



**EPAAC WP8 Research Workshop,
Key milestones and key issues related to Pilot Project 3
“Building a Knowledge Hub in Cancer Epidemiology and Public Health Research”
EPHECAN HUB proposal.**

1. Background

Objectives of Pilot Project 3

The EPAAC WP8 Pilot Project 3 (PP3) “Knowledge Hub in Cancer Epidemiology and Public Health Research”, hereinafter EPHECAN HUB, intends to be a **virtual multicentre and multidisciplinary research centre** that enhances Cancer Epidemiology and Public Health (EPH) Research in Europe. This virtual research centre could be composed by a network of quality research groups, emergent groups and groups in less favoured regions of the EU focused on Cancer EPH. EPHECAN HUB should involve not only researchers, but national funding agencies and other relevant stakeholders in the field.

The Mission:

EPHECAN HUB will increase efficacy and excellence in European Cancer EPH research:

- By **fostering collaboration** to simplify large population studies, including dimensions such as different analytical studies examining the risk associated with environmental and behavioural exposures, studies on early detection of cancer, impact analysis of all policies on health, and policy scenarios for cancer prevention.
- By raising the amount of European coordinated research projects funded by national research agencies as a way of contributing to the **coordination of Cancer EPH research agendas** at European, national and regional level.
- By **mapping strengths and gaps across European**, to enable national and European founders to develop collaborative targeted research in cancer prevention and control.
- By facilitating the **innovation processes** and the effective **knowledge translation** from Cancer EPH studies to Cancer prevention public policies and interventions.
- By enhancing **educational efforts** in all areas to implement EPH knowledge into intervention programmes as fast as possible.
- By **reducing the fragmentation** of European Cancer EPH research through harmonization of methodologies, development of specific technological platforms and implementation of common standards.

The PP3 objective in the intermediate term is to test the feasibility of the EPHECAN HUB through the development of four key tasks identified by the participants:

1. Create a **map of cancer prevention and control research and innovation across EU** Member States and regions, drawing on key informants from research agencies, cancer control authorities, professional groups, NGOs, Ministries of Health and previous project outcomes.
2. **Identify leading research initiatives across Europe** for shared issues (aetiological, interventional), review gaps and prepare programme for future work.
3. **Review past research** for prevention and control, identify successes and failures in uptake and impact, measures of outcome and change in policy (including ‘do not do’) in association with national/regional technology advisory bodies and policy organisations.



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4. Hold coordinating meetings between leading research and innovation agencies to **develop targeted research programmes**.

For a more detailed description of the project proposal please see [Appendix 1](#).

Moving towards PP3: steps taken and main achievements

Identification and prioritization of areas in cancer research following consultation with the cancer community: Over 200 experts from the cancer field, including patients, researchers, epidemiologists, public health experts, biotechnology experts, immunologists, clinicians, nurses and allied professionals, pathologists and industry representatives, gave feedback through the questionnaire.

Epidemiology and public health cancer research was identified as an important area to target in coordination efforts. This area contains a wide range of subjects that were mentioned in the questionnaire:

- etiological research with large cohorts
- epidemiological studies
- screening
- research and development of biomarkers
- health impact of environment and lifestyle
- evaluation of interventions
- communication
- inequalities in cancer
- epigenetic and exposome studies (in collaboration with BBMRI)

According to the questionnaire, all these single proposals are in need of coordination at European level and at that moment cross-border research networks emerged as the best vehicle to achieve this goal. Networks have the potential to boost research capacity by connecting specialised research groups in cancer epidemiology and by including less experienced research groups in large European studies. Sharing the knowledge gained with the population—essentially including them as a node in the network approach—also helps in getting population support on board and advocacy for evidence-based prevention policies.

EPAAC WP8 Research Forum (Brussels, July 2012): During the panel discussion with founders, researchers, clinicians, patients, industry, public health experts and policy makers the general agreement was that prevention and public health research is another highly relevant and important area. For these reasons the 3rd pilot project should be focus on this subject and Spain (CSISP and ISCIII) compromise to lead the proposal.

Follow-up workshop (Paris, October 2012): The first ideas were presented at an EPAAC workshop in Paris (October 2012), where participants expressed their enthusiastic support to the proposal.

