

WG1, WG2, WG3, and WG4 Joint Meeting

23rd June 2015

9:00 a.m. – 4:35 p.m.

Toledo, Spain

Participants:

Nuria Malats (Chair), Alfredo Carrato (WG4), Anders Molven (WG1), Angela Brand (WG4), Bill Greenhalf (WG1), Bruno Sainz (WG3), Carlo La Vecchia (WG1), **Gheorghe Cristian Romana**, Cristina Bosetti (WG1), Dilek Yazcici (WG3), Eithne Costello (WG1, WG3), Elin Kure (WG1, WG2), Esther Molina (WG1, WG2, WG3, WG4), Eva Vaquero (WG3), Fátima Al-Shahrour Núñez (WG2), Fiona O'Neill (WG4), Francisco X. Real (WG2, WG4), **Frederick Lemaigre**, Giedrius Barauskas (WG1), Irene Esposito (WG1), Julie Earl (WG3), Laufey Amundadóttir (WG1, WG2), Maria Gazouli (WG3), Marlene Dufresne (WG3), Marta Rava (WG2), Mert Erkan (WG3), Mirari Marquez (WG2), **Naomi Walsh**, Patrick Jacquemin (WG3), Paulina Gómez (WG1, WG3), Rolf Ehrnström (WG3), Patricia Benedit (WG4), Sonja Eriksson Steigen (WG1), Traian Sorin Barbu (WG4), Vita Dolzan (WG1, WG3), Xavier Molero (WG3)

1. Welcome and Update from the Action Chair

Chair: Núria Malats

The Chair presented an update of members by country, distinguishing by inclusiveness and non-inclusiveness country, non-COST country, gender, WGs and early career investigators (ECIs).

The Action counts with 185 multidisciplinary members. The Czech Republic joined recently the Action and there are at present 22 countries involved in the Action. It has been not possible yet to officially include in COST the participation of other 3 countries (Switzerland, Croatia and Sweden) that expressed the interest to join the Action.

Private biotechnological companies participating in the Action are: INTEGROMICS (Spain), IDD Therapeutics (Israel), ALACRIS (Germany), and PHOTONICS (UK). Celgene (Spain) has also joined the Action.

The gender ratio is well balanced, as well as the inclusiveness countries participation. However, the participation of ECIs is rather low (n=28), especially with regard to inclusiveness countries.

The Chair presented the expenditures for the 2nd GP and the new budget for the 3rd GP (from 02/06/2015 till 01/06/2016), for which the budget allocated is EUR 127,937.20 EUR, including the maximum of 15% of overheads of the GH Institution. This budget has been recently approved by the MC. A detailed budget by type of networking tools was presented.

2. WG1 (Harmonization of research tools). Past, current and future plans.

Coordinator: Irene Esposito

Irene Esposito presented the main achievements of WG1:

- Meetings:

- 1) June 2013 (Madrid, Spain). Kick-off meeting.
- 2) November 2013 (Madrid, Spain), during the First EUPancreas Annual Conference in the Pancreas Cancer Forum
- 3) May 2014 (Milan, Italy)
- 4) November 2014 (Liege, Belgium), during the Annual Conference and Capida Selecta in Complex Disease Analysis Conference.
- 5) April 2015 (Heidelberg, Germany), organized jointly with the PDAC biobanking workshop. Members from different workgroups of COST Action BM1204 visited during this workshop the NCT and EPZ biobanks and were informed by the biobank leaders, Esther Herpel (NCT) and Nathalia Giese (EPZ), about organizational features, protocols and standard operating procedures that are in place at these facilities.

- Activities:

- Standardization of tools to be applied in the new scientific initiatives by EU countries, including homogenous pathological definitions of pancreatic lesions, epidemiological questionnaires, and standardized operating procedures (SOPs) for pancreatic cancer biobanking. The latter one is being currently developed (a first draft is being prepared), but several challenges were posed: among the big biobank initiatives in Europe (Tubafrost, BBMRI, IARC,...), there are not any specific SOP for pancreatic cancer biobanking published.

The WG discussed the possibility of launching a virtual pancreas biobank for the Action by the use of a survey of samples available in European biobanks. This was considered to be unfeasible.

- Standardization of questionnaires for clinical studies on pancreas cancer. This will be already done within the European Pancreas Cancer Registry (PancreOS).

