from 1991 the International Association of the Cancer Registries (IACR) had proposed one series of guidelines for maintaining the confidentiality of the data. In 2002, European Network of Cancer Registries (ENCR) has distributed new guidelines regarding confidentiality for the population registries of the European Union. In 2004, an internal report from IACR updated these criteria to an international version, underlying once again the great significance of ethical commitment of the CR operators concerning the handling of these sensitive data. [...] *this document is not a set of rules, but should be considered in the light of legislation, or lack of it, in the area where the cancer registry is situated.* (*Hans H. Storm, Internal Report n. 2004/03. IACR*). Finally, a technical-scientific Committee composed of the principal Health administrators of the involved area as well as other local authority representatives either directly or indirectly implicated in the CR operation, should be constituted in order various scientific, technical and maybe ethical issued can be faced and solved.

1.6 Conclusions

Cancer Registries represent a powerful source of data for

- Health authorities
- Health professionals
- Physicians
- Epidemiologists
- Politicians
- Patients
- Citizens

Aims

- *Planning and health surveillance*
 - Evaluation of public health services and activities
 - Prevention and Screening
- *Epidemiological Research*
 - Described studies
 - Analytic studies
 - Incidence
 - Prevalence
 - Mortality
 - Time trends
 - Geographic estimations
 - Survival
 - *Support for clinicians (not only oncologists) and for cancer research*

Indispensable requirements

- The regarding data of the population as well as the geographical depiction of the area covered from the CR
- Available health services in the covered area
- Existence of an effective information network
- Human and Material Resources
- An appropriate ethical "code"

Chapter 2 – Activity performed in Greece for EUROCHIP-2

2.1 Activity description

On the basis of the aforesaid data we commenced our research in June 2006, which lasted through January 2007. During the research we looked for information sources in all the possible bearers who possess relevant data.

Health planning in Hellas is instrumented by the Ministry of Health and Social Solidarity. For better coordination the Hellenic sanitary territory is divided to 17 Hygienic Districts Directorates (HDD) (Figure 2). Attica is divided to 3 HDDs (A,B,C), Central Macedonia to 2 HDDs (A,B) and South Egean to 2 HDDs (A,B)

The HDDs during the period of carrying out the research came up to 17 while, after their merging, come up to 7 (1st Hygienic District of Attica, 2nd Hygienic District of Piraeus and Aegean, 3^d Hygienic District of Macedonia, 4th Hygienic District of Macedonia and Thrace, 5th Hygienic District of Thessaly and Sterea Ellada, 6th Hygienic District of Peloponissos, Epirus, Ionian Islands and West Greece, 7th Hygienic District of Crete).

Public /civil services are operating under the Ministry of Interior, Public Administration and Decentralization. Hellas is divided *τεταρτοβάθμια* in 13 administrative districts 54 Prefectures and more than 1000 Local Self-Administration Organizations (LSAOs). In relation to our survey, prefectures are responsible in providing licenses of operation to private clinics and laboratories while LSAOs are responsible for the collection and analysis of demographic data.

In Hellas, infirmaries (health services) are divided in legal persons of public law (including the health centers), legal persons of private law and totally private ones. Each of these has the corresponding departments and laboratories. Prefectures are responsible for granting operation licenses to laboratories and the infirmaries of private character, while the laboratories and the infirmaries of public character are subject to the local Hygienic Districts Directorates (HDD).

The feasibility study was organized to collect information on historic development of Hellenic Cancer Registry (paragraph 2.2), infirmaries and hospitalization movement in Greece (paragraph 2.3), demographic data and death certificates (paragraph 2.4). After this information we summarized data collected by each HDD (paragraph 2.5).

To collect this information various sources were contacted: Ministry of Health and Social Solidarity, Ministry of Interior, Public Administration and Decentralization, Hellenic Center for Diseases Control and Prevention, Secretariat general of the national statistical service of Hellas, each HDD and each Prefecture.

All the answers we received through the end of February 2007 were classified and analyzed. The results per category are stated below.

2.2 Historic development of the Hellenic cancer registry

Searching the till to day activities of the National Cancer Registry, its present and its future we addressed ourselves to the Public Hygiene Directorate of the Ministry of Health and Social Solidarity, to the Hellenic Center for Diseases Control and Prevention and to the Central Health Council. The following table summarizes the information received.

| Institutions Contacted | INFO OBTAINED |
|------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Public Hygiene Directorate of the Ministry of Health and Social Solidarity | <p>NCR was established in 2003 as a service of the Ministry of Health. It collects data of cancer patients with the purpose of the analysis of the said from the whole Hellas.</p> <p>Before that NCR was an activity of the Central Health Council (CHC) which also issued the results.</p> <p>In 2005 the NCR went under the Hellenic Center for Diseases Control and Prevention (HCDCP). The delivery of the service has not been carried out yet.</p> <p>The patients' data are protected by laws and for the collection - analysis of the same there is being required the license of the Personal Data Protection Authority</p> |
| Public Hygiene Directorate of the Ministry of Health and Social Solidarity* | Our claim was transmitted to the HCDCP without any answer through the present time |
| Hellenic Center for Diseases Control and Prevention | No response |
| Central Health Council | No response |

*Second application clarifying that no personal data are requested and analyzing our request

2.3 Questionnaire on infirmaries and hospitalization movement

In the endeavor to investigate the present situation of the infirmaries and the hospitalization movement in Greece we contacted the Health Units Development Directorate of the Ministry of Health and Social Solidarity (MoH). Table 1 synthesizes information requested and obtained.