Presentation of PP3 at the TRANSCAN meetings (Athens, June 2013): the state of PP3 development, as of the Valencia meeting, was presented to the funding organisations partnering in the ERA-NET on Translational Cancer Research TRANSCAN.



2. Valencia meeting. 3th April 2013, Valencia (Spain)

The PP3 parallel session in the EPAAC WP8 workshop held in Valencia had the main objective of sharing the first ideas presented in Paris with a selected group of relevant European researchers in epidemiology and public health. The main outcomes of this meeting are reported in this section.

During the Second Research Forum held in Valencia, a formal kick-off was organised with a group of about 20 European researchers in cancer epidemiology and public health. In-depth discussions brought to light some key coordination issues and helped to chart a path forward in the implementation of a knowledge hub in cancer epidemiology and public health research.

During the meeting, the proposal is seen to carry a lot of weight due to its innovative and inclusive nature, bringing together researchers, funders, patients, the scientific community and industry. It is also understood to be very timely due to current institutional developments at European level and the potential opportunities afforded at this time.

DG Research was in the process of putting together plans for Horizon 2020, the successor to FP7 and therefore close links should be retained in order to input ideas and recommendations at a timely stage. Public health research was very modestly funded under FP7, but it is anticipated that Horizon 2020 will support networks of research institutions (which may involve research into public health). Furthermore, the Joint Research Centre in Ispra is setting up activities in this field, including a network of cancer registries and a network of screening prevention, and as such should be approached about possible support mechanisms for an initiative in public health and epidemiology research. DG Sanco is the owner of the EPAAC project and as such continued collaboration is important.

During the meeting several key issues were discussed, such as:

Why do we need the coordination and what kind of coordination: An understanding and common agreement is needed on the added value of collaboration in cancer epidemiology and public health research, in order to convince policymakers and national research funding organisations alike to invest in coordinated initiatives. With regard to 'selling' the idea at European level, it is necessary to describe the problem at hand, explain how addressing it will respond to societal challenges, and state how added value can be gained by tackling it at European level and with respect for European values such as equity and subsidiarity.

Drawing lessons from the Spanish experience and other networking initiatives: Important lessons may be learnt from the Spanish CIBERESP experience for a European level initiative, even if the idea is not to extend this model to the European level. The EU assigns very little money to epidemiology, and therefore by collaborating and speaking with a single voice the community has more power to leverage support and funds for its interests. The conceptual framework for such an initiative needs to be clearly explained, and added value for Member States illustrated; some countries and regions are already very well organised, e.g. Nordic Cancer Union, and the value or coordination with other countries and regions may not be immediately obvious.

Funding: While it is noted that in many countries the vast majority of research funding goes to biomedical research rather than epidemiological research, it is considered important to promote investigations into the links between molecular markers and prevention. Regarding funding of a European initiative, it should be noted that there are differences between Member States regarding sources of funding. For example, in



north-west Europe cancer societies play a strong role while in south-west Europe they play a lesser role and government money is more heavily relied on.

Another strategy for attracting funds that was discussed during the meeting was by mobilising the different epidemiological communities on a national and international level. The involvement of key persons with wide experience in their fields who emphasise the need for epidemiology funding in Europe is a means of reaching potential funders.

Links with other projects: A crucial issue was the way in which the hub could link up with large projects in a highly stable and scientifically productive network such as the European Prospective Investigation into Cancer and Nutrition (EPIC), Eurocadet or PHIRE, among others.

Moreover, the hub will support the improvement and evolution of better research practices to benefit the European research community by (a) leading initiatives focused on research quality enhancement; (b) identifying and developing infrastructures and tools for research to be used in a more efficient way between Member States; (c) cooperating with other European organisations to address common priorities; and (d) disseminating new developments in cancer prevention to citizens' and patients' organisations.

