

COST Action no. BM1204 An integrated European platform for pancreas cancer research: from basic science to clinical and public health interventions for a rare disease

Minutes

2nd Management Committee Meeting

November 30, 2013, 14:30h - 18h

CIOCC- Hospital Sanchinarro

Represented countries:

Belgium (Kristel VAN STEEN), Bosnia Herzegovina (Drazenka MACIć and Timur CERIć Stephan), Germany (HAHN and Jorg KLEEF), Greece (Maria GAZOULI), Israel (Anwar RAYAN), Italy (Carlo La VECCHIA), Lithuania (Audrius SILEIKIS and Giedrius BARAUSKAS), The Netherlands (Angela BRAND), Norway (Elin KURE and Knut J LABORI), Poland (Ewa MALECKA-PANAS), Portugal (Filipe SANTOS SILVA), Romania (Traian Sorin BARBU), Slovakia (Magdalena MAJEKOVA), Slovenia (Vita DOLZAN), Spain (Alfredo CARRATO and Núria MALATS), Turkey (Ali CAGIR), United Kingdom (Tania CRNOGORAC-JURCEVIC)

Countries not represented:

France, Hungary, and Ireland

Other participants:

Rosa Bjork BARKARDOTTIR (DC Rapporteur), Jeannette NCHUNG (Administrative Officer), Irene ESPOSITO (WG1 coordinator, invited*), William Greenhalf (invited*)

* invited participants did not have a vote

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1. Welcome to participants
 2. The agenda of the meeting was adopted by all participants
 3. The minutes and matters arising in last MC meeting were approved
 4. Update from the Action Chair
 - a. The status of the Action, including participating countries was presented and covered the following aspects:

- Dates to keep in mind are:
 - Starting date – 14 December 2012
 - 1st MC meeting (kick-off) – 14 December 2012
 - 1st Grant Agreement – 1 April 2013
 - 1st period– 1 April 2013 till 31 March 2014. **This has actually been extended to 31 May 2014 due to the need to adapt to the H2020 agenda.**
 - Ending date – 13 December 2016
- 6 additional countries (Bosnia and Herzegovina, Greece, Hungary, Poland, Portugal, and Turkey) joined the Action after the Kick-off meeting in December 2012 making a total of 20 countries contributing to the Action.
- At present, there are over 100 multidisciplinary members participating in the Action.
- A list of governmental and non-governmental institutions that have been contacted and that expressed their interest in contributing to the Action is provided in the minutes of WG4. It is worth emphasizing the European Alliance of Personalized Medicine (EAPM).
- Private biotechnological companies participating in the Action are: INTEGROMICS (Spain), IDD Therapeutics (Israel), ALACRIS (Germany), and PHOTONICS (UK).
- Additional contacts have been done with: European Pancreatic Club (EPC2014/2015), International Cancer Genome Consortium (ICGC, pancreas working group), Pancreatic Cancer Case-Control Consortium (PanC4), COST Action BM1006 – Next Generation Sequencing Data Analysis Consortium (Dr Bongcam-Rudloff, coordinator), and Dr. Jang and Dr. Namkung from South Korea leading a consortium on pancreas cancer. These contacts are being followed-up to explore the possibility of collaborations.
- 4 Working Groups have been established with multidisciplinary members experts in the related domains. Each WG is managed by a coordinator and 2 co-leaders (see point 10 and minutes of WG meetings).
- Periodic teleconferences have been conducted with the Scientific Committee (SC) to follow the Action up and plan on the activities of the 1st period.
- The First Annual Conference was organized jointly with the Pancreatic Cancer Forum 2013 (Nov2013, Madrid)
- A first design of the WEBpage of the Action was done with the given domain www.eupancreas.com.
- A following publication describing the details of the Action was submitted to Public Health Genomics upon invitation. It will be published at the end of the year:

Milne R, La Vecchia C, Van Steen K, Hahn S, Buchholz M, Costello E, Esposito I, Hoheisel JD, Lange B, Lopez-Bigas N, Michalski CW, Real FX, Brand A, Malats N, on behalf of the COST Action BM1204 participants. EU Pancreas - An Integrated European Platform for Pancreas Cancer Research: from Basic Science to Clinical and Public Health Interventions for a Rare Disease. Public Health Genomics 2013;16(6):305-12
- The following oral/poster presentation of the Action have been done:
 - PanC4 meeting (Baltimore, Mar2013) by N Malats
 - Club Français du Pancreas XXVIII meeting (Amiens, Sept2013) by M Dufresne
 - ICGC-pancreas meeting 2013 (Toronto, Oct2013) by N Malats
 - FP7/H2020 Meeting (Dublin, Nov2013) by N Malats
 - Pancreas Society of Great Britain 39th meeting (Liverpool, Nov2013) by E Costello-Golding

b. At November 2013, the status of the Action budget presented in the MC meeting was the following. The meetings costs were not updated.