- Common project on PDAC associated morbidities using PanGenEU resources. It is planned to replicate/expand results using the UK Primary Care data, as a collaboration with WG3 (Geri Keane, UCL).

- Histological confirmation of cases within the PanGenEU study

- STSMs: Four STSMs were completed (V Rosato, P Gomez)

Paulina Gomez presented the research studies conducted thanks to the STSM. During her stay at Mario Negri Institute in Italy, a set of standardized epidemiological questionnaires were prepared and uploaded in the webpage so as to be offered to the scientific community as a basis for harmonizing epidemiological research on pancreatic diseases across Europe. Paulina also presented the results of the study on multi-morbidities in the aetiology of pancreatic cancer, which was performed by both Valentina Rosato (STSM awardee) from Mario Negri Institute in CNIO (Spain) and Paulina.

- Training school: "Pathology of the Exocrine pancreas of mice and men", held in December 2014. During this 3-day workshop, experts in the field provided detailed knowledge about pathology and genetics of the main inflammatory and neoplastic diseases of the pancreas, as well as on current animal models for pancreatic diseases.

- Publications

Members of WG1 published three scientific publications acknowledging the COST Action. A fourth one is currently under review in a *peer-reviewed* journal.

Activities planned for the 3rd GP are:

- Development of the SOP for pancreatic cancer biobanking
- To establish collaborations with existing networks of European biobanks
- Joint WG meeting with Panc4 (International Consortium of Pancreas Cancer Case-Control Studies) in 2016
- Standardization of clinical questionnaires

3. WG2 (Integration of omics data). Past, current and future plans.

Coordinator: Fátima Al-Shahrour Núñez, on behalf of Kristel van Steen

Fátima Al-Shahrour presented the main achievements of WG2:

- Meetings:

- 1) November 2013 (Madrid, Spain), during the First EUPancreas Annual Conference in the Pancreas Cancer Forum
- 2) February 2014 (Heidelberg, Germany). At the same time, the workshop "Omics integrations" was held.
- 3) November 2014 (Liege, Belgium), during the Annual Conference and Capida Selecta in Complex Disease Analysis Conference. WG2 organized a scientific Workshops during the Conference on "data fusion and integration to improve mechanistic insights in rare diseases".

- Activities:

- A survey to assess the available PDAC omics data was distributed among the Action members and the responses have been summarized. This will be soon uploaded in the webpage.
- A data repository has been consensuated with an existing database designed by Claude Chelala. Because of confidentiality issues, several problems emerged in sharing the data. Further agreements are required. This issue needs to be discussed further in the next WG meeting.
- Establishment of standardized approaches for omics data deposit.

- Publications

A scientific publication and two book chapters (Identifying and documenting available algorithms for omics data integration) have been published.

- STSMs: There were three STSMs awarded (S Pineda, F Gadaleta, K Van Steen)

- Workshops: Omics integration. 14 February 2014. Heidelberg, Germany

Activities planned for the 3rd GP are:

- Collaborations with other Pancreas Cancer Research initiatives to investigate the application of newly developed integrated data analysis method within WG2 on their data
- Discussions with organizations such as EORTC, to involve them in the network
- Building a compendium of data with the databases
- Training school: "Statistical Interactions/Interactome" jointly organized with the Belgian Society of Statistics" (April 2016)
- Workshop: OMICS INTEGRATION IN PDAC WORKSHOP: "Cancer genomics and personalised medicine workshop: focus on pancreas cancer" (July 2015)

4. WG3 (Translation Research). Past, current and future plans.

Coordinator: Eithne Costello-Goldring, on behalf of Stephan Hahn

Eithne Costello presented the main achievements of WG3:

- Meetings:

- 1) June 2013 (Bochum, Germany). Kick-off meeting.
- 2) November 2013 (Madrid, Spain), during the First EUPancreas Annual Conference in the Pancreas Cancer Forum
- 3) March 2014 (Liverpool, UK). At the same time, the workshop "The London Pancreatic Workshop 2014. A forum for state of the art clinical and basic research in pancreatic cancer", was held in Bart's Cancer Inst. London, UK.
- 4) November 2014 (Liege, Belgium), during the Annual Conference and Capida Selecta in Complex Disease Analysis Conference.
- 5) March 2015 (Liverpool, UK). Discussions for the next steps towards a H2020 application.