Drawing on lessons learned and suggestions made, some conclusions were made to implement the European initiative in epidemiology and public health research:

- It is not possible to build on existing initiatives (JPI on healthy diet and healthy lives, TRANSCAN, ESFRI, JPI on urban mobility etc) but rather a new initiative/model is required.
- Social innovation is the key issue. It is necessary to explore how innovation can be applied to coordination.
- Proper funding is required for the new initiative, at least for meetings and potentially a secretariat.
- It may be best to start with an informal network which could grow and develop into something more official at a later stage.
- The soon to be formed European Association on Cancer Epidemiology (together with the JRC) could be a platform for hosting/organising meetings.
- A European initiative in epidemiology and public health research could consider including not only Cancer but also other chronic diseases.
- A 'knowledge hub' could serve as a forum for research groups to answer questions that need to be answered such as: where are the gaps in European research?.
- Ground rules must be defined and common objectives and functions well laid out.
- Policymakers at national and European level should be clearly informed about the need for such an initiative.
- It is recommended that more focus is placed on "health" than on "disease", specifically on prevention. The environment and risk factors are extremely important at young ages. Especially with longer life expectancy and a growing elderly population, it is very important to also start to focus on the healthy young population.
- It is essential to create awareness for epidemiology linked to biomarker research. Linking these two areas would give more opportunities for funding.
- There are many excellent research groups in this field, they together produce the results, and single researchers need the power and resources in their organization to initiate scientific projects or structural changes.
- A long application and approval process will reduce the number of good brains in the organization. Good brains already have their collaborators. A short procedure is required, this should also allow newcomers in the field to enter. These people might not have many publications, but they do have good ideas and the drive to move forward.



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- With regard to the areas of EPH cancer research to be included in the proposal, it was suggested that an ideal scenario would include all areas in a current priority ranking, as priorities change depending on society and the environment or the economy. The representatives of these areas should have the capacity to vote on which areas are to be included perhaps using some kind of proportional system.

3. PP3 developments during and following the EPAAC WP8 Workshop in Madrid

The PP3 parallel session in the EPAAC WP8 workshop held in Madrid had the main objective of consolidating the PP3 proposal by defining the details, in terms of structure, objectives and activities and delineating the steps needed for its implementation. These objectives were achieved during the discussion with selected experts, for a detailed list of participants see [Appendix 2](#). To consult the details of the presentations see [Appendix 3](#). The main outcomes of the meeting are reported in the following section.

Opening of the session and introduction to the Pilot Project 3 (PP3)

Teresa Corral from Institute of Health Carlos III (ISCIII, Spain) presented the Agenda for the parallel session.

Rosana Peiró, from Valencia Public Health Research Centre (CSISP-FISABIO, Spain) briefly explained the how the proposal of PP3 was shaped within the framework of the EPAAC joint action, taking advantage of the already running model at the Spanish CIBERESP (Biomedical Research Networking Centre for Epidemiology and Public Health), its objectives, the roadmap for its progress, project present state, and future steps for its development.

Main objectives of Valencia and Madrid meetings are to:

- Gather support from key researchers and institutions
- Agree on the basic structure of the Knowledge Hub (KH)

A further step needed for the viability of this project is to gather the support of the national funding agencies.

Participation by Skype: Drawbacks detected during the Eurocan+Plus project for research coordination on prevention. How can an EPH-KH overcome the barriers? *José M Martín-Moreno. University of Valencia, Spain*

The experts participating in the work package devoted to cancer epidemiology and prevention of The Eurocan+Plus project concluded that research in these areas is fragmented, and there is a strong need for more coordination (the final report is available through the Eurocan+ website). Barriers, including those rooted in culture, institutions and in communication, were identified and analysed, and solutions were proposed in six areas: Education and mobility; Data and information; Legal issues; Funding; Coordination barriers; and Cultural barriers.

José María Martín-Moreno explained that since the end of the project in 2007 the scenario has changed, but some of the findings are still valid, and their integration in the KH proposal would increase its interest. KH is an initiative that could promote and foster research in cancer



epidemiology, but both Member States and researchers must make an explicit commitment to this initiative in order for it to flourish.

As a result of the discussion of the report it was agreed that it would be necessary to update the report, and publish it in a peer-review journal. This report would also become then part of the PP3 report and its funding recommendations should be forwarded as recommendations for inclusion into Horizon 2020. José María Martín-Moreno and Markus Pasterk agreed on drafting an update for circulation.

