ANNEX 1b

Acronym: EPAAC

Title: European Partnership for Action Against Cancer

Objectives

A general objective of this Joint Action (JA) "European Partnership for Action against Cancer" (EPAAC) for the period 2010-2013 is to contribute to the reduction of cancer burden in the EU by actions in the areas of health promotion and prevention, screening and early diagnosis, cancer related health care, coordination of cancer research and cancer information and data. The overall objective is to support Member States (MSs) in the development of their National Cancer Plans (NCPs). Integrated NCPs are public health programmes designed to ensure coordinated and centrally managed implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment, rehabilitation, palliation and research for innovative solutions, and to evaluate outcomes. EPAAC will help to raise awareness about cancer promotion and prevention, especially among target groups in Europe, by disseminating the European Code Against Cancer using proven communication strategies and messages, and by engaging policy-makers at the European, national, and sub national levels. EPAAC will contribute to the improvement of the implementation of the Council Recommendation on Cancer Screening by alleviating key barriers, to make screening of appropriate quality, as recommended by the Council of the EU, accessible to all citizens who may benefit. Further added value will be created by promoting synergy between cancer screening and other areas of early detection. Collaboration in cancer research across Europe is planned to be improved and gaps within the cancer research continuum where coordination is essential identified. EPAAC will bring together MSs/AC, NGOs including patient organisations and healthcare professionals, industry and other stakeholders in the cancer research continuum, with the aim of developing a concerted approach to achieve coordination of one third of research from all funding sources by 2013 within selected areas of cancer research. Best practices across European health services, promoting the exchange of experiences focusing on innovative organizational approaches, including patient's perspective are planned to be identified and assessed. Clinical Guidelines (CG) will be developed, reviewed and harmonized. EPAAC will help to implement a training strategy to improve psychosocial and communication skills among health care providers. A comprehensive cancer information system for European Union will be built.

Strategic relevance & contribution to the programme

In accordance with the second Health Programme (SHP) and Annual Work Plan (AWP), JA EPAAC contributes to health protection and safety of citizens through actions in the field of cancer control. It contributes to better knowledge of and information on the prevention, diagnosis and control of cancer, as an ageing related topic. It places emphasis on promoting a healthy lifestyle. EPAAC helps to identify the causes of cancer inequalities within the EU and to exchange the best practices to tackle them. This issue is one of the priorities of the SHP, due to the enlargement of the European Union and possible further enlargements. EPAAC is a response to an explicit request by EC and MSs for bringing considerable added value in tackling major health challenges more effectively, through information sharing and exchange of expertise and best practice. It will bring added value to the existing knowledge regarding cancer and will enhance its use. EPAAC contributes to the collection of data, the promotion and development of methods and tools and the establishment of networks. Activities are wherever possible build on existing work, all in accordance with SHP. EPAAC promotes cooperation between MSs and enhances the effectiveness of existing and future networks in the field of cancer. The participation of national, regional and local authorities at the appropriate level in accordance with the national systems is taken into account in regard to the implementation of the SHP. EPAAC is implemented according to the AWP 2010. It is supporting MSs and other stakeholders to

more efficiently and effectively work together at EU level in addressing the burden of cancer, using innovative cooperation and governance structures. EPAAC, by bringing together EU stakeholders with a common objective and commitment to reduce the cancer burden is providing MSs and other stakeholders with a framework for sharing information, resources, best practise and expertise in cancer prevention and control.

General objective of the joint action

The objective of the Commission Communication on Action Against Cancer: European Partnership (COM (2009) 291final) is that by the end of the Partnership, all MSs should have integrated cancer plans. The more long-term aim is to reduce cancer incidence by 15% by 2020. EPAAC aims to contribute to the achievement of these goals by supporting activities in the following areas (also identified in the Commission Communication): health promotion and prevention, screening and early diagnosis, identification and promotion of good practice in cancer-related health care, a coordinated and collaborative approach to cancer research, and health information and comparable data. The overall objective is to support MSs in development of NCPs. Integrated NCPs are public health programmes designed to ensure coordinated and centrally managed implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment, rehabilitation, palliation and research for innovative solutions, and to evaluate outcomes. Such integrated approach can reduce the number of cancer cases and deaths and improve quality of life of cancer patients. EPAAC will provide a framework for identifying and sharing information, capacity and expertise in cancer prevention and control. As demonstrated by the existing stark differences and inequalities in cancer incidence and mortality throughout the European Community, there is considerable added value in working together at EU level to prevent and control cancer more effectively.
A strong network/partnership, which will include medical and scientific research institutions with outstanding experiences regarding cancer, institutions with strong methodological development and production of assessments, industry representatives as well as non-governmental patients' coalitions from all MSs will be created.