A. SUMMARY BUDGET		LEFT (aprox)
(1) MEETINGS	85,600 €	33,996 €
(2) SHORT-TERM SCIENTIFIC MISSIONS	6,000 €	34 €
(3) TRAINING SCHOOLS	0 €	
(4) PUBLICATIONS, DISSEMINATION, OUTREACH	4,500 €	2,000 €
(5) OERSA	3,000 €	1,000 €
B. TOTAL SCIENCE EXPENDITURE (sum of (1) to (5))	99,100 €	36,990 €
C. Financial & Scientific Administration and Coordination (max. of 15% of B.)	14,865 €	0 €
D. TOTAL EXPENDITURE (B+C)	113,965 €	36,990 €

c. Dr. La Vecchia updated on the STSM status and new applications

- A first STSM call was publicised in September 2013 among MC members and WG managers. 4 STSMs were approved out of 5 applications. The awardees being:

Beneficiary	Original centre	Hosting centre	Period	Amount
D Vangala	Ruhr-University Bochum, Bochum, Germany	CNIO, Spain	October 2013	766€
S Pineda	CNIO, Spain	Ulg, Belgium	Feb-March 2014	2200€
JM Mazarico	CNIO, Spain	Imperial College o London, UK	Jan-April 2014	1500€
A Maziukiene	Lithuanian university of health sciences, Kaunas, Lithuania	TUM, Germany	Nov-Dec 2013,	1500€

→ A proposal of a new STSM call being open December 2014 was proposed and agreed. The possibility of 5 STSM to be conducted between Jan-Feb was considered. They should last between 1-4 weeks. A discussion on the criteria for selection of candidates aiming to increase the field benefits of this activity was held. The criterium proposed was to consider as potential candidates scientists/technicians with at least 1 publication on PDAC. Due to the prematurity of the call and the multidisciplinary nature of the Action, it was agreed to postpone this discussion to future calls.

5. Promotion of gender balance and of Early Stage Researchers (ESR)

- At November 2013, 41% of the delegates are women. The woman/man ratio among MC members is 0.82 and for positions of responsibility is 0.8
- It is still too premature to assess ESR balance.

6. Among the actions undertaken by the Grant Holder (CNIO) during the first period there are the:

- Action and grant agreement establishment. The grant agreement was signed in April 2013. Funding was available afterwards.
- Training on COST administrative aspects and on eCOST system.
- Administrative tasks including meeting invitations, delegate registration, STSM management, conference organization.
- Design and construction of the WEBpage and request of the e-domain. Still it needs to be implemented.
- Some delays occurred due to several issues encountered during the first months of the Action, among them: the Grant Holder was not used to the particularities of the COST administration and a new eCOST informatics system appeared during this period; the first project manager at CNIO responsible for the Action (Miss Lilit Manukian) left last August and Mrs Lola Liebanes had to take responsibilities of the Action without being trained; the Rapporteur and the Scientific and the Administrative officers also changed during the period. Roger Milne (Dissemination manager and WG1 coordinator) left CNIO last September and a new WG1 coordinator (Dr. Irene Esposito) was invited to take charge of the position, the Dissemination manager position is still pending to be covered; we also encountered low response of approached experts due to summertime and end and starting academic year to organize the WG2 and WG4 kick-off meetings.
- At present, the Action is already established, members are registered in the system and the online eCOST is being managed correctly, though it still requires of a lot of time investment. No additional caveats are foreseen. MC members were requested to fulfil terms in presenting the reimbursement application and complete registries and profiles.
- The following agreements were taken:
 - Dr. Filipe Silva Santos (Portugal) will act as Dissemination Manager. Among his responsibilities is that of completing and monitor the WEBpage. Links to Facebook, Twitter, and Linkedink will be set up.
 - Dr. Malats expressed the need of support for the Action scientific coordination and proposed to supplement the salary of an early-stage researcher to help in this regard. The budget allocated to this concept would be part of the FSAC Budget (15% assigned to the Grant Holder, chapter C). While the MC agreed on this, Mrs. Jeannette NCHUNG expressed her doubts and committed herself to discuss this possibility with the COST officers.

7. Update from the COST Office

Among the topics covered by Mrs. Jeannette NCHUNG were the following. Details of the presentation can be found in the attached ppt file.

