Minutes

Welcome
Dr. Núria Malats & Dr. Alfredo Carrato

The objective of the kick-off meeting is presented: to launch the PancreOS registry and to establish a network of collaboration for data exchange on the clinical management of pancreatic cancer in Europe. For this purpose, the meeting’s aim will be to discuss and consolidate several issues, mainly regarding outcomes, partners, legal and ethical aspects, data considerations, challenges, resources, etc.

Participants by country and supporters of the PancreOS are presented:
- Pancreatic Cancer Europe - A Carrato
- EUPancreas COST - Nuria Malats
- TTD Spanish Cooperative Group - Inma Ruiz
- ENCR/JCR/EU - Carmen Martos

Attendees:

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<td>Ambily, Archana</td>
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Several key facts about pancreatic cancer epidemiology in Europe were described: Over 100,000 patients are diagnosed with pancreatic cancer every year in Europe. There are only 4% 10-year survivors. If we do not face this problem, this cancer will become second in mortality after lung cancer. In addition, there are no national cancer plans dedicated to pancreatic cancer in Europe.

Therefore, a call to action started on November 12, 2014 in order to create the EU-Multistakeholder platform, also known as Pancreatic Cancer Europe (PCE), with the aim to ensure that pancreatic cancer is included in key European initiatives aimed at fighting cancer, with a focus on: 1) Increasing research to better understand the disease; 2) Improving data collection (registries); 3) Identifying tools for earlier diagnosis; 4) Providing educational programs; and 5) Improving standard of care with a focus on active treatment. PCE is becoming a legal society operating from Brussels.

The main PCE work streams are: awareness, diagnosis and registries. Within the registries work stream it was decided to pursue the creation of a European Pancreatic Cancer Registry “PancreOS”. This registry will enable us to implement efficient data collection across Europe, improve data on diagnosis, treatment and outcome. Thus, the PancreOS project will enhance cancer data available on pancreatic cancer (PC), providing an opportunity for the exploration of patterns of PC patient management across Europe.

Afterwards, AC focussed primary aims of the PancreOS project: 1) To develop a large EU-based pancreatic cancer registry (CR); 2) To gather information related to all aspects of the management of patients with pancreatic cancer – from initial symptoms, diagnosis and throughout the treatment continuum; and 3) To increase the knowledge in the biology of the different pancreatic cancer tumours to identify high-risk subgroups and to customize treatment.
It was stated that to launch PancreOS and make the registry operative from its start, an agreement on the minimum data to be collected from the PancreOS registries needs to be reached. Results of the pilot study conducted by TTD have revealed that the questionnaire can take 1 hour to fill-in. It must be shortened to only include the most relevant variables.

The objectives of PancreOS were emphasized: 1) Improve information; 2) Permanent and sustainable on line standardised data exchange; 3) All centres start at the same time with the same methodology (high-quality data and data standardization). With this information we will be able in the future to identify areas of improvement for the benefit of the patients (for example: differing time from diagnosis to treatment).

Resources supporting PancreOS (!): TTD Spanish Cooperative Group and Pivotal

Inma Ruiz and Jose Javier García

Dr. Inma Ruiz TTD - Spanish Digestive Tumor Group

TTD is working since 1986 in the development and design of clinical protocols in digestive cancers. TTD has conducted 82 clinical trials between 1986 and 2015 and elaborated several consensus documents. There are 303 members and 140 hospitals participating.

The Spanish PancreOS pilot study is presented. It was carried out to examine the feasibility of the registry and to propose modifications. A total number of 67 pancreatic cancer cases were included from 7 centres during July to October 2015. For the second phase of the PancreOS registry in Spain it is planned to include around 600 cases from 15 centers.

 Afterwards, the PancreOS questionnaire was shown by sections and variables.

Dr. JJ García – Pivotal (JJ)

PIVOTAL is responsible for PancreOS Registry Data Base, which is based on an ORACLE platform. Some results of the pilot study were presented by JJ to show the type of information that can be collected and exploited, and to check the feasibility of the data collection procedures. Results were presented by age, sex, diabetes, types of presenting symptoms and the frequency, stage at diagnosis (showing missing data), type of treatment, surgery, radiotherapy, and on median days from 1st symptom to diagnosis. Few patients were available to analyze data thoroughly. Therefore, interpretation of the results presented should be taken with caution. These results serve only to validate and test the variables included in the questionnaire.
JJ stressed that the aim will be to obtain the minimum data from all countries, so that all PancreOS partners can share this minimum data and integrate it in the common PancreOS Europe database.