Table 1. Information requested to the MoH about infirmaries and hospitalization movement

| INFO REQUESTED | INFO OBTAINED |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Which infirmaries legal persons of public law (including the health centers), legal persons of private law and totally private are there in the Hellenic territory (per Prefecture) as well as their communication particulars? | Analytical tables with the NHS Hospitals of the country and their communication particulars, the country's private clinics and the Radiotherapeutical departments / laboratories and the Chemotherapy Units (of NHS and Universities) as the same are placed among the Medical Service of the respective Hospitals |
| Which do the departments - clinics exist in each of the aforesaid infirmaries? | |
| Which infirmaries keep records of hospitalization movement in printed a/o in electronic form? | For the rest of the data being requested the specific service has no information. Notification of the application took place by the specific service to the Primary Health Care Directorate as well as to the Public Hygiene Directorate requesting them their own activities in regard with them, yet without receiving any answer. |
| Which data of the patient are being recorded (full name, father's name, date of birth, etc)? | |
| Which data referring to the hospitalization (admission date, clinic - department in which he/she was hospitalized, tests, hospitalization duration, discharge diagnosis, scheduled follow up etc.) are recorded in each infirmary? | |
| Is any codification system followed for the discharge diagnosis (discharge note) (e.g. ICD 9)? | |
| In which infirmaries are there "one-day" units and also departments, units or clinics where chemotherapies and radiotherapies take place? Which of the aforesaid keep records for the patients who visit them, in which form (printed or electronic) and which data are being recorded? | |
| Are the files and the discharge notes of patients in each infirmary being kept? If yes for how long (for finding cancer cases which need further investigation by specialized scientific personnel) | |
| Does any central service exists collecting all the aforesaid particulars from all the infirmaries? | |

As far as it concerns the available data for cancers, *Secretariat general of the national statistical service of Hellas* informed us in regard with the Research of Closed Hospitalization which is carried out by the National Statistical Service of Hellas. In specific, it refers to the patients discharged who have been hospitalized at least one day in Public Hospitals or Private Infirmaries (Clinics). The research's periodicity is monthly and the initial year is 1962.

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece

The research covers the following variables: sex, age, permanent residence and place of birth, family status, occupation, days of stay, class of the hospitalization bed, main disease which was diagnosed, number of operations, outcome of the hospitalization (cure, improvement etc.). The last available data are those of the year 2001, while it is forecasted that through the end of 2006 there will be available the data for the years 2002 and 2003. The disposal way may be:

- a) Printed form: Annual Publication of the Social Solidarity and Hygiene and Statistical Yearbook
- b) Electronic form: In the web page (available data to the total of the country).
- c) Tables in the library in the Secretariat General of the National Statistical Service of Hellas. (In printed and electronic form, in the total of the country, in peripheral level and prefecture).
- d) Record with the primary material. The record is available following a decision of the Committee of Statistical Secrecy provided that there are not disclosed any particulars in regard with the patient's identity and the Hospital's identity.

In regard with the variable "main disease which was diagnosed" the particulars are filled in by the administrative employees of the Hospitals (patients' forwarding office) on the basis of the physician's opinion. They are being codified and processed by employees of the Secretariat General of the National Statistical Service of Hellas, in accordance with the International Classification of diseases, injuries and causes of death (ICD-9) of the World Health Organization (WHO) (brief catalogue - three digits codes). In the main disease there are also included the cases of cancers with description which refers to the disease's behavior (benign, malignant, in situ). Finally there is no special registration or distinction for the primary cases of cancers.

We addressed the same applications to the 17 Hygienic Districts Directorate (HDD) (Figure 2) and the Health Directorate of the 55 Prefectures (Figure 3) of the country. In paragraph 2.6 we synthesized information by HDD.

From the aforesaid data there results that, except of isolated cases, no collective analytical data exist which refer to the hospitalization movement of patients who suffer from cancers.

2.4 Questionnaire on specialized laboratories

In the search for specialized laboratories in Greece we requested specific information to the Health Units Development Directorate and Primary Health Care Directorate of the Ministry of Health and Social Solidarity (MoH). Table 2 synthesizes information requested and obtained.

Table 2. Details of information requested to the MoH about specialized laboratories

| INFO REQUESTED | INFO OBTAINED |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| In which infirmaries and diagnostic centers in Hellas, both of the public and the private sector, are there specialized laboratories (Pathology, Haematology, Immuno-cytochemistry or Molecular Biology Laboratory)? | Analytical tables of the Laboratories of the National Health System (NHS) and of the University Laboratories as they are classified in the Medical Service of the respective Hospitals. As far as it concerns the operation of the specific Laboratories in the Private Clinics of the country, the service does not possess such data, since their operation falls under the competency of the local prefectures. |
| Is the Ministry of Health and Social Solidarity aware of the operation of the aforesaid laboratories in general and more specifically regarding the cases of cancers? | NO REPLY |
| Do analytical particulars of the patient exist, since when the recording exists and what kind of type it is (printed and/or electronic); which data of the patient are being recorded and if each laboratory uses any codification system and which one (for example ICD, ICD-O, SNOMED)? | NO REPLY |

We addressed the same applications to the 16 Hygienic Districts Directorate (HDD) (Figure 2) and the Health Directorate of the 55 Prefectures (Figure 3) of the country. In paragraph 2.6 we synthesized information by HDD.