Problem analysis including evidence base

Cancer is one of the major causes of ill health in the European Union, associated with a considerable cost to society. It was the second most common cause of death (after circulatory diseases) in 2006, accounting for two out of ten deaths in women and three out of ten deaths in men, equating to approximately 3.2 million Europeans diagnosed with cancer each year. Despite the progress in recent times, cancer still takes an enormous toll on European society. Considering the socio-economic implications of the expected rise of cancer as the European population ages, it is crucial to tackle this disease effectively in the EU. There are stark differences and inequalities in cancer incidence and mortality throughout the EU Community. It has been estimated that around one third of all cancers could be prevented by modifying or avoiding key risk factors. The European Code against Cancer is a key prevention tool with recommendations which provide citizens with two clear messages: certain cancers may be avoided by adopting healthier lifestyle, and the prospects of cancer cure greatly increase if the disease is detected at an early stage. There is scope for further improvements in cancer prevention efforts. Furthermore, despite all efforts screening programmes for breast, colorectal and cervical cancer as recommended by the Council Recommendation of 2 December 2003 on cancer screening have still not been fully implemented in MSs. Lack of cancer research coordination translates into duplication of efforts, creates gaps and limits the progress in fight against cancer. Comprehensive national cancer plans that have proven effective in improving cancer services and outcomes are not implemented in all MSs. Working together on the European level to prevent and control cancer effectively would be of crucial importance. There is an added value in exchange of best practices and in better sharing of knowledge and expertise among different countries and also among different stakeholders.

Target groups

Regarding the extent of the involvement in the JA EPAAC, primary, secondary and tertiary target groups will be organized. Primary target group will consist of all those MSs and organizations who will be directly involved in JA EPAAC. Member States, all important stakeholders, governmental as well as non-governmental organizations will represent the primary target group. EPAAC will help them regarding different cancer related topic issues as the accessibility of the information, research planning, treatment guidelines etc. Secondary target group will consist of different scientific organizations and committees such as medical organizations, nurses' organizations and other professional organizations who will gain direct benefit from EPAAC with respect to exchange of best practices and better sharing of knowledge and expertise. Cancer patients as well as general population and all those who will gain direct benefit from JA EPAAC will represent the tertiary target group. Cancer patients should have the access to all available treatment centres and therapies, psychological help and proper palliative treatment. General population should be aware of the importance of choosing a healthy lifestyle, life in healthy environment and should take care of proper health.

Methods and means

Different methods will be used. The state-of-play in the development of NCPs in the EU will be established. An analysis of the content of the existing plans will be conducted using specifically prepared questionnaires. Areas of key importance will be identified and guidelines for a high level standard NCP which will include the listed key areas will be prepared. To promote cancer prevention measures EU Week against Cancer II-EWAC II will be organized, agreement on the theme for the EWAC II will be jointly decided. Schools of Screening Management will be initiated (continued training essential to implementing and constantly improving the quality of cancer screening programmes and complementary primary prevention programmes) and exchange of information and collaboration between MSs will be promoted. Best practices in cancer care will be identified and assessed. Published experiences will be reviewed, existing regional networks will be mapped and workshop with experts will be organized. Surveys, mapping and workshops will be used and organized to develop, review and harmonize clinical guidelines. For implementation of a training strategy, which will improve psychosocial and communication skills among health care providers, mapping of needs and resources in communication skills and psychosocial care will be done and web based survey to map the needs and resources will be produced. A training tool in communication skills and psychosocial care will be developed.

Questionnaires on cancer research will be prepared and analysed with the aim to develop a comprehensive coordination of cancer research. Based on the outcomes of the questionnaires, workshops will be organized with researchers from various disciplines to discuss key challenges, gaps and research priorities in the identified cancer priorities, and make proposals on main actions to be undertaken in collaboration. Follow up meetings with the member states authorities, financing agencies, stakeholders, etc, will then be organized to prepare the road map for implementing the research coordination in selected areas based on the above proposals. To make available and disseminate cancer burden indicators, a European map of cancer information will be built, using the indicators identified by EUROCHIP and ECHI. The map will identify areas of data availability and data needs. An inventory of statistical methods to analyse population based cancer data will be developed.