Some concerns were raised:

- There is a need to specify what type of chemotherapy was given. AC replied that it is difficult to standardize this type of data because treatment is very heterogeneous. It might be more efficient to collect very basic information and later on, to go into more detail.
- The clinician may not find the epidemiological data useful. NM and AC commented that everything will be shortened. The pilot study is providing useful information in this regard. For example, ABO blood group variable was poorly collected and will be removed. With the pilot study we will decide which variables are important and feasible for the clinician to fill-in. Individual registries may decide to collect additional information. However at the European level only the minimal data will be requested.
- Based on the experience of some registries, there is a need to continually update the database, enter the patient at diagnosis and then add data with regard to therapy when it comes available. It is not always easy to follow-up patients if they receive treatment in other centers. It is discussed whether a data manager supporting the clinician with the data collection would solve the problem. AC thinks that this is difficult at the beginning. To keep working on a long-term and on an efficient basis, funding needs to be sought.
- Standardization of data is another issue. The EUROCARE high-resolution studies have experience in this regard and ENCR will support this task also for the PancreOS registry.
- Importance to include the different anatomical locations of the tumour. Whether cystic lesions or neuroendocrine tumours could be also included was under debate. NM and AC propose to start with pancreatic ductal adenocarcinoma to make PancreOS feasible for the moment. In the future, it might of scientific interest to also include other locations, pre-malignant lesions and other histological types.

Resources supporting PancreOs (II): “Collaboration between PancreOS and JCR/ENCR
Dr. Carmen Martos (CM)

CM presented the Joint Research Centre (JRC) and the European Network on Cancer Registries (ENCR) and their activities related to data collection standards. The JRC's mission is to provide EU policies with independent, evidence-based scientific and technical support throughout the whole policy cycle. One of the main Public Health Policy Support Unit commitments is to build an integrated and harmonised cancer information system in Europe (ECIS) to facilitate more specific research and answer more questions (e.g. related to diagnosis and treatment efficacy), requiring at least: 1) Extension to the number of variables collected; 2) Inter-linkage with other data sources; and 3) Uncomplicated access to more detailed subject data (including clinical databases).
The ENCR was established (1990) within the framework of the Europe Against Cancer Programme of the European Commission. The objectives are: 1) To promote collaboration between cancer registries; 2) To define data collection standards; 3) To provide training for registry personnel; and 4) To disseminate information (incidence, mortality and survival) on cancer in the European Union and Europe. ENCR is affiliated to the International Association of Cancer Registries (IACR).

After presenting some epidemiological facts about the burden of pancreatic cancer in Europe, CM stressed the need of establishing collaborations between population-based cancer registries (PBCR) (limitation: data is not up-to-date and treatment information, for example, is not collected), and clinical cancer registries (limitation: presence of case selection bias). JCR considers that this collaboration is essential. During the one-day workshop held in Madrid in October 2015, it was agreed that a maximum collaboration would be established between the Spanish PBCR and PancreOS. In this scenario, the oncologists, participating in PancreOS, would provide an information source of the population-based CR operating in their area. Firstly, when a new patient with pancreatic cancer is identified by the oncologists and having the informed consent, they report the case to the CR. The CR staffs prospectively collect the information, according to a data collection protocol. Secondly, when the CR has collected the information on all cases occurred in the study period, the selection biases could be analysed. Depending on the results, a retrospective data collection could be carried out by the CR to complete the data of the cases not included previously in PancreOS. In this scenario, it is possible to obtain updated and detailed information on clinical management of pancreatic cancer. This proposal could be a sustainable data collection strategy that could be extended to other European geographical areas covered by PBCRs.

The data and working protocols are being prepared for the PancreOS registry, based on the experience of ENCR and results of the pilot study. To this end, a systematic review on clinical guidelines is also being undertaken so as to consider all potential variables needed for future studies exploring whether differences in the adherence to the clinical guidelines may explain differences in pancreatic cancer care and survival across Europe.

Resources supporting PancreOS (III): EUPancreas COST Action
Dr. Nuria Malats (NM)

NM emphasized again the need to tackle pancreatic cancer fight from different levels, primary, secondary and tertiary prevention. PancreOS data may help step up the fight against pancreatic cancer through tertiary prevention. Pancreatic cancer has been defined as a recalcitrant cancer in the US and specific funds have been allocated for PC research. In Europe, actions are warranted at the national and international level; the EC should be aware of this public health problem and support pancreatic cancer research.
EUPancreas COST Action was introduced thereafter. The aims of this Action is to unite groups across Europe interested in pancreas cancer research and provides an innovative and unique platform for collaborating and sharing information, ideas and experience. The platform consists of over 200 multidisciplinary members from: 22 EU countries, 5 EU governmental and non-governmental institutions, 3 Biotech companies (SME) and 1 Pharma company.