Both for the private as well as for the public laboratories there is no central service which collects the data, therefore the bearer for the registration of cancers is being required to contact each laboratory separately and to establish a proper system for the collection of information, taking into consideration matters such as the lack of codification and computerization and the protection of the personal data.

2.5 Questionnaire on demographic data and death certificates

In order to investigate the demographic data and to be aware of the particulars for the composition of the population we initially addressed ourselves to the Ministry of Health and Social Solidarity (MoH). Table 3 synthesizes information requested and obtained.

Table 3. Details of information requested to the MoH about demographic data

| INFO REQUESTED | INFO OBTAINED |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Does any collective and/or analytical data in regard with the population of the natives and the aliens in Hellas for each year per: sex, age, geographical district, prefecture and municipality / community exist? | From the MoH our application was transmitted to the (HCDCP) (Office of Chairman for the NCR) and b) to the CBHS (Chairman of PMT Chart of Health and Social Solidarity), without having any answer through now. At the same time we addressed the same questions to the Ministry of Interior, Public Administration and Decentralization, where from the Administrative Support Directorate General, Civil and Municipal Status Directorate, Records and Registries Department informed us that they had transferred our claim to the Directorates of Organization and Operation of the Local Self-Administration Organizations (LSAO) and Aliens and Migration. From this service the claim was transmitted to the Ministry of Economics and Finance, General Secretariat of the National Statistical Service of Hellas. (without having any answer through now) |
| Which is their update frequency, how often are the records updated, which are the information sources, how the information is updated (active or passive), through which year there are official available data, which is the time period of the available - processed data from now and what is forecasted in regard with the immediate future, in which form are the data (electronic or printed) and to which years they refer? | |
| In case of existence of analytical data, to which do they refer (first name, surname, father's name, date of birth, residence address etc? If there are forecasts for the following years and if yes until when and, finally, under which prerequisites are these records available to a competent bearer for the Registration of Cancers in Hellas? | |

In order to cross check our information we addressed the same questions to the HDD of Hellas, asking furthermore to provide to us the communication particulars of the persons competent for the update of the date, per municipality and community of each district. In next paragraphs we synthesized information by HDD.

In order to investigate the information sources for cancer mortality as well as the information from the death certificates, we initially addressed ourselves to the Ministry of Health and Social Solidarity (MoH). From the MoH our claim was transmitted: a) to the Hellenic Center for Diseases Control and Prevention (HCDCP) (Chairman's Office for the NCR) and b) to the Coordinating Body of Health Sector (CBHS) (Chairman of the Project Management Team (PMT) Health and Social Solidarity Charter), without having received any answer through the moment. At the same time, we addressed ourselves to the Ministry of Interior, Public Administration and Decentralization (MoI). Table 4 and 5 synthesizes information requested and obtained.

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece

Table 4. Details of information requested to the MoH about death certificates

| INFO REQUESTED | INFO OBTAINED |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|
| Does any available data for the crude, age-specific and sex-specific mortality in total and per district, prefecture or municipality in Hellas? If yes, since when are they available and in which form (electronic or printed) exist? | No info obtained |
| If available mortality data exist, are they specific in proportion with: <i>topography, histology image, behavior</i> (benign, malignant, in situ)? If yes, since when are they available and in which form (electronic or printed)? | |
| Which are the sources from which the information originates? How often are the records updated? Which is the time period of the available- processed data from the present time and what is forecasted for the immediate future? If there are forecasts for the following years and, if yes, for how long there are? | |
| Furthermore we have requested to be informed if codification of the aforesaid data for all the diseases and more specific for cancers exists, and, if yes, on the basis of which codification system (for example ICD 9)? When did codification commence, through which year has it been completed and by which personnel is it materialized? | |

Table 5. Details of information requested to the MoI about death certificates

| INFO REQUESTED | INFO OBTAINED |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| If there are death certificates filed per Prefecture, municipality or community and in which form (printed and/or electronic), if any type of codification is followed for the cause of death and, if yes, which one (for example ICD), since when and who is performing it, which particulars are recorded that would help the identification of each incident (name, surname, father's name, address, other demographic particulars), since when are the relevant records being kept, which is their update frequency, if the certificates are collected in a central service and, if yes, which particulars are recorded (name, surname, father's name, address, other demographic particulars). | From the Ministry of Interior, Public Administration and Decentralization and, in specific, from the Administrative Support Directorate General, Civil and Municipal Status Directorate, Records and Registries Department they answered to us that the death certificates which are issued by the physicians, as well as the Registrar's Acts of Death which are drawn up at the place where the death occurred or the deceased was transported for burial are not recorded per Prefecture, municipality or community. The medical death certificates which are required for the execution of the relevant registrar's death certificates are kept with the competent Registries of the Municipalities and the Communities of the country in the same files per type, in accordance with the provisions of article 21 of the Presidential Decree 850/1976 (Government Gazette A' 311). The registrar's acts of death are recorded in the registries of death which are kept in every Registrar's Office and they are public, pursuant with the provisions of article 8 of the Law 344/1976 (Government Gazette A' 143). |

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece

For the more complete investigation of possible information sources we addressed all the aforesaid questions in regard with the population's demographic data, and the mortality data to the *Secretariat general of the national statistical service of Hellas*.