Expected Outcomes

The reached goals of EPAAC will be noticed in improved quality of health care, as well as in the improved quality of peoples' life. Member States will be supported in the development of their National Cancer Plans

(NCPs), public health programmes designed to ensure coordinated and centrally managed implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment, rehabilitation, palliation and research for innovative solutions, and to evaluate outcomes. The EPAAC activities will contribute to the higher awareness of the importance of cancer prevention and positive change in people's behaviour is expected. EU citizens will be enabled to make informed decision regarding their lifestyle change, including alcohol consumption, tobacco use, sun exposure, physical activity and nutrition as fruit and vegetable intake. Early diagnosis of cancer, which is crucial for the outcome of the cancer treatment will be facilitated by improved population based cancer screening programmes and improved quality of screening procedures. Medical knowledge of health professionals regarding screening and early diagnosis will be enhanced due to easier accessibility and better quality of cancer screening learning programmes.
Treatment of cancer patients in all MSs will be improved due to reviewed and harmonized clinical guidelines for managers and clinicians and due to the introduction of new clinical guidelines. Financial resources for cancer research will be used properly, because a concerted approach to achieve coordination of one third of research from all funding sources by 2013 within selected areas of cancer research will be developed. Data regarding cancer prevalence, incidence, mortality, survival rate, cancer costs from all MSs will be readily available in one united EU Data map, which will allow a more detailed look into cancer situation in every single MS and facilitate decision making.

External and internal risk analysis and contingency planning

Due to the extensiveness of the partnership, internal and external risks were analyzed and contingency plans were adopted. Regarding the strong experience of the MP and APs, the risks if turned up would be managed and problems solved. Many of the partners involved in EU Partnership Cancer have already participated in different EU projects and some of them have already been partners in the same EU projects, they know how to react in possible crises. Some of the most possible risks and appropriate contingency plans: - Risk: Difficulty in project management and coordination due to extremely high number of APs. Contingency plan: MP has strong experience in coordination and management of large EU projects and enough high quality experts. Strong central coordination with assistance of WP leaders, good communication, using specially created e-mail address of JA, enabling quick responsiveness of MP, daily telephone communication with partners, monthly audio conferences with WP leaders who will help to coordinate APs of the proper WP, in-advance distribution of information and tasks to partners are among the topics in contingency plan. A strategy to require preliminary reporting 30 days prior to final reporting date will be developed early. A separate consortium agreement will be developed for signature by all the AP of the JA to detail the responsibilities and repercussions of not performing according to the agreed-upon division of responsibilities. - Risk: Turnover of work staff in the APs or MP Contingency plan: Continuous monitoring of changes needed of a 3-year Work Plan to get new staff quickly integrated. Constant communication through MP on the progress in the individual WP will keep the work force updated. - Risk: Management or financial crises in one of the AP organizations Contingency plan: Good internal communication and distribution of tasks among partner organizations should contain the risk of WPs becoming diverted from focus or timetable.

Horizontal Work packages - Description of the work

Work package number 1

This Work Package (WP1) concerns the overall management and coordination of the Joint Action to be led by the Slovenian National Institute of Public Health (NIPH). The design of the WP ensures that the action progresses according to the specified work plan, that its milestones are achieved on time, constant monitoring