The EUPancreas objectives are: 1) To integrate knowledge and experience in a multidisciplinary way “from cell to Society”; 2) To foster collaborative research to improve our understanding of pancreas cancer and its prevention, early diagnosis and treatment under the Personalized Medicine umbrella; 3) To promote the application of uniform study tools and protocols their optimal use by researchers; 4) To enhance the mobility and training of researchers; and 5) To disseminate the results produced to the broader society.

There are four working groups integrating everything in pancreatic cancer research: Working group (WG) 1 focuses on harmonization of research tools, WG 2 focuses on integration of “omics” data, WG3 focuses on translation research, and WG4 focuses on patient management.

PancreOS is placed between WG1 and WG4 interests and activities. An example of a policy paper produced within the EUPancreas Action is the “Pancreatic Cancer White Paper”

Another project collecting clinical data of around 1,000 pancreatic cancer cases is the PanGenEU study. It is a case-control study of over 2,000 cases and 1,000 controls, recruited in 6 European countries. Most of the cases recruited were followed up and very detailed information on the diagnostic procedures, treatment and clinical management of the diseases has been collected.

Presentation of other initiatives
Hungarian Pancreatic Cancer Registry
Dr. Andrea Szentesi

This registry was initiated by the Hungarian pancreatic group. Dr. Gabor Lakatos is the Director.

Prognosis of pancreatic cancer in Hungary is worse than in western countries due to limited access to diagnostic tools, lack of guidelines and financing problems.

The Hungarian registry started in 2011. The informed consent, questionnaire, blood samples, tissue samples and data collected by the centres are uploaded to a common database. Biological samples are processed in a central facility.
In this registry, the clinicians collect the data, thought they can ask for administrative help in the centres. Data management and quality controls are done on a regular basis and following this flow: 1) the administrator, 2) local doctor, 3) central administrator controls, 4) head of the registry.

All individual centres contributing with data can see the data they upload and permission needs to be retrieved to use the data for a specific research project. Over 2,000 pancreatic cancer cases have been included not only from Hungary but also from other countries, such as Italy and Finland. Thus, the Hungarian Registry collects data from Central and Eastern European centres. Several studies have been already published using data from the registry.

The data is collected prospectively and through personal interviews. Electronic medical charts are used to complete the data. According to their experience, it is essential to count with the patient’s collaboration for data retrieval. Surgical treatment and diagnosis often happens in different hospitals and it is to some extent tough to collect this data in Hungary. The variables collected are similar to those collected by the PancreOS registry; this has been already evaluated and confirmed. NM comments that the Hungarian Registry questionnaire is very detailed but may need to adopt some changes to make the integration of data in the PancreOS database possible, mainly regarding the follow-up data.

The biobank started in 2012. Only blood samples (not tumor tissue) of the pancreatic cancer patients included are collected. Blood samples are collected from different places and are shipped to the biobank.

The Hungarian registry has been renewed in 2015 to complete the variables and translate the questionnaire to English language so as to facilitate international collaborations.

France/BACAP
Dr. Barbara Bournet

BACAP was funded by the France National Cancer Institute. It constitutes a clinical and biological database of pancreatic cancer and is based on a network of 16 clinicians from different participating centers, 2 epidemiologists and 5 researchers from other fields. It is not a biomedical research project but a multi-centric prospective project that aims collecting data, to build a clinical and biological database, for future research studies. Three committees evaluate the performance of BACAP: scientific committee, coordination center, steering committee.

The mission of this prospective project is to make available to the scientific community a clinical biological base from patients with pancreatic adenocarcinoma.
As an example, some of the research projects supported by BACAP will seek to understand the development of pancreatic carcinogenesis, determine an early diagnostic and screening of pancreatic adenocarcinoma with the identification of biomarkers, evaluate clinical and biological development of cachexia from patients with pancreatic cancer, etc.

The questionnaire includes sections on demographics, risk factors, and a large set of variables regarding clinical data, including diagnostic procedures and treatment at diagnosis and during the patient’s follow-up. NM comments that overall, the main variables overlap with that to be collected by the PancreOS registry. Integration of BACAP data will be therefore feasible.