They informed us that there are available data in regard with the number of death per cause (from cancer, ICD-9), sex, age, geographical district (the four digits cause code is available), Nome (the three digits brief cause is available), municipality or community (the two digits brief cause code is available) and nationality for the years 2004 and 2005 (as during the previous years there is no distinction between natives and aliens, due to the non codification of the nationality). The records of the Population Physical Movement Research are monthly updated and the information sources are the registrar's offices of the municipalities and the communities of the country. The data exist both in printed as well as electronic form (since 1980) and are disposed to the users in the form they appear (grouped) in the relevant tables.

In order to cross check our information we addressed the same questions to the 13 administrative districts (Figure 2) of Hellas asking, furthermore, to provide to us the communication particulars of the persons who are responsible for updating the records, per municipality of each district. It is important to note that, at the time of our research, the administrative districts correspond to the Hygienic Districts Directorates.

In paragraph 2.6 we synthesized information by HDD.

2.6 Information collected from Hygienic District Directorate (HDD) and Prefectures

HDD-1: ATTICA

Attica is divided to 3 HDDs, which cover different geographical areas.

The A' HDD of Attica (1) does not keep the data being required for cancers, but it forwarded to us the communication particulars of the Hospitals in its responsibility area and the web site of the service where the Hospitals' departments are shown.

The C' HDD of Attica (1) gave us an analytical list with the Providers of Health and Social Solidarity and the departments which operate in the Hospitals of the service's competency. The service is being informed, on an annual basis, for the movement of each department (mainly in electronic form) but not in analytical form (for example per examination type, per operation type, per disease etc.) and no personal data of the patients are being provided to the service, as they constitute data of personal character. For more information they directed us to the respective Bearer. For the Infirmaries of private character they directed us to the competent Prefectures.

The B' HDD of Attica (1) did not answer.

| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
|-----------|-------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------|
| 1A | Athens | | - |
| 1B | East Attica | It directed us to the partial laboratories - Infirmaries in order to get information for the data we needed | |
| 1C | Piraeus | We received a list of the private clinics which operate at the specific prefecture in order to address ourselves to them, since the service does not possess the data we requested | |
| 1D | West Attica | | - |

DEMOGRAPHIC DATA: In the service there are not being kept any records with the requested data and they proposed to us to ask for demographic data by the National Statistical Service of Hellas and, on the other hand, the death certificates to the respective LSAO of the a' degree.

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece

HDD-2: STEREA ELLADA

| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
|----|------------|------------------------------------------|-------------------------------|
| 2 | Evia | - | It does not possess any data. |
| 3 | Evrytania | - | - |
| 4 | Phocis | - | - |
| 5 | Phthiotis | - | - |
| 6 | Boeotia | - | - |

DEMOGRAPHIC DATA: From some municipalities communication particulars with the competent employees have been provided

HDD-3: CENTRAL MACEDONIA

It sent to us tables with the medical departments and the university clinics of hospitals of the service's competency per sector. It does not keep any epidemiology data, for the registration of which the Hellenic National Statistical Service is responsible.

| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
|----|--------------|---------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 7 | Chalcidice | It forwarded our application to the Poligiros Hospital for further activities, without having received any answer through the present time. | No specialized laboratories operate, except of 6 Microbiology ones. |
| 8 | Imathia | - | - |
| 9 | Kilkis | - | There operates a Pathology laboratory in the Kilkis General Hospital without the Health Directorate to be informed in regard with the laboratory's operation. There is a printed (since 1986) and an electronic (since 2001) filing and there are being recorded the full name, clinical information and SNOMED is the codification system. |
| 10 | Pella | - | - |
| 11 | Pieria | - | - |
| 12 | Serres | - | - |
| 13 | Thessaloniki | It informed us that it does not possess any data in regard with the Hospitalization Movement | It sent analytically the Pathology and Cytology laboratories which operate in the service's competency |

DEMOGRAPHIC DATA: They sent us the communication particulars with the competent employees of the municipalities.