- Activities:

- Prospective evaluation of a novel early symptom algorithm and rapid assessment pathway for diagnosis of PDAC in primary care:

- New onset diabetes subgroup as a high-risk group to identify early risk prediction biomarkers for PDAC (EURONOD study).
- European IPMN study, with the aim to develop a tissue biobank and to identify diagnosis and prognostic biomarkers for IPMN
- Pancreatic cancer comorbidities and multimorbidities study

For all these initiatives it is considered that the standardized tools developed by WG1 should be applied. Funding to support these initiatives is being searched through applications to H2020. International collaborations with USA, Japan, and South Korea are being established. It was suggested to contact the European Society of Diabetes too.

- Publications

There are three scientific publications published by members belonging to WG3, acknowledging the Action.

- STSMs: Five members of WG3 were awardees of a STSM (D Vangala, A Maziukene, N Cieplik, I Sangrador, S Benitz)

- Workshops:

- 1) London Pancreas Workshop. May 2014. London, UK
- 2) "Cystic Tumours of the Pancreas Patient & Public Forum". 3rd October, 2014. Royal Free Hospital. London. UK.
- 3) IPMN Session organized in the 46th Annual meeting of the European Pancreatic Club. 24-28 June 2014. Southampton, UK.

- Activities planned for the 3rd GP are:

- IPMN: To set up a registry for already available samples and to establish SOPs for cystic fluid and blood collection
- To set up the new-onset diabetes study
- Training school on "Genomic Medicine – Bridging research and the clinic" jointly organized with ARTEMIDA, Golden Helix Institute of Biomedical Research Genomic Medicine Alliance (May 2016)
- Fostering international collaboration for the studies ongoing (IPMN registry).

5. WG4 (Patient management). Past, current and future plans.

Coordinator: Angela Brand

Angela Brand presented the main achievements of WG4:

- Meetings:

November 2013 (Madrid, Spain), during the First EUPancreas Annual Conference in the Pancreas Cancer Forum

November 2014 (Liege, Belgium), during the Annual Conference and Capida Selecta in Complex Disease Analysis Conference.

- Activities:

- An Index of Barriers for Personalized Medicine in PCAD patient management has been elaborated by this WG pointing to the lack of established structures for PDAC patient treatment and care, lack of data on biomarkers, lack of research and funding, among others.
- Involvement of national Pancreas Cancer organisations via EAPM (European Alliance for Personalized Medicine) and the EU Multi-Stakeholder on Pancreatic cancer
- Guiding policy guidelines translations into the EU through:
 - Participation in the 3rd Annual Conference of EAPM in June 2015 (Brussel, Belgium). During this round table, the EU-Pancreas translation into healthcare was endorsed, being the Action presented.
 - Participation in the Italian Presidency Conference of EAPM to integrate personalized medicine in the EU strategy in September 2014 (Brussel, Belgium)

- STSMs: Three STSMs were completed (M Jansen, JM Mazarico, S Benitz). A report on barriers regarding the implementation of EU Pancreas in Europe was produced.

Activities planned for the 3rd GP are:

- Development of an index-SRIA
- Literature review of policy papers of personalized medicine
- Training school: "Genomics and Genthics" Organized jointly with CHIP-ME Cost Action (IS1303), the European Society for Pharmacogenomics and Theranostics, and Golden Helix Genomic Medicine Alliance (September 2015)

6. Goals met. Challenges and gaps. Opportunities for improvement and collaborative management

The Chair presented an overview of the discussions and debates held during the joint WGs meeting. The major issues raised were:

WG1:

- Training in pathological diagnosis: was held in December 2014 and will be repeated in the 4th GP
- Developing SOPs for pancreatic cancer biobanking poses several challenges and difficulties due to the lack of literature and information on this issue
- Establish contacts/collaborations with the ongoing biobanking initiatives (common SOP for pancreas tissue collection)
- Standardized tools (pathological definitions, epidemiological questionnaires and SOP for pancreatic cancer biobanking) to be applied in the scientific initiatives of the Action
- Following-up the morbidity study of WG3
- Extend the Pancreos registry participation to the EUPancreas groups/members
- Dissemination of SOPs and questionnaires (including clinical questionnaires) to be applied in pancreas cancer research studies

WG2:

- Standardization of data collection and analysis needs to be done
- To obtain and re-analyze available data
- Identification of new algorithms
- Identification of top scientific questions
- Fostering international collaborations: elixir, ICGC, EORTC
- More STSM&Training participation
- Dissemination planned: book chapter, white paper, integromics for prevention

WG3:

- Extend the participation in the IPMN registry (WG1: SOPs and questionnaires)
- Fostering International collaborations
- Possibility to extend the PAPERPAC (Patient Perceptions of long-term surveillance in pancreatic cancer screening programs) study
- Population risk-morbidities study
- Setting up an Europe-wide registry of new-onset diabetes
- Increasing the awareness of the T2D-PDAC among GPs
- Seeking sources for funding
- Fostering international collaborations, e.g. for the IPMN initiative

WG4:

- Development of guidelines on clinical trials for pancreas cancer
- Evaluation of EAPM/ESMOCT guidelines applied to PDAC (by October 2016)
- Keep lobbying in EC for pancreas cancer research and funding
- Having pancreas cancer recognized as a "rare cancer"
- Raising the "PDAC patient management barriers" report to the policy makers

7. Dissemination plans

Coordinator: Filipe Silva

Dissemination activities of the Action were presented by Esther Molina (on behalf of the coordinator, Filipe Silva).

Over the last months, the following dissemination activities were carried out:

- Updates of all web contents in www.eupancreas.com
- Structural changes of the web (home page, navigation bar and sections) to make it more user-friendly and to facilitate the monitoring processes
- Implementation of new dissemination tools in the web:
 - o Two Newsletters highlighting news of the Action and related topics have been designed and circulated among all Action members.
 - o e-Library as a documentation repository for pancreas cancer research
 - o Activation of twitter (46 followers and following 65 members/organizations) and LinkedIn.
 - o A podcast about the action and its impacts has been filmed and is almost ready to be uploaded in the webpage.
 - o Some webinars are planned for the next training schools. Access will be provided through the web
- 6 scientific articles, 2 book chapters, and a couple of reports have been published.
- The Action was presented in various scientific events (as oral and poster presentations)
- The cootie catcher is the dissemination material of the Action to be distributed whenever possible

The Action members were encouraged to participate in the dissemination activities in various ways: acknowledging the Action in their publications, using the EUPancreas logo in presentations and email, becoming a follower of Twitter and LinkedIn, taking advantage of press releases, etc.

8. Short Term Scientific Missions (STSM)

Coordinator: Carlo La Vecchia

Professor La Vecchia presented an update of the STMS activities. So far, there have been 4 calls publicized:

1st call September 2013

2nd call January 2014

3rd call July 2014

4th call December 2014

There were 14 STSMs awardees:

Beneficiary	Original centre	Hosting centre	WG	Period
D Vangala	Ruhr-University Bochum, Germany	CNIO, Spain	WG3	October 2013
A Maziukiene	Lithuanian university of health sciences, Lithuania	TUM, Germany	WG3	Nov-Dec 2013
JM Mazarico	CNIO, Spain	Imperial College of London, UK	WG4	Jan-April 2014
F Gadaleta	ULg, Belgium	Integromics, Spain	WG2	Febr-March 2014
S Pineda	CNIO, Spain	ULg, Belgium	WG2	Feb-March 2014
V Rosato	Mario Negri, Italy	ICO Barcelona	WG1	April-May 2014
M Jansen	U Maastricht, Netherlands	EAPM, Belgium	WG4	April-May 2014
P Gomez	CNIO, Spain	Mario Negri, Italy	WG1	November 2014
V Rosato	Mario Negri, Italy	ICO Barcelona	WG1	Nov- Dec 2014
K Van Steen	ULg, Belgium	CNIO, Spain	WG2	January 2015
N Cieplik	Hannover Medical School, Germany	UCL, Medical School, UK	WG3	Feb-April 2015
I Sangrador	Fundació Clinic, Spain	Barts Cancer Institute, UK	WG3	February 2015
S Benitz	Technical University of Munich, Germany	CNIO, Spain	WG3/4	April 2015
V Rosato	Mario Negri, Italy	CNIO, Spain	WG1	March-May 2015

Reports of all STMS have been posted in the website. In addition, a short summary book reporting the experiences of some awardees is being displayed in the website.

The number of participants in STMS can be considered relatively high. However, given that STMS are particularly intended for young researchers, it is emphasized that efforts should be made to encourage ECIs to apply for a STMS in the next call.