BACAP also collects biological samples: tumour tissue (along with DNA and RNA from tumour cells, taken from FNA samples) and blood samples (serum and plasma) before treatment, and saliva. No further samples are taken during the follow-up. So far, the biobank stores 8,500 samples from 424 patients. Biological samples are preserved in each center and common SOPs are used for the samples collection and preservation. To collect data and biological samples, BACAP has obtained all regulatory authorizations.

Germany/EUROCAN
Dr. Masoud Babei

EUROCAN platform work package 11 project is introduced. It is a consortium of major cancer centers in Europe with several countries participating. The major aim is to fill in the gaps between preclinical and clinical research and clinical trials.

With regard to pancreatic cancer, the EUROCAN platform is currently leading a research study on pancreatic cancer outcomes based on the clinical management of the disease and resection practices in Europe using data from PBCRs (e.g. Norway, The Netherlands, etc.) and institution-based data (e.g. PanGenEU study).

Survival data from Germany and the USA was presented for comparison purposes to establish that there are differences in survival rates that might be explained by varying practices in the clinical management of pancreatic cancer in the USA. Comparing clinical data by country is therefore a highly interesting task.

Preliminary results from the Norwegian and Portuguese data were presented. Concerns were raised regarding the high rate of missing data for differentiation grade and clinical stage (cTNM) in the PBCRs. Again, it is stressed that clinical cancer registries are needed to complement this information.

EUROCAN partners contributing to the pancreatic cancer project will be contacted to join the PancreOS initiative. Centres from Germany are being contacted to also join this initiative.
Italy/Reggia Emilia Cancer Registry

The partners from the Cancer Registry Reggia Emilia could not attend the meeting, but sent a presentation to introduce their registry. They have confirmed their willingness and interest to collaborate and join PancreOS.
Pamela Minicozzi from Istituto Nazionale dei Tumori (INT) and EUROCARE has been working with this registry data and comments about some issues. The data is collected in a very exhaustive manner. In addition, every week, each case and data is discussed by a multidisciplinary team.

Based on the experience of the Reggia Emilia Cancer Registry, INT in Milan is planning to set up a clinical pancreatic cancer registry for future high-resolution studies. Pamela emphasizes the importance of working at the population-based level.

Round: Interests of other groups participating in the meeting

- Marta Herreros from Amadix, Spain: She joined the Spanish Association of Gastroenterology to create a pancreatic cancer registry (EpiPancreas) linked to a biobank. Involving a multidisciplinary team in each PancreOS recruiting center would be desirable and biobanking is mandatory, as well as following the same working protocols in all European registries.

- Eva Vaquero from the Spanish Association of Gastroenterology: Gastroenterologists are an important piece in the diagnostic process of these patients.

- Rafael Marcos from the Girona PB Cancer Registry, Spain: stresses the importance of PBCR being involved in PancreOS.

- María Dolores Chirlaque from ENCR and Murcia Cancer Registry, Spain: reinforces the same idea. It will be crucial to involve PBCR to avoid selection bias and to provide exhaustive data.

- Adelaida García from the Hospital Jose True registry, Gerona, Spain. They work with a pancreatic cancer team where pathologists, gastroenterologists, oncologists and surgeons are involved. The working scheme should be the multidisciplinary team + PBCR.

- Natacha Bolaños from GEPAC: From the patients’ perspective, every patient should be registered, but this may pose a big challenge and difficulties. Primary care settings need to be aware of this important initiative. They should initiate the cycle: primary care – hospital. Natacha comments on the recently celebrated meeting with different medical associations to increase awareness about pancreatic cancer in Spain, where this issue was discussed. It is agreed that it would be important to consider primary care as an information source of PancreOS.
- Mert Erkan from Koc University in Istanbul, Turkey: He proposes to collect cystic lesions. Its incidence is increasing and they are a pre-malignant status of pancreatic cancer. NM comments about the PACIFIC study in Amsterdam, a project aimed at collecting data from patients with cystic lesions. Mert thinks that this registry is less clinic-related, whereas PancreOS is more clinically oriented and an opportunity to collect this data. It is agreed that this is an important issue to be considered for the future, once the PancreOS registry has been established.

- Cristina Bossetti from Mario Negri Institute, Milano, Italy: There is interest in setting-up the PancreOS registry in Italy (Milan). She contacted oncologists from the main hospitals in Milan, and the National Cancer Institute in Milan, also Niguarda hospital because of the EUS unit. Some oncologists from these hospitals agreed to participate in PancreOS.