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece

| HDD-4: CRETA | | | |
|---------------------|-------------------|------------------------------------------------------------------------------------|-----------------------------------------------------------|
| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
| 14 | Chania | - | - |
| 15 | Heraklion | An attached table was sent to us with the Nome's private clinics for communication | No private clinic operates with the specific laboratories |
| 16 | Lasithi | - | - |
| 17 | Rethymno | - | - |

DEMOGRAPHIC DATA: They sent us a table of the Prefecture's municipalities for communication with them.

| HDD-5: EAST MACEDONIA AND THRACE | | | |
|-----------------------------------------|-------------------|-------------------------------------------------|-----------------------------------------------------------|
| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
| 18 | Drama | - | - |
| 19 | Evros | - | - |
| 20 | Kavala | - | - |
| 21 | Rhodope | - | - |
| 22 | Xanthi | - | No private clinic operates with the specific laboratories |

DEMOGRAPHIC DATA: The claim was transmitted to the LSAOs of the district. From some communities we received the communication telephones with the municipalities or the communities. From the Civil Status Aliens and Migration Directorate we were informed that they may only inform us in regard with the number of residence licences which have been issued through the present time per year and Prefecture of the District and as of the date of establishment of the service. They also informed us that the provision of data per sex and age is not possible, while the data which are kept by this service are renewed every time that the alien applies for a renewal of a residence permit, as well as from relevant documents of the competent Police Directorates and the jointly competent bearers. As far as it concerns the death certificates they informed us that the death certificates which are issued by physicians are registered in the registries of each municipality in printed form, while there are being written the full name, father's name, mother's name, address while alive, family status, municipal data and the cause of death of the deceased. Each death is being registered on the death certificate immediately at the Registry, while the death certificates are collected in the Registrar's office of the city where the death occurred and the registrar's acts of death are registered with all the particulars written in the aforesaid certificates. In conclusion, they informed us that codification for the cause of death is probably followed by the Statistical Service.

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece

HDD-6: EPIRUS

It informed us in regard with the Hospitalization Operation of the Arta Hospital. There are files in electronic form (in the Patients' Forwarding Department) for admissions and discharges since Feb 2006. There are being recorded the name, father's name, date of birth, address, discharge diagnosis and the insured person's number and the Statistical Service of the Ministry of Health and Social Solidarity collects the said data. The codification system ICD10 is being followed. The hospitalization files and the patients' discharge notes are kept with the Files Record since 1996.

| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
|----|------------|-------------------------------------------------------------------------------------------------------------------------------------|------------------------------|
| 23 | Arta | The Department of Health forwarded the application to the Arta General Hospital. No answer has been received. | It does not possess any data |
| 24 | Ioannina | - | - |
| 25 | Preveza | The Health Department forwarded our application to the Preveza Hospital and the Nome's Health Centers. No answer has been received. | It does not possess any data |
| 26 | Thesprotia | - | - |

DEMOGRAPHIC DATA: From some municipalities communication particulars with the competent employees have been provided

HDD-7: IONIAN ISLAND

It does not supervise Infirmaries or diagnostic centers - laboratories of private character. It does not keep the requested data and it directed us to the competent Hospital of the HDD, communication particulars of which were forwarded to us.

| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
|----|------------|-------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 27 | Corfu | - | - |
| 28 | Kefallinia | - | - |
| 29 | Lefkada | No private clinics operate. Lefkada Prefecture directed us to the Lefkada General Hospital in order to find data. | There are not any specialized laboratories |
| 30 | Zakynthos | - | We were informed that one Pathology laboratory exists, for the operation of which the Health Directorate is not being informed. Following a communication of the service with the pathologist in charge we were informed as follows: the laboratory keeps a record since 1999, originally printed and since 2000 electronic. There are being recorded the full name, the father's name, the age, the telephone and clinical information without the use of any codification system. |

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece**HDD-8: NORTH AEGEAN**

NO INFO. In order to get information there is being required the concordant opinion of the Ministry of Health and Social Solidarity.

| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
|----|------------|------------------------------------------|------------------------------------------------------------------------------------------------------|
| 31 | Chios | - | - |
| 32 | Lesbos | - | - |
| 33 | Samos | - | Directed us to the Samos Hospital and the Prefecture's Health Centers for the information we request |

HDD-9: PELOPONNISSOS

It informed us for the Pathology, Haematology and cytology laboratories that operate in the Prefectures of its competency. For more information it directed us to the respective laboratories.

| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
|----|------------|------------------------------------------|-----------------------------------------------------------------------------|
| 34 | Arcadia | - | It has not issued operation licence of specialized diagnostic laboratories. |
| 35 | Argolis | No private clinics operate | There do not operate any specialized laboratories |
| 36 | Corinthia | - | - |
| 37 | Laconia | - | - |
| 38 | Messinia | - | - |

DEMOGRAPHIC DATA: It forwarded our claim to the HDD of Peloponnissos without any further information for us.

HDD-10: SOUTH AEGEAN

| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
|----|------------|----------------------------------------------------------------------------------------------------|-----------------------------------------------------------|
| 39 | Cyclades | It directed us to the Samos Hospital and the Nome's Health Centers for the information we request. | - |
| 40 | Dodecanese | It directed us to the Infirmaries of Rhodes, Kos, Kalimnos and Leros for further information. | No private clinic operates with the specific laboratories |

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece

HDD-11: THESSALY

It has no competencies for the establishment of a cancer registry and, furthermore, it does not have detailed information for the relevant activities of the laboratories. Nevertheless, many of the required information are a subject being published by the Ministry of Health and Solidarity, through the Health and Solidarity Chart, as well as by the National Statistical Service

| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
|----|------------|------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 41 | Karditsa | It directed us to the Karditsa General Hospital for information. | It does not possess data for cancer cases, nor do they operate respective departments in private clinics. A private Haematology laboratory operates in the Nome. |
| 42 | Larissa | - | We have been informed in regard with the existence of public and private Pathology laboratories. The Prefecture is not informed for the operation of the laboratories. |
| 43 | Magnesia | - | We received analytically the Pathology and Cytology laboratories which operate in the Prefecture. We were also informed that a Pathology laboratory operates in the Volos Hospital with immunocytochemistry department. The Department participates to the registration of malignant and marginally malignant cancers since 1990, since the Hellenic Cancer Registry (HCR) started operating. |
| 44 | Trikala | - | - |

DEMOGRAPHIC DATA: There are no data in regard with the existence of cancers.