- 1) The actions approved in the recent COST calls.
- 2) The next BMBS APC / DC MEETING that will be held in La Velleja, Malta during April 28-30, 2014. N Malats are required to present the progress of the Action during this meeting.
- 3) On the Action information and budgetary issues indicating that the 2nd instalment of the first period (39,889€) needs to be requested before the end of the year.
- 4) Particularities of ending an Action, including the final meeting the final evaluation report, final publication.

8. Update from the DC Rapporteur

Dr. Rosa Bjork BARKARDOTTIR stressed the importance and urgency to get the WEBpage to disseminate information from the Action as well as an internal tool of communication and evaluation.

Besides this, she also acknowledged the dynamism of the Action.

9. Next Annual Progress Conference is scheduled in April 28-30 in La Vellela, Malta. N Malats has been requested to report on the Action during this meeting. More information will be provided as the event approaches.

10. Each WG coordinator reported on the follow-up of MoU objectives and progress of their WG. Details can be found in the attached minutes of the 4 WG meetings held before the Annual Conference. These include the kick-off meetings of WG1 (13June2013, Madrid), WG2 (28Nov2013, Madrid), WG3 (17June2013, Bochum), WG4 (28Nov2013, Madrid) and the WGs meetings all held in 29Nov2013, Madrid.

11. Scientific planning for the 2nd period

a. Scientific strategy

The overall scientific strategy for the 2nd period is to give dynamism to the pancreas cancer research in the European arena by initiating and strengthen multidisciplinary collaborations and building common resources, including training. Dissemination of the Action activities is among our priorities.

The following list summarizes the specific aims of each WG for the 2nd period:

WG1-1: Comparison across groups and countries, and across settings and contexts, of definitions and terminology for sporadic, hereditary and familial pancreas cancer. Standardized definition of PDAC and establishment of key terminology.

WG1-2: Development of protocols for patient enrolment and monitoring. Standardization of epidemiological and clinical questionnaires.

WG1-3: Standardization of biological sample collection, processing and storage protocols. Establishment of criteria to assess the quality of existing biobanks for pancreas cancer research. Interconnection about biorepositories and databases.

WG2-1: Identification of pancreas cancer omics databases and omics-related data standardization or optimization. To evaluate confidentiality issues and issues related to data sharing

WG2-2: (Integrated) Omics analysis

WG3-1: To initiate a study on "Prospective evaluation of a novel early symptom algorithm and rapid assessment pathway for diagnosis of pancreatic cancer in primary care".

WG3-2: To set up a COST registry for already available biomaterial from early stage pancreatic cancer patients and tumors

WG3-3: To set up a COST initiated European IPMN study group to develop and test risk prediction biomarkers for IPMN

WG4-1: Identification of European centres focused on individualized medicine approaches for pancreatic cancer treatment

WG4-2: Establishing the framework for the development of evidence-based PDAC-best practice guidelines (HTA) and their translation into the healthcare systems in Europe by involving all relevant stakeholders (HIA)

b. Action Budget Planning for the 2nd period

(1) MEETINGS (2MC, 2WG, 1AC)	€ 83,000
(2) SHORT-TERM SCIENTIFIC MISSIONS (5-10)	€ 12,000
(3) TRAINING SCHOOLS (2)	€ 38,000
(4) PUBLICATIONS, DISSEMINATION, OUTREACH	€ 2,000
(5) OTHERS	€ 0
B. TOTAL SCIENCE EXPENDITURE (sum of (1) to (5))	€ 135,000
C. Financial & Scientific Administration and Coordination (max. of 15% of B.)	€ 20,250
D. TOTAL EXPENDITURE (B+C)	€ 155,250

c. Long-term planning (including anticipated locations and dates of future activities)

- 3rd MC meeting during the EPC&IAP2014 – Southampton, 24-28 June 2014
- 2nd Annual Conference + 4th MC meeting during the CSCDA – Liège, November 24-26, 2014
- WG2: Training school for WG2 as part of the CSCDA2014 "regular" half day training
- WG1: Workshop on Bioethics. Munich. Dates will be communicated at due time.
- WG1: Training school 2014 - Tutorial on pancreas pathology, CNIO December 4-5, 2014
- 5th MC meeting – EPC2015 – Toledo, June 2015
- 3rd Annual Conference + 6th MC meeting jointly with the PanC4 meeting – Milano, November 2015

d. Among the actions planned to disseminate the Action activities are:

- Up-date and complete the Action WEBpage. Consider the number of visitors and the time spent during their e-visit. While an Intranet space was suggested it will not be implemented immediately.
- Activate LinkedIn, Facebook, and Twitter associated with the Action.
- Circulate 2 slides summarizing the Action so that all members can use them to disseminate the existence and activities of the Action.
- It was proposed that the following text is added to the email signature of the members:
EU Pancreas - BM1204 COST Action
www.eupancreas.com
- Two book chapters have been scheduled within WG2.
- Publications from members of the Action may acknowledge the Action using the following formula:
*"European Cooperation in Science and Technology (COST Action
#BM1204: EU_Pancreas)"*
- Presentation (oral/poster) of the Action activities in scientific meetings.
- Presentation of the Action in lay forums: families, general population, Mass Media.
- Contact the Private sector.
- Contact other Actions and International Consortia.

12. As requests by new members, Dr. Matthias Löhr from Karolinska Institute, Stockholm, Sweden, expressed his interest to participate in the Action. Apparently, he encountered some resistance by the COST National Coordinator and the process was stopped.

Also Dr Bongcam-Rudloff, coordinator of the COST Action BM1006 –Next Generation Sequencing Data Analysis Consortium was approached with the objective to establish a collaboration. We still are pending from a response.

13. The following non-COST associations have been approached and invited to either actively participate to or collaborate with the Action

- EUAPM – European Alliance for Personalised Medicine (<http://euapm.eu/>)
- IARC – International Agency for Research on Cancer (<http://www.iarc.fr/>)
- ICGC International Cancer Genome Consortium (<http://icgc.org/icgc/cgp/68/392/810>)
- PanC4 - Pancreas Cancer Case-Control Consortium (<http://panc4.org/>)
- EORTC – European Organization for Research and Treatment Cancer (<http://www.eortc.org/>)
- ELIXIR - European life-sciences Infrastructure for biological Information (<http://www.elixir-europe.org/>)
- SPIDIA - Standardisation and improvement of generic pre-analytical tools and procedures for in-vitro diagnostics (www.spidia.eu)
- m4 biobank alliance (www.m4.de)
- EPAAC - European Partnership for Action Against Cancer (<http://www.epaac.eu/>)
- RarecareNet – Information network on Rare Cancers (<http://www.rarecarenet.eu/rarecarenet/>)
- EUCERD - European Union Committee of Experts on Rare Diseases (<http://www.eucerd.eu/>)
- EUROCANplatform (<http://eurocanplatform.eu/>)
- OEI - Organisation of European Cancer Institutes (<http://www.oeci.eu/>)
- NCI - National Cancer Institutes (<http://www.cancer.gov/>)
- BBMRI ERIC - pan-European Biobanking and Biomolecular Resources Research Infrastructure / European Research Infrastructure Consortium (<http://bbmri-eric.eu/es>)

14. No other business were raised

15. The next MC meeting will be held jointly with the EPC&IAP2014 Conference in Southampton, UK, during 24-28 June 2014. Further details will be communicated in due time.

16. Summary of MC decisions:

- Dr. Filipe Silva Santos (Portugal) was nominated the new Dissemination Manager of the Action. He will take responsibility of the WEBpage design and monitoring.
- To update and complete the Action WEBpage and to activate Facebook, Twitter and LinkedIn associated with the Action.
- To extend the Action with International Organizations/Foundations and to establish collaborations with other COST Actions.
- To allocate part of the FSAC Budget (15% assigned to the Grant Holder, chapter C) to partially supplement the salary of an earlier-stage researcher to help in the scientific coordination of the Action. While the MC agreed on this, Mrs. Jeannette NCHUNG expressed her doubts and committed herself to discuss this possibility with the COST officers.

1st period activities

- New call for 5 STSMs in December 2014 to be done during February-March 2014.
- WG2 meeting and Integromics workshop in Heidelberg during February 2014.
- WG3 meeting and the London Pancreas Workshop 2014 to be held on 1-2 May.
- WG1 meeting in Milan, May 20th 2014.

2nd period

- New call for STSMs
- 3rd MC meeting + EU-Pancreas workshop during the EPC/IAMP meeting in Southampton 24-28 July 2014.
- WG1: Workshop on Bioethics, Munich. Dates will be communicated.
- WG1: Training school on pancreatic pathology, CNIO, Madrid, December 4-5 2014
- WG2: training school during the as part of the CSCDA2014 "regular" half day training
- WG4: Presentation of the survey at the Italian Presidency meeting in September 2014 (roadmap of PM: unmet needs) and recommendations for EHFG PerMed session in October 2014.