- Alessandro Zerbi from Hospital Humanitas and Italian Association of Pancreatatology, and C. Catsouglo, Italy. They stated that more efforts should be made to specifically collect some variables or to focus the registry in a particular topic, such as reasons of delay in diagnosis, compare high and low throughput centers, types of specialized support for the patients, etc. Also, a flow to recruit patients from different units should be established: surgeons, oncologists, but also radiologists. Another effort is to have a real picture about the possible sources of problems in the hospital settings when it comes to the clinical management of pancreatic cancer.

- Ambily Archana from UK biobank, UK: They are working on setting up a national biobank + clinical data + bioinformatics study. All collaborators will contribute to the tissue bank and they count with administrative support for the collection of data. Data is being collected retrospectively but they are considering whether the questionnaire should be shortened. Archana expressed that UK Biobank would be willing to contribute to PancreOS.

- Sorin Barbu from the Romanian Pancreatic Club, Romania. In 2008 he participated in the creation of a Romanian pancreatic cancer registry but it did not work. He proposes to start with a feasible aim: pancreatic ductal adenocarcinoma and main clinical variables. They could provide around 1,000 patients per year to the PancreOS registry.

- M Erkan from Koc University, Istanbul, Turkey. They are starting to set up a pancreatic cancer database and started with resected cancer cases. Their objective is to isolate primary tumors and at the same time they are collecting clinical data. At the moment, they could contribute with a small number of cases but expect to increase their target population in the near future. He will contact organizations and centers in Turkey that are working on pancreatic cancer to invite them to join PancreOS.

- M Heckle from DKFZ, Germany: They have a big database and biobank with samples of pancreatic cancer tumors, mainly from oncology patients, in Heidelberg.
Round-table: Joining efforts to run a European Pancreatic Cancer Registry

**Consensus on variables:**

A summary template of the variables included in the PancreOS questionnaire was presented. As agreed during the meeting, this variable list needs to be shortened, based on the results of the pilot study, ENCR guidance and the consensus adopted among the partners.

However, the main variables are most likely collected by all the registries. By looking at the PancreOS overlap with other registries, it could be confirmed that the overlap is about 90%.

All variables needed to evaluate the adherence to the ESMO clinical guideline will be collected. Therefore, new variables considered to be of interest for PancreOS might be, for example, the ratio of lymph nodes involved/examined.

All those variables inefficiently collected, as derived from the pilot study results, might be removed; some information might not be available to the clinician (e.g. blood group). For some variables, however, it might be important to know missing rates. Missing data is potential information to be reported to the public if the variables are relevant from the prognostic point of view. For example, a variable that is particularly difficult to obtain and frequently missing is the TNM. Pathological data is not always available.

NM commented that the clinical information is the most important and feasible one but epidemiological data is more difficult to obtain from the medical records.

AC commented that the variables also need to be clearly defined. This will be made available at the time of performing the questionnaire.

Comment: when the patients do not undergo the whole treatment in the same center, collecting this data may become a major issue. NM replies that this issue might be center-specific.

NM stated that despite these limitations all countries should be encouraged to collect what data they can, and at least the set of core variables that will be integrated in the PancreOS database.

Comment: it would be better to have a data manager to collect the data. Every center may need to explore whether they can use resources such as study nurses, research fellows, etc.

**Data Sharing:**

Issues on high quality data, multidisciplinary teams and data protection policy were presented.

Manuals/protocols for data collection are being defined, including data/variable definitions, under the guidance of ENCR. This will be the key element to ensure data integration and harmonization.
A data sharing process was proposed: each PancreOS center contributes with data to the PancreOS Europe database. Likewise, the ongoing initiatives would integrate their data after data harmonization.

**Ethical and Legal Issues:**

PancreOS will comply with all legal and ethical rules. Each centre needs to obtain its own informed consent form and ethical approval. Owing to the fact that ethical legislation varies across Europe, each center may need to adopt their documentation to seeking ethical approval. PancreOS has already obtained ethical approval.

PancreOS will circulate the ethical approval and protocol of the project to help other centres with their application.

AC: In Spain there is only one ethical approval for all the collaborating centres. There may be a different consent needed for the biobanking of samples. Two informed consent forms will be circulated among the PancreOS participating centers for both options, i.e pancreatic cancer registry with and without bio-banking.

Some aspects of the data ownership and legal basis of PancreOS were stated. In principle, the registry holder will be PCE. The policy document defining this legal basis is being formalized.