HDD-13: WEST MACEDONIA

| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
|----|------------|----------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------|
| 48 | Florina | - | - |
| 49 | Grevena | - | - |
| 50 | Kastoria | - | - |
| 51 | Kozani | We received analytically the communication particulars of the Kozani Hospital, the Health Centers and the private clinics of the Nome. | We received analytically the Microbiology, Histopathology, Cytology and Diagnostic Laboratories which operate in the service's competency. |

| HDD-12: WEST GREECE | | | |
|----------------------------|-------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| NR | PREFECTURE | INFIRMARIES AND HOSPITALIZATION MOVEMENT | SPECIALIZED LABORATORIES |
| 45 | Achaea | - | - |
| 46 | Aetoloacarnania | <p>In the Mesolonghi Hospital. In the Hospital there exist a printed filing (since 2000) and an electronic record (since 2003) where there are being written the full name, father's name and other demographic data. In relation with the hospitalization there are being written: admission date, treatment clinic, duration of hospitalization and discharge diagnosis. No codification system is being followed. Chemotherapies are performed in the Mesolonghi Hospital and a printed as well as an electronic record is being kept, while the patients' files are kept with the Hospital.</p> <p>In the General Private Clinic "Ippokratio" there is being a printed and an electronic record where there are being written the full name, the father's name, other demographics. In relation with the treatment there are being recorded: admission date, treatment clinic, duration of hospitalization and discharge diagnosis. No codification system is being followed and chemotherapies are not performed. Patients' files are kept for the last six years.</p> <p>In the Agrinio General Hospital there is being kept a record of hospitalization movement in printed (since 1937) and electronic (since 2001) form and there are being kept relevant data as stated above. Patients' files are being kept where the hospitalization data are being recorded. No chemotherapies are performed in the Hospital.</p> | <p>In the Mesolonghi Hospital there operates a Pathology, Haematology and Immunocytochemistry laboratory. There exists printed and electronic filing since 2000 and no codification system is being kept. Full name, age and clinical information of the patient are being recorded. In the General Private Clinic "Ippokratio" there are no specialized laboratories.</p> <p>In the General Hospital of Agrinio there is a Pathology laboratory since 1988 but the laboratory operates since 1990 and immunohistochemical smears are being also carried out. There is printed and electronic filing and codification by the S.N.O.P. system where there are being recorded the full name, age and clinical information. An Immunology laboratory operates in the Microbiology department and an electronic registry is being kept since 1997.</p> |
| 47 | Ilia | - | - |

PS: All the info collected will be available in Greek on the EUROCHIP web Site (www.tumori.net/eurochip)

2.7 Other sources of information

Family Physician

For the investigation of the situation in the Primary Health Care and the statute of the family physician we addressed ourselves to the Primary Health Care Directorate (Ministry of Health and Social Solidarity) and requested to be informed for what is provided by the legislation for the statute of the family physician and in which materialization phase it is. The precise legal provisions were given to us in regard with the specific matter and we were informed that the statute of the family physician, as far as it concerns the units of primary health care of the National Health System, has not been applied up to now.

Therefore at this stage of the creation of the cancer registration bearer the specific information source is probably not available.

Insurance Funds

Also, addressing ourselves to many insurance funds we requested to be informed in regard with the number of the insured persons to whom each fund offers sanitary cover and how are they separated per geographical district, prefecture, municipality and service from which they originate. We also asked if patients suffering from cancer are registered in the records of the fund and which data are registered precisely. Also if there are registered indirect information sources for the identification of those suffering from cancer (for example decisions of sanitary committees for patients travelling abroad, medical and pharmaceutical exemptions etc.), since when the relevant registries are being kept and in which form (printed and/or electronic) and with which frequency they are updated.

We referred to 23 hygienic funds and the Ministry of Employment and Social Protection (Social Insurance Secretariat General) to which the insurance funds are subject.

We received an answer from 6 funds.

The Freelancers Insurance Organization - Fund of Practitioners and Craftsmen of Hellas (FIO - FPCH) answered that it covers for allowances of the Disease Branch the directly insured persons and their dependants, who for 2005 come up to 1.452.511 (attached an analytical table per Directorate, Department and Office of FPCH). There are no registered data of patients who suffer from cancer. Yet there are numerical and financial data for insured persons who travel abroad for tumour therapy. They finally informed us that effort is being given for the establishment of a computerized system.