Presentation: Building a Knowledge Hub in Cancer Epidemiology and Public Health Research.
Rosana Peiró. Valencia Public Health Research Centre (CSISP-FISABIO)

Rosana Peiró presented the basic features of the KH, motivation to create it, general research objectives and organisational objectives, and how this proposal can contribute to coordinate and strengthen Epidemiology and Public Health (EPH) research at European level. In this line, the KH should promote that national/local agencies fund the research groups and the KH only fund the coordination activities.

The key research areas included in the proposal were presented

- Three main areas
 - Area 1: Environmental Occupational and Population Health Research*
 - Area 2. Impact of public policies in cancer and health economics*
 - Area 3. Early detection of Cancer*
- Three transversal areas
 - Area 4. Inequalities and social determinants*
 - Area 5. Molecular epidemiology and bio-banking*
 - Area 6. Education and mobility*

As well as the common activities to develop within each area:

- To identify potentially interested and relevant groups
- Reach agreement on work proposals
- To contribute to a common research agenda in Europe.
- To identify key databases useful for research proposals.
- To identify validated questionnaires

Beatriz Pérez pointed out the need of a short-term reward. In relation with this, it was highlighted that at Valencia EPAAC meeting it was suggested that local funding agencies may consider the participation of the researchers in this KH as a merit to obtain local funds.

Presentation: KH structure.
Ana Levin. Valencia Public Health Research Centre (CSISP-FISABIO)

The KH managing structure will be composed by a Management Board (MB) constituted by members of funding agencies (national and European level) in charge of decision-making, assisted by two advisory bodies: Scientific Advisory Board (recognised specialists in the EPH area) and



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Stakeholder Advisory Board (Research Institutions, European Commission, opinion leaders, patient associations, industry). The MB will develop the criteria for selection of excellent/emerging groups. The secretariat will provide technical support to the MB, and will be in charge of executive tasks such as KH Communication Platform, knowledge transfer, Intellectual Property Rights (IPR) advice, and reporting.

The Communication Platform main features will be: website, compiling relevant websites and databases in cancer EPH, communication and dissemination plan (considering social media), and exploitation plan (IPR consultancy, technological catalogue, patent application management) to assure knowledge transfer.

Minimal human resources needed will be one project manager and one/two technical officers.

Pros and Cons of Knowledge Hub proposal

Presentation: Experiences in a network of cancer research centres for translational research: EurocanPlatform.

Cornelia Ulrich. National Center for Tumor Diseases. Heidelberg. Germany

Cornelia Ulrich briefly described the Division on Prevention Oncology that she leads within the National Center for Tumor Diseases, NCT Heidelberg. Within this division, the group *Cancer Prognosis, Survivorship & Pharmacogenetics* (led by Dr. Schrotz-King/ Dr. Staffa) is conducting two major studies related to cancer prevention: the Colocare project and the Eurocan Platform.

The Eurocan Platform WP11 aims to create a platform for joint translational cancer research among European clinical cancer registries. Joining forces inside the project has positively influenced the research results as it has been shown through different pilot projects including initial cross-national study protocols. These pilot studies show that relevant studies are possible within the Platform using already existing data and their initial findings demonstrate utility and clinical relevance of mutual studies in clinical epidemiology.

Public health should involve molecular techniques and new diagnostic and screening tests at population level and that this should be taken into account by EPAAC project. She would like to participate in the EPAAC initiative if it moves forward, but there is a need for assessment of resources needs for comprehensive activities.

Cornelia Ulrich and collaborators in Germany have developed a new *Molecular Public Health* vision (to employ beyond state-of-the-art molecular tools for prolonging life, preventing disease and promoting health through organized community efforts) that aims to result in interventions at public health level.

It was highlighted the unknown character of some of the relevant data presented and the need to communicate some of those research findings to the public.



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Prevention research projects should also address how policy-makers uptake the results and transform them into useful health policies for society. An Eranet such as TRANSCAN would be an idea of the kind of projects that can be coordinated through the KH.

The KH should have resources that go beyond general funding of networks, and should include also funds for activities such as student funding or staff funding, ideally with student exchange. Additionally, it would serve to link and joint forces of other networks and projects in the area.

Rosana Peiró underlined that the implementation of prevention policies is also a mechanism for economic development and there is a wide field for intervention. Molecular epidemiology area is very important and the *Molecular Public Health* vision seems very relevant.