**Requirements to become a partner:**

Some requirements were established: Minimum 2-3 years commitment, ethical approval, work under coordinating centre guidance, data quality controls, population based registries (recommendable), multi-disciplinary team involved (recommendable).

No restrictions based on the number of cases included will be made, but exhaustive collection of pancreatic cancer cases is mandatory to participate in PancreOS.

Comment: What happens if the patient has not signed the informed consent or do not want to sign the consent form? NM states that it will be important to define the data variables to be collected for these cases (it might be needed to compare these patients with those included in the registry to rule out selection biases).

It will be needed to involve more centers and countries in PancreOS as some countries are underrepresented or even do not participate (e.g. Poland, Denmark, etc.). The procedure established to apply to become a PancreOS member was defined.
Other difficulties and challenges:

The challenges commented and brought into discussion were:

1) Legal issues concerning registry set-up. Legal backgrounds differ greatly across Europe and every center may need to comply with particular legal and ethical requests.
2) Involvement of stakeholders is desirable
3) Involvement of other centres and countries: i) lack of centres in some Northern and Eastern European countries; ii) some countries are under-represented: more centers are needed
4) Balance between accuracy and timelines: to meet this requirement, it was emphasized that the registration process should be done in a regulated and up-to-date fashion
5) Data quality and exhaustiveness: common quality control tools will be needed.
6) Registry transparency and openness for research purposes: at local/national level, and at PancreOS-European level

Steering committee and coordinating centre:

The structure of the PancreOS governance was proposed.

Composition:

- The coordinator: EPC;
- The Steering Committee;
- The PancreOS supporting organizations;
- The individual PancreOS registries;
- Stakeholders

Missions of the Steering Committee:

- Determines the inclusion of new centers and possible exclusion of participating centers;
- Decides about data management/exploitation and research studies;
- Establishes the annual activity report;
Steering committee members: 1 representative/country (>>5 centres), 1 ENCR, 1 pancreatic cancer Europe, 1 TTD.

**Strategic plans and timelines:** April-Dec 2016.

The timelines were presented.

The most urgent and immediate tasks are regarding obtaining ethical approval. In the meantime, the PancreOS coordination center will be working on accomplishing the working materials.

**Dissemination:**

Some dissemination strategies were proposed: white paper, newsletters, website.

It was agreed that dissemination is important to make PancreOS more visible, to involve stakeholders and to lobby for funding in the future.

It was suggested that a general statement for the patients should be considered.

**Funding:**

*Public sector*
- At national/local level
- At international level: H2020

*Private sector*
- Pharma companies (e.g. Celgene, Baxalta, Merck, etc.)
- Bank foundations
- NGOs (non-governmental organizations, i.e., charities)
- Patient organizations and scientific associations, for example, organizing fund-raising campaigns.

It was agreed that PancreOS needs to develop a funding strategy, but each PancreOS national registry will need to seek funding individually.

**Other issues: biobanking**

Those PancreOS registries deciding to also implement a biobank, linked to the clinical data, should use common SOPs for tumor tissue sample retrieval and storage. In EUPancreas COST Action a SOP has been developed for this purpose. To share the biobanking data and to show samples available, a virtual biobank would be established: the repository of samples would be displayed via a web portal.

**Other issues: resources**

Each PancreOS center will be responsible for resources needed for: data collection, financial issues, and data protection policies.
PancreOS will supply to each PancreOS center the tools for data collection, and at the same time, PancreOS-Europe will be in charge of the data management, main quality controls, data dissemination, and will also provide statistical/epidemiological support to all centers.

Actions agreed:

1) Complete the legal establishment process of PancreOS (policy document).
2) Reduce the questionnaire and the variables to be collected, removing variables that are not useful or difficult to obtain, e.g. blood group, and other issues agreed upon the meeting.
3) Perform final adaptations of the software.
4) Distribution of software, data documentation files and protocols.
5) To facilitate documentation for the ethical approval process that centers/countries will need, in the first instance, to join PancreOS. Processing of the ethical approval by the centers/countries.
6) Develop a funding strategy for PancreOS, considering the EC, national resources, and the private sectors.
7) Establishment of collaborations with cancer registries when possible. Linkage of data with cancer registries.
8) Use of common SOPs for biobanking in centers implementing biobanks.
9) Involve other countries/centers to increase representativeness of PancreOS at the European level and the rate of participating centers per country.
10) Look for synergies with other similar initiatives running at the supra-international level, such as the Japan Pancreatic Cancer Registry and the American Pancreatic Cancer Registry.
11) Next meeting: to be scheduled.