The Freelancers Insurance Organization - Tradesmen Fund informed us that the service is not computerized and, therefore, they are unable to answer our questions.

EUROCHIP-2 Final Report – Annex 09 – EUROCHIP-2 in Greece

At the Pensions Fund of Engineers and Public Works Contractors there does not operate a system of automatic classification in files of the Fund's insured persons which will show the data we request and, therefore, they could not provide any particulars.

The Organization for Care of Insured Persons of the State (OTIPS - Legal Entity of Public Law) informed us that the direct and indirect insured persons come up to approximately 1.500.000 and that the beneficiaries of hygienic coverage are listed in the relevant Government Gazette. The Organization does not keep registries and records of persons suffering from cancer.

The District Lawyers' Health Fund answered that the insured patients who suffer from cancers are not registered in the Fund's Registries and, therefore, they may not answer the relevant questions. On 31.12.2005 the Fund had 20.983 directly and indirectly insured members and the members are analytically given per categories.

Finally the Social Insurance Institution (SII) informed us that the matters of registration of cancers in Hellas are the sole and exclusive responsibility of the Hellenic Cancer Registry of the Ministry of Health and Social Solidarity to which we must address ourselves in order to be provided with information and instructions on the matter. The SII has no competency for the collection, registration and disposal of the specific information. As far as it concerns the number of insured persons to whom the ISS provides hygienic coverage there are being issued annual lists which state the coverage beneficiaries in the total of Hellas.

Therefore, as there results from the aforesaid answers, the specific information source is not available for the moment.

2.8 Conclusions from the municipal registries and the death certificates

- Each Hellene citizen is municipal subject of a municipality or a community.
- Each municipality and each community constitute a separate registrar's district.
- Books of births, marriages and deaths are kept in each Registry for the certification of the civil status of the physical person.
- The Registries are public.
- In the registries there are being registered the act which have as subject the certification of birth, marriage or death of the physical person, the alteration of the content or the correction of the aforesaid registrar's acts.
- The death certificates issued by physicians are registered in the registries of each municipality in printed form, while there are being recorded the full name, father's name, mother's name, address while alive, family status, municipal data and cause of death of the deceased.
- The death certificates are collected in the Registrar's office of the city where the death occurred and the registrar's acts of death are registered with all the particulars written in the aforesaid certificates.
- Municipal registry is kept in each municipality and community in which there are registered, at the request of the parties concerned or ipso jure, the citizens of both sexes, per family, with a special number for each family.
- In the Municipal Registry there are being recorded the number of the family column, the serial number of registration of each member in the family column, the registration date, the surname, the first name, the father's name, the mother's name, the date of birth, the place of birth, the residence, the religion, the way and the date of obtaining the Hellenic nationality and the capacity of the citizen and other relevant particulars.
- In the code of decrees for the municipal registries there are being included instructions in regard with the registration of particulars, the inspection and the registration of the changes, the multiple recordings and other matters in regard with the operation of the municipal registries.
- Especially for the demographic data of aliens, in the central service of the Ministry of Interior, Public Administration and Decentralization (Civil and Municipal Status Directorate) there are the particulars for all the legitimate immigrants, regardless of age, in the Hellenic area. In the same service there also exist the data of the municipal registries for the Hellenes over 18.

From all stated above there results that the data from the demographic particulars and the death certificates there will be available to a service for the registration of cancers, under the safeguarding of the legality of the transfer of personal data and following the establishment of the communication of the services involved.