via regular progress reports from Work Package Leaders (WPLs) at regular Joint Action Advisory Committee (JA AC) meetings, that the overall budget is managed according to the specified parameters and the delivery of interim and final technical and financial reports to the Executive Agency for Health and Consumers (EAHC). The first step will be to create a **Joint Action Governance Structure** with a clear division of responsibilities and tasks, consisting of three levels of action: The JOINT ACTION MANAGEMENT TEAM (JA MT), the JOINT ACTION ADVISORY COMMITEE (JA AC) and the PARTNERSHIP STEERING COMMITTEE (SC). All three levels will benefit from the technical and expert support of the Joint Action Partnership Secretariat (see WP4). The JA MT will have overall responsibility for the execution of the Action. It will thus be the official liaison for the European Commission (EC) and Executive Agency for Health and Consumers (EAHC) as regards reporting requirements, budgetary management and timely delivery of the Action's core objectives. The JA MT will be responsible for the day-to-day management of the Action and will closely monitor all stages of its progress, as well as identify any issues that bear an impact on the specified deliverables and milestones of the Action. Regular communication will therefore be scheduled in the detailed work plan between members of the JA MT and the EC to discuss any matters in this regard. The JA MT will be composed of a close operational team of approx. 5-7 people responsible for the overall coordination and management of the Action, led by the Slovenian Institute of Public Health (NIPH), in collaboration with the Slovenian Ministry of Health (MoH), (the JA Secretariat, which oversees Open Forum and overall meeting organisation is described in Work Package 4 for specific organisational reasons). The MT will be designated within one month (M1) of the beginning of the Joint Action. The Project Leader will have overall responsibility for the Action and will be the official contact person vis-a-vis the EC and the EAHC. The rest of the JA MT (to be appointed) will perform operational functions, such as those of project manager, technical expert, financial officer and project administrator with clearly defined responsibilities and will also include the Joint Action Partnership Secretariat (see WP4), as well as a representative of the Slovenian Ministry of Health. The NIPH may also seek advice from external experts as needed. Financial and technical reporting will be completed within this WP; the JA MT will, together with the coordinator, ensure timely and accurate reports in liaison with partners and the EC and EAHC. The information on progress in regards to timeframes will be provided by Work Package Leaders (WPLs) using collaborative project management tools (e.g. telephony, videoconferencing, webconferences, e-mail, faxing, electronic meetings, closed section of the Virtual Partnership). The JA MT will also liaise with all associated partners regularly for provision of the deliverables and involve other key stakeholders during the process as needed. The team will meet at JA and JA AC meetings and will hold audio conferences when required, and will liaise by phone and e-mail between conference calls. The kick-off JA meeting, joining the first JA, AC and SC meetings, is to be held in Ireland on 1-2 March 2011. At this meeting, the JA MT will notify all partners about the organisational methods to be employed in the Joint Action, obligations concerning financial and administrative reports, tracking of expenditure and results of individual Work Packages. To ensure the sound management of the Action, a Consortium Agreement will be concluded and signed by all the project partners; this will establish the common ground and legal aspects of the project, clearly define responsibilities and relationships between partners, as well as provide assistance in potential conflicts.

The JA AC will be established to advise the JA MT on the direction and execution of the Action as well as oversee the activities of the 5 Stakeholder Working Groups and 3 Open Forum (OF) events (see WP4). It will provide strategic guidance and support to the JA MT to ensure that the expected results meet the Action’s objectives. The JA AC will be chaired by the project coordinator (NIPH) and consist of the JA Management Team (JA MT) and Work Package Leaders (WPL). The responsibilities and duties of the JA AC members are: To review the project outcomes and identify the strong / weak points with respect to the objectives and the implementation of the results, To promote the exposure of the Joint Action and link it to other similar European and international efforts, To consider other potential applicants that may join the Action, Open Forum and Virtual Partnership in the future. The Action, as an open partnership, will be

inclusive and involve as many interested stakeholders as possible during the lifetime of the initiative. The JA AC will deliberate and decide on the method and terms by which potential partners can join the Action (as collaborating partners). The JA AC will meet six times during the life cycle of the project and will be convened together with the Partnership Steering Committee (see WP 10) and will report to the Open Forum (see WP 4). At every JA AC meeting, the WPLs will also present a progress report on their activities, milestones and deliverables vis-a- vis the work package. Members of the JA AC will communicate regularly using collaborative project management tools and the Virtual Partnership (see WP 2).

The main task of the SC is to review and confirm decisions made by the JA AC. The SC will therefore serve as an oversight committee and will literally 'steer' the Joint Action in regards to the Action's main objectives and anticipated goals. They will also review the results of all the WPs and make additional suggestions as to the course of action to be taken in the future. In this manner, diversions from the original goals of the Action can be avoided or more efficient methods of achieving goals can be found. One of the main responsibilities of the SC will be to oversee the progress being made in regards to National Cancer Plans (for full description, please see WP 10). The SC will consist of the Joint Action Advisory Committee, representatives of all Member States, representatives from Iceland and Norway, IARC, EOHSP, and industry and patient associations, as well as international organisations, the World Health Organisation Europe, EUREGHA, the European Commission and individual renowned experts.

The decision making process of the JA Governance Structure will be based on consensus and mediation. It will follow the principles of:

i. Inclusivity: involving stakeholders ;
ii. Participation: the consensus process will actively solicit the input and participation of all decision-makers;
iii. Cooperation: participants in an effective consensus process will strive to reach the best possible decision for the group and all of its members, rather than opt to pursue a majority opinion, potentially to the detriment of a minority;
iv. Egalitarian approach: all members of a consensus decision-making body will be afforded, as much as possible, equal input into the process,
v. Solution oriented: striving to emphasize common agreement over differences and reach effective decisions using compromise and other techniques to avoid or resolve mutually-exclusive positions within the group.