It was raised the question on the relevance of some of the risk factors for many health research areas but it was agreed that the molecular area has to be specific for cancer and the focus of the KH should be in cancer, although open enough to collaborate with other diseases or areas.

Discussion of the KH proposal and implementation

Markus Pasterk mentioned that the idea is feasible. Regarding the secretariat, it is proposed that national or local funding agencies may provide funds to support it. One or several countries may propose it and the MB should choose the best option.

It was pointed out that decisions should be very transparent and conflict of interest between Scientific Advisory Board (SAB) members and research areas beneficiaries should be avoided. The SHAB (Stakeholder Advisory Board) should include all type of stakeholders, such as patients, ethics committees, European Commission, industry, etc. In order to have research results generated by this KH implemented into health policies or new interventions, it was proposed that health authorities (ministries, social security services or any structure who implements or prepares or develops the policies) should be involved in the KH decisions (SHAB or MB) so the results can be transferred to society.

Beatriz Pérez highlighted that the KH should serve to influence public health policies and Rosana Peiró that its focus should be in the determinants instead of in the disease.

Potential Scientific areas of the Knowledge Hub

Presentation: Prevention policies: the impact of the epidemiology and public health cancer research. Lessons learnt from Eurocadet project.

Jan Willem Coebergh. Erasmus University. The Netherlands.

Eurocadet delivered a piece of software that estimates the impact on incidence of different cancer prevention policies (Prevent model). As conclusion of the Eurocadet project, it was found that prevention could be large (25-40%) and feasible, but that many forces need to be mobilized (awareness) and effective interventions remain rare and are implemented after many years of



having the data (smoking, alcohol consumption, physical exercise). This model could be used through the KH as part of common armentarium: needed repository of scenarios. Guidance would be needed from Erasmus MC dept of Public Health, as well as compilation of recent data on trends in incidence from the EUREG database based at IARC and exposures from cohort studies / Eurostat data.

General discussion

Regarding the scientific areas of the KH, bio-banking contributes to every other group and not only to areas 1 and 3. Research on bio-banks always raises ethical and legal issues with data protection; these are important in bio-banking and should be taken into account. Any research on bio-banking should be done in coordination with the BBMRI-ERIC research infrastructure.

From the Eurocan+Plus project experiences it is known that there should be mobility not only among students, but also among trained clinical oncologists and other scientific postdocs in all interdisciplinary fields of cancer research within Europe. There are not such tools to help that mobility or virtual mobility; so this might be an issue to address at the KH.

Within FP7, the IMI EMTRAIN training project in life sciences (and its course catalogue “on-course”) might be a good tool to identify educational courses in Public Health around Europe. What is missing is an agreed curriculum for Cancer Public Health. We should find some universities that want to join to develop such a curriculum and are interested in implementation.

Promotion of awareness might be an important issue to work through the communication platform of the KH.

Public authorities are the ones in charge to turn the evidence in policies, so it was agreed that public health authorities and policy-makers should be part of the management structure of the KH, probably within the Stakeholder advisory board (SHAB).

It was mentioned that since the KH is a platform to enhance collaboration the research areas description should not be very detailed and no areas should be excluded.

To summarize:

- The general proposed structure for the KH was approved
- Scientist interested in working at any of the proposed areas are asked to contact proposal leaders
- It is a pending issue to gather the support of funding agencies
- The research areas proposed are correct but there should be some changes: name of the Environmental, Occupational and Population Cancer Research should change to Environmental and Behavioural cancer research, and areas should be more interconnected.
- Communication with society, advocacy groups and patients has to be active and is a very important part of the KH- Communication Platform.
- There is a need to work on the transfer of research results into public health policies
- Educational efforts in all areas in order to implement knowledge into interventions are needed.



4. Future steps

- To develop an **implementation roadmap** following the activities described on section 1 with relevant stakeholders and scientists.
- Request for **implementation advice** to different EC bodies. DG Research and DG Sanco have been contacted to discuss the issue of implementation and sustainability and first contact meetings are being set. We would like to explore the possibility of applying for funding for a feasibility study under the first Work Programme of Horizon 2020.
- At the same time, we are **seeking for support** of the scientific community as well as international funding agencies, previously funded project leaders or interested organizations to build the initial network of participants. The already received Letters of Support are listed on [Appendix 4](#).