2.9 Conclusions

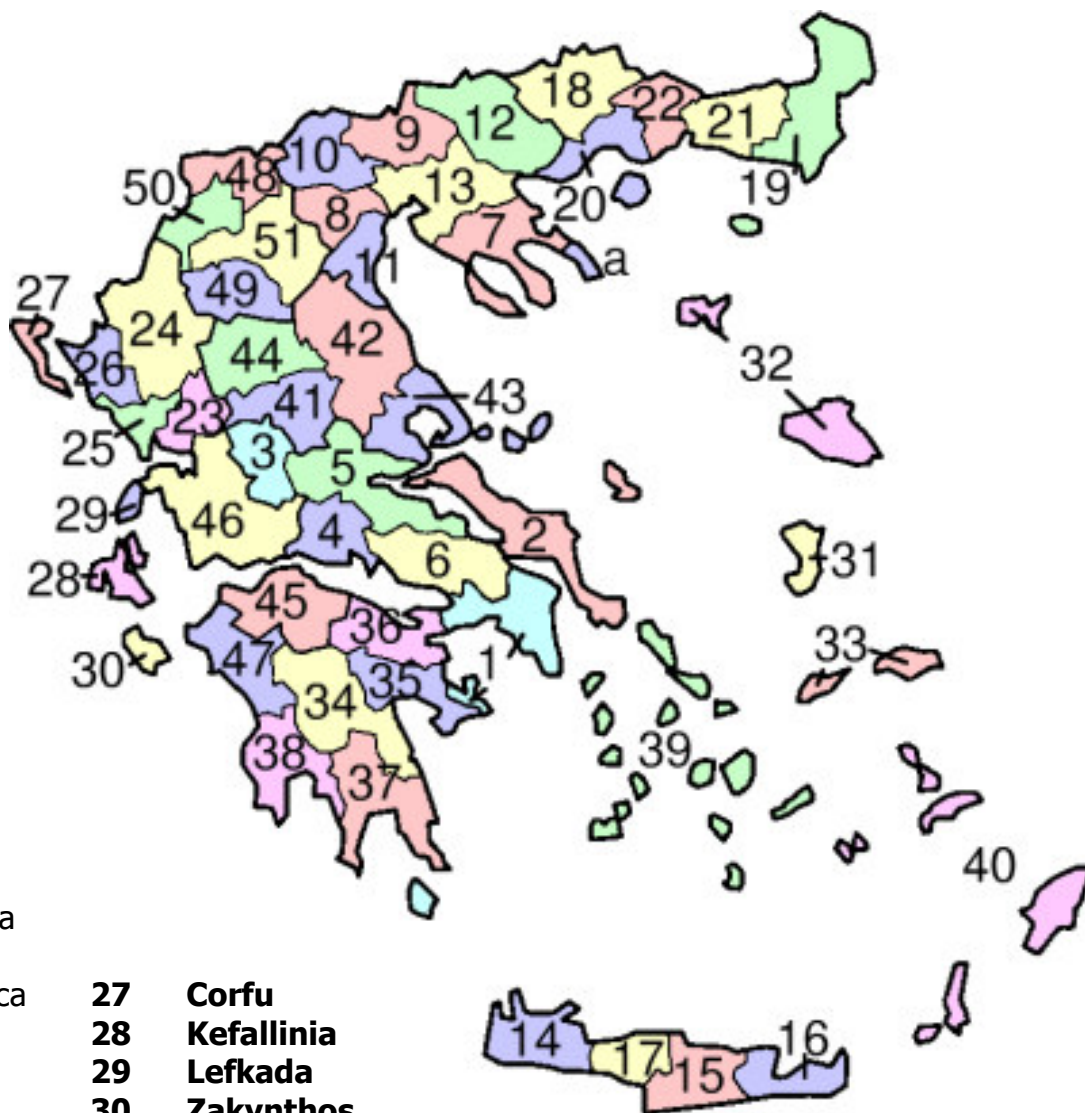
The results of the research indicate that important matters must be handled for the establishment of the population-based National Cancer Registry in Hellas. The low percentage of answers we had from all the services does not allow us to have the precise recording of the information sources. Nevertheless, we consider that the answers which were given to us constitute a representative sample of the Hellenic reality. Therefore, it appears that both the correct district registration and codification of the incidents, as well as the central collection and analysis of the incidents are indispensable for the materialization of the NCR. Also, the security of the sensitive personal data is another important parameter which must be jointly considered in the final planning. Moreover, the expansion and evaluation of the National Statistical Service of Hellas (NSSH) could be the first significant step for the materialization of the NCR.

Although the comparison of the information sources in Hellas with the structure of the Cancer Registry in Reggio Emilia was a part of our research, we consider that this is rather impossible since there are still important deficiencies in the Hellenic area. We believe that although many obstacles must be overpassed, the proper cooperation of the Ministry of Health and Social Solidarity, of the Hellenic Center for Diseases Control and Prevention (HCDCP) and the European Union (through the Eurochip) will manage to materialize this necessity for Hellas.



1. Attica (3HDD-A, B & C)
2. Sterea Ellada
3. Central Macedonia (2 HDD-A & B)
4. Crete
5. East Macedonia and Thrace
6. Epirus
7. Ionian Island
8. North Aegean
9. Peloponnissos
10. South Aegean (2 HDD, A & B)
11. Thessaly
12. West Greece
13. West Macedonia

Figure 2: Hygienic Districts Directorates (HDD)



1. Attica

- Athens
- East Attica
- Piraeus
- West Attica

| | | | |
|-----------|---------------------|-----------|------------------------|
| 2 | Evia | 27 | Corfu |
| 3 | Evrytania | 28 | Kefallinia |
| 4 | Phocis | 29 | Lefkada |
| 5 | Phthiotis | 30 | Zakynthos |
| 6 | Boeotia | 31 | Chios |
| 7 | Chalcidice | 32 | Lesbos |
| 8 | Imathia | 33 | Samos |
| 9 | Kilkis | 34 | Arcadia |
| 10 | Pella | 35 | Argolis |
| 11 | Pieria | 36 | Corinthia |
| 12 | Serres | 37 | Laconia |
| 13 | Thessaloniki | 38 | Messinia |
| 14 | Chania | 39 | Cyclades |
| 15 | Heraklion | 40 | Dodecanese |
| 16 | Lasithi | 41 | Karditsa |
| 17 | Rethymno | 42 | Larissa |
| 18 | Drama | 43 | Magnesia |
| 19 | Evros | 44 | Trikala |
| 20 | Kavala | 45 | Achaea |
| 21 | Rhodope | 46 | Aetoloacarnania |
| 22 | Xanthi | 47 | Ilia |
| 23 | Arta | 48 | Florina |
| 24 | Ioannina | 49 | Grevena |
| 25 | Preveza | 50 | Kastoria |
| 26 | Thesprotia | 51 | Kozani |

Figure 3: Prefectures