The sound management of the JA will require efficient coordination amongst the 38 associated partners and all of the collaborating partners and other key stakeholders. To ensure efficient and smooth communication the following tools have been established:

i. an e-mail address dedicated solely to the JA to ensure quick and effective communication;
ii. specific mailing lists have been developed according to specific work packages, tasks and responsibilities and can be easily updated as needed;
iii. the web-based platform Virtual Partnership will facilitate access and distribution of all the materials between partners and sharing of knowledge and resources (see WP 2);
iv. the partners will meet in person at 6 JA AC meetings, 4 JA meetings and 3 OFs (see WP4). To reduce the overall costs of the meetings, the 4 JA meetings will be combined with JA AC meetings and OF events;
v. the JA MT team will use standard collaborative software (hold audio conferences as needed, phone, e-mail) to communicate with parters;
vi. A Pyramid System will be used to communicate with WPLs, in which each WPL will communicate onwards with their respective partners.

Due to the extensiveness of the partnership and the complexity of the Action, the governance structure, coupled with the experience many of the partners possess by having already participated in EU projects, will ensure that the mechanisms will be ready to react if unexpected problems arise. The Joint Action management will therefore be based on the principles of rapid, direct and open communication. Effective

internal communication and a clear distribution of tasks should curtail the risks of WPs being diverted from their objectives and timelines. Due to the large number of associated partners participating in the Action, efficient financial management is of vital importance. The JA MT must therefore be informed of all spending, as regular cost reviews will be carried out. The JA MT will employ an external auditing agency, which will be both cost and time efficient in achieving complete control over budget expenditure and will aid the JA MT with their wealth of experience. Modules for financial management will be developed by the JA MT to ensure that a user-friendly system is in place to be used by WPLs which will enable regular reporting of the current state of budget expenditure (overall and WP-specific). The financial management tools will be ready for use within 3 months of the beginning of the Joint Action (M3). The JA MT's internal auditing unit will also review the documents before they are sent to the EAHC, ensuring that unnecessary and time-consuming errors are avoided. A financial report to be used at SC meetings will be prepared every 6 months in addition to the Interim and Final Reports, ensuring that the overview of budget expenditure is complete, with the goal of keeping the JA budget on track.

In relation with the work of this WP, an interim financial and technical report will be sent at M12+2, at M24+2 and a final financial and technical report will be sent at M36+2. These deliverables are presented in annexe Ia as Deliverable 1.

Work package number 2

The dissemination of all information related to the European Partnership Against Cancer (EPAAC) Joint Action will be performed through the creation of a specially dedicated website called the Virtual Partnership (VP). The VP will be one of the main EPAAC dissemination channels, though not exclusively so as it will be one of many different dissemination methods (details are listed under 'Dissemination Channels'). The VP will serve as both an internal and external communication tool, facilitating easy and rapid information sharing between partners and enabling members of the public and EPAAC stakeholders to be informed of all EPAAC related news. There will be less focus on printed material, except for the final EPAAC Joint Action Report including all conclusions and findings, which will be distributed to all partners and stakeholders (policy makers, cancer experts, academia, civil society, healthcare professionals, industry/patient/international health organizations). The VP will have a section with limited access that will be password protected for members of the EPAAC Joint Action consortium; this will enable internal communication within all the partners. The purpose of the internal section will be to maximize the efficiency of communication, either between EPAAC partners and the Partnership Secretariat or between Work Package leaders, etc. Additionally, documents will be posted on the closed section of the website, allowing all partners to quickly access administrative/financial documents and comment on how work is progressing in other Work Packages. Partners will have specific tasks in specific sections of the VP, in accordance with the Work Packages they are part of. It is proposed that the VP share the HEIDI (Health in Europe: Information and Data Interface) platform, set up by the European Commission and DG Health and Consumers. Confirmation of this and a detailed technical plan will be delivered in M10. The open section of the VP will be aimed at all EPAAC stakeholders and the general public, as well as media. It will have dedicated sections for selected target groups, allowing each target group (details will be specified in the dissemination plan to be delivered in M1) to be addressed with a different approach and with different information. While one of the main purposes of the VP is to inform the public on general cancer-related information as well as new research and conclusions of the EPAAC Joint Action, the VP will also include interactivity as one of its main focuses. As such, there will be opportunity for website visitors to give their opinions on the information posted or the Joint Action in general via the discussion forum, comments section of each press release/article and links to social networking sites (i.e. Facebook), microblogging platforms (i.e. Twitter) and links to media sharing sites such as Youtube. The VP will also give users the opportunity to share information using popular e-content sharing tools (i.e. Digg).