The fifth call will be launched in July 2015.

9. Discussion: Strategic plans and activities within & between WGs, timelines, other issues

- Activities within & between WGs planned for the 3rd GP

WG1:

- Training in pathological diagnosis: has been postponed to the 4th GP
- To follow-up the morbidity study (interaction with WG3)
- To establish contacts/collaborations with the ongoing biobanking initiatives. To develop a common SOP for pancreas tissue collection
- Extend the Pancreas registry participation to the EUPancreas groups/members (interaction with WG3 and WG4)
- Dissemination of SOPs and questionnaires to the EUPancreas groups/members (interaction with all WGs)

WG2:

- Standardize data collection/analysis (interaction with WG1)
- To obtain data and re-analyze available data
- To further identify and test algorithms
- To foster international collaborations: elixir, ICGC, **EORTC**
- Dissemination activities: book chapter, white paper, integromics for prevention

WG3:

- To extend the participation in the IPMN registry (interaction with WG1: SOPs for biobanking and questionnaires)
- Possibility to extend PAPERPAC (Patient perceptions of long-term surveillance in pancreatic cancer screening programs) study
- Populations risk-morbidities (interaction with WG1)
- To pursue the Europe-wide registry of new-onset diabetes (interaction with WG1)
- To increase the awareness of the T2D-PDAC among GPs (interaction with WG4)
- To look for funding sources
- To seek international collaborations, e.g. for the IPMN initiative

WG4:

- To develop guidelines on clinical trials for pancreas cancer (interaction with WG1)
- To examine EAPM/ESMOCT guidelines applied to PDAC (October 2016)
- To continue to lobby in EC on pancreas cancer research
- To raise awareness of pancreas cancer in the EC: include pancreas cancer as a “rare cancer”
- To raise the “PDAC patient management barriers” report to the policy makers

- Next WG meeting:

ANNUAL CONFERENCE, WG MEETINGS, MC MEETING JOINT WORKSHOP WITH UEG, EPC, EFISDS, and EAPM ON: “Burning Issues in Pancreatology”

Sorin Barbu (WG4) presented the agenda of the next WG and MC meeting to be held during 5-7 November 2015 in Cluj-Napoca in Romania. A Workshop is organized in parallel. It will cover emerging needs for pancreas cancer research and management as well as aspects related to acute and chronic pancreatitis, precursor lesions of pancreatic cancer, pancreatic cancer, and surgical-related issues. EUPancreas is actively participating in the organization of this event and has planned a three Roundtable on Evidences from epidemiology on pancreas cancer etiologic factors, Omics contribution to disentangle the molecular complexity of pancreatic cancer, and Personalized medicine for pancreatic cancer, the latter one is co-organized jointly with the European Alliance for Personalized Medicine. It was stressed that the participation of ECIs will be specially promoted for this event.

- Projects proposals and sources for funding

It is commonly agreed that it is needed to explore funding sources to conduct research projects/studies and to maintain the network functioning after the COST Action.

Pancreos – Pancreatic Cancer Overall Survival Registry Europe: the pilot study in Spain.
Speaker: Alfredo Carrato

Professor Carrato (member of WG4) presented the initiative of the pancreatic cancer registry Pancreos, which is being pursued by the Spanish Cooperative Group on Digestive Tract Tumors (TTD – Tratamiento de los Tumores Digestivos), and which is running under the MultiStakeholder Platform on Pancreas cancer. This project aims at collecting a comprehensive set of prospective data from pancreatic cancer patients at any stage of the disease.

The pilot project is being launched at first in Spain, based on several observations and statements:

- Noticeable increase in the incidence and mortality of pancreatic cancer, which is set to be the second cause of mortality by cancer in a few years, but data are mostly missing.
- Need to identify high-risk populations, in particular in order to improve prevention and screening
- Need to help reach earlier diagnosis

The pilot project involves 7 centers throughout Spain, and will lead to a larger European-wide pancreatic cancer registry. The data is registered automatically, and used in a prospective way and with a view to make the standardization of the data possible. The PanGen study is used as a reference. There are multiple objectives to this pilot project, but the main goal is mainly to improve knowledge of pancreatic cancer in all its aspects to reach better health outcomes for patients, thus fitting with the priorities defined in WG1, WG3 and WG4. The Action will support this initiative.

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