Specific features of VP closed section:

- Forum enabling partners to post documents and receive feedback,
- Download of documents posted by the Partnership Secretariat and access to all EPAAC Joint Action official documents/reports, conference books, meeting minutes, multimedia relating to conferences/EPAAC events; this will facilitate rapid editing and correction of documents
- Dedicated section for Open Forum, with links to agendas, agenda proposals, official Open Forum report and Open Forum multimedia content (all Powerpoint presentations presented, speeches given, video of important workshops, etc), to be posted 2 months after Open Forum event,
- Access management (i.e. password protected sections for each individual Work Package, enabling only partners participating in the Work Package to view the contents),
- 'Status' section, a quick link to the status of each Work Package. Each Work Package leader will be responsible for sending a quick status update to the VP administrators every two months, consisting of a few sentences on the progress of the Work Package, what has been done, what remains to be done, what deliverable/milestone has been achieved, etc. In this way, all EPAAC Joint Action partners will have a complete overview of the status of the project at several points throughout the year, increasing accountability and transparency.

Specific features of VP open section

The following features will be available for all target groups:

- General information on EPAAC, its goals, organizational structure, contact information (VP administration team),
- Sections for each Work Package, providing overviews of goals and deliverables/milestones, download of important documents/reports according to Work Package,
- Section on Open Forum, overview, minutes, download of presentations, reports and multimedia content,
- 'Search' capability, with capacity to search through all reports and documents for keywords,
- Section on 'EPAAC in the Media' with press clippings, press releases and interviews of key participants, footage of events.

Additional features according to target groups:

Target Group: STAKEHOLDERS (policy makers, cancer experts, academia, civil society, healthcare professionals, industry/patient/international health organizations)

- Recommendations given by EPAAC partners at the end of each Open Forum (compiled by Secretariat), with specific implications and guidelines for policy and legislation (altogether 3 documents over the course of the Joint Action)
- For healthcare professionals: guidelines on diagnoses, screening and other cancer-related information.

Target Group: PUBLIC, EU CITIZENS

- Information and statistics on cancer in Europe, comparison of statistics to other industrialized regions of the world, EU guidelines/actions in the field of cancer healthcare, links to portals with related content,
- General information on prevention, screening, symptoms of specific cancers – information will be provided by links to other related health portals

- Links to enable cross-posting and content sharing on common social networking and micro blogging platforms, such as Facebook, Twitter, Digg, etc..

Target Group: MEDIA

- Dedicated section for Media Training, with media training materials linked to the Open Forum workshop available for download,
- Capability of hosting online events for media, such as 'webinars' on effective reporting on cancer,
- Electronic Press Room, containing an archive of press releases and up to date selection of press releases based on results and conclusions of Joint Action.

Dissemination Channels

The internet will be used as the primary dissemination channel for all EPAAC Joint Action dissemination. The Virtual Partnership will be the main communication channel for external communication to stakeholders and the general public, as it will be cost-efficient and easily updated. It is requested that partners cooperate in the dissemination of specific documents related to their activities, such as the translation of important press releases in all national languages that are contained within the EPAAC Joint Action.

Alongside the VP portal, the EPAAC Joint Action will also actively disseminate relevant information and engage the general public using the social networking platform, Facebook, and the microblogging platform, Twitter, by creating dedicated 'profiles' and 'groups'. In order to increase the interest and awareness of the general public in EPAAC, proposed strategies include a competition with prizes and possibile celebrity engagement (either by donating prizes to give away or through endorsements, more direct contact with the content).

It is anticipated that printed material will be kept at a minimum. While the Open Forum will produce documents such as the Media Training Package and Official Report, these will be disseminated via e-mail and hard copies will be kept to a minimum. It is anticipated that there will be an Official Report of the EPAAC Joint Action issued after the conclusion of the project and this will be disseminated in hard copy to partners and stakeholders.

The media will be also be utilized as a dissemination channel – generally, journalists will be encouraged to access press releases and be informed of new results and conclusions of the EPAAC Joint Action as they become available. Where seminal EPAAC events are concerned (Open Forums), the Secretariat and the Local Organising Committee of Open Forum host countries will coordinate to ensure local press coverage of the event in broadcast, print and online media.

Another key dissemination channel will be the presentation of the EPAAC Joint Action at the three EPAAC Joint Action Open Forums and other related events, conferences, etc. The methods by which these presentations will be executed, i.e. who will be authorized to present the Partnership, official presentation slides, etc. will be decided upon during the first Steering Committee meeting in March 2011. The Project Management Team will also carry out dissemination of the Joint Action by attending relevant conferences and events, at which they will present and promote EPAAC; funds for dissemination at conferences have been allocated in the budget. Additionally, press releases and official documents generated by the Partnership will be circulated to various online portals (including some EU-operated) dealing with similar content to increase dissemination of information and promote synergy between related content. Other European based internet portals with related content will be contacted in order to arrange the presence of hyperlinks from other portals to the EPAAC VP, thereby increasing traffic to the VP. Usage and traffic will be monitored and

analyzed (source of reference, trends, etc.). Dissemination of content via social networks will also be monitored using URL shortener usage tracking, analysis of Facebook groups and Twitter activity. Specific methods for analyzing dissemination and obtaining tracking information will be delivered in M10 with the technical plan.

ORGANISATIONAL STRUCTURE

The organizational structure of the Partnership Communications Team will consist of the Work Package Leader, who will oversee all activities and the operational team, which will consist of three people. The operational team will be comprised by two communications experts and one IT manager. The communications experts will be responsible for the timely posting of all EPAAC related content on the VP, communication with all WP leaders and partners regarding content and the actual writing of content to be posted on the website and disseminated through other online communications channels and online social networks, and overall community management. They will also serve as the first point of contact for the press and parties interested in receiving more information on the EPAAC Joint Action. The IT manager will be responsible for the regular maintenance of the VP and will also serve as a content administrator for the open section, monitoring all public posts and comments before they are published.

The Editorial Board (EB) will serve as an oversight committee for the Partnership Communications team and will confirm significant decisions for the VP and dissemination. It is anticipated that the EB will consist of all WP leaders, individual healthcare and communications professionals and representatives of the European Commission. The EB will meet three times in the course of the Joint Action, namely once a year and will communicate during more regular intervals via audio-conferences and by telephone and e-mail.

The responsibilities of the Editorial Board are the following:

- to establish who is entitled to access the closed section of the Virtual Partnership,
- to decide on additional documents, links to be added to the Virtual Partnership, which are not products of the EPAAC Joint Action
- to establish the general rules for permissible content in the open section, establish rules for action for VP administrators,
- to establish, in conjunction with the Partnership Communications Team, a VP updating strategy, determining the intervals for updates and the content, according to WPs and target groups, to be updated,
- to be actively involved in the creation of new and innovative dissemination strategies for all the dedicated target groups of the EPPAC Joint Action and communicate them to the Partnership Communications Team accordingly and in a timely fashion.

A detailed plan for dissemination will be sent to EAHC at M2. The report on VP set up will be due at M12 (deliverable 2)

Work package number 3

Work in this package will be concerned with the assessment of the project's performance against the objectives defined in the overall project EPAAC (general level of the evaluation – delivered in the final evaluation report – month 36) and specified according to the objectives and deliverables of the particular work package (particular level of the evaluation – evaluation of the work packages in every year of the project's duration; midterm evaluation reports are expected to be delivered in the framework of 3 Open

Forum events). Timeline of the evaluation outcomes will be directly related to the milestones defined in particular WP. According to this timeline we will evaluate promised deliverables for particular phases of each and every WP (outcome of the project) and organisation of particular phases of each WP (process of the project). Methodology will be developed according to the specific deliverables of the particular WP and of the project as a whole. Deliverables are specified in description of every work package. We will evaluate: if deliverables were met according to the schedule (if deliverables are produced on time) and
if deliverables are developed and achieved to the satisfaction of the target group (certain evaluation will focus on external public, the one that is supposed to be a prime user of the developed application, tools etc; for example WP 5 promises cancer prevention campaigns: short standardised questionnaire will be developed to evaluate perceived usefulness of toolkits and guidelines for improving public awareness in cancer prevention, among a sample of national experts. The Process of the project will be evaluated through the study of management, coordination and organisational structure of the project. This will be studied with mixing methods (qualitative: semi-structured personal interviews and quantitative: standardised questioners (online survey)). We will study satisfaction of the participating partners with management and coordination of the tasks and their understanding of specific assignments in the framework of the particular WP with standardised questioner. In addition, midterm reports of each WP will be studied and compared with initial objectives and defined deliverables. Possible discrepancies will be discussed with leaders of the WP in question and with the EPAAC leader. Midterm evaluation findings will be presented and discussed with the EPAAC project partners in the framework of open forum events.
Main objective of WP3: to look for possible barriers and opportunities for the project's development and outcomes.
The research plan and methodology design for the process evaluation will be ready at M3. The Evaluation reports will be included in the financial and technical reports.

Core Work Packages - Description of the work

Work package number 4

Work plan of the WP:

The work of the Partnership will be presented and actions discussed in three annual Open Forum (OF) conferences over the life-cycle of the project. Each event will be organised as a high-level plenary of the European network of policy makers, cancer experts, academia, civil society, patient associations, health professionals and will provide a platform for all the members of the Partnership and other interested key stakeholders at EU level to deepen their understanding of the challenges of cancer for Member States. It is expected that the Open Forum will lead to the identification of common actions that can bring genuine added value to national efforts in combating the burden of cancer. The work package will also include the JA Partnership Secretariat, which will be the main support for the organisation of the Open Forum as well as support for JA AC and SC meetings. Each of the three events will be organised as a one and a half day event, planned to be held in Madrid, Spain (June 2011), Rome, Italy (May 2012) and Brdo pri Kranju, Slovenia (October 2013). Each event will be designed to host between 150-250 delegates, with high-level attendance from EU Member States expected. Each OF conference will provide the opportunity to showcase and discuss available results and the progress of all Work Packages. Space will also be provided for external stakeholders to present other relevant initiatives and results of relevant research and studies. Along with the presentation of progress and results of each Work Package, it is proposed that the Open Forums are thematic, focusing on two themes for each Forum:

- Open Forum 1, to be on Cancer Healthcare and Research

- Open Forum 2, to be on Information and Prevention
- Open Forum 3, to be on National Cancer Plans and Screening

The benefit of hosting thematic Open Forums is that different aspects of Work Packages will be highlighted, exposing different uses for the results EPAAC is producing. In this manner, each Work Package will present their progress as well as link to the theme of the Open Forum and present their conclusions thus far as they apply to the theme, highlighting guidelines and challenges for the future. The JA Partnership Secretariat will propose links between Work Packages and OF themes and set general parameters for content presentation (time, format) and send them to WP leaders for discussion and recommendations. Each WP leader will prepare a detailed plan of what they will report in regards to the OF theme and which speakers and resources they require or feel would benefit the OF. WP leaders will be responsible for coordinating with the partners in the WP and coordinating input for OF content. Communication between WP leaders, partners and the JA Partnership Secretariat will be held daily by e-mail, telephone and monthly by web/telephone conference with exchange of documents facilitated by the internal communication resource on the Virtual Partnership. The JA Partnership Secretariat will then coordinate content to be presented with individual partners and submit the content and draft programme to the JA AC and then to the SC for confirmation and input. Deadlines will be put in place to ensure the timely cooperation of WP leaders in contributing ideas and content for the OF, with final plans being submitted minimum two months prior to the conference.

The dissemination strategy for OF content will link with the overall EPAAC dissemination strategy (see Work Package 2). The multimedia content presented at the OF (audio, video, images) will be posted on the public section of the Virtual Partnership, where it will be available for download by interested stakeholders and members of the public and must be on the site 2 months after the OF, at latest. The official report of each OF will also be available for download on the Virtual Partnership and it is recommended that individual news/content items be taken out of the report and made into individual press releases that are simple and easily comprehensible to facilitate the dissemination of information to a wide public and ensure that mainstream journalists report on the event.

One of the integral features of the Open Forum is also proposed to be media training with health and science journalists from selected Member States, as part of an overall dissemination strategy to report more effectively on cancer control issues in their countries. Due to a low level of anticipated press interest at the beginning of the Joint Action (too few results/conclusions), the media training is set to take place during the 2012 Open Forum. This media training will encompass three elements: a one-day pre-conference workshop in the form of a training session for journalists from all EU Member States, scheduled one day prior to the Open Forum, a 'Meet the Press' event, allowing invited journalists to meet key speakers/participants, giving the press an overview as well as allowing for in-depth questions/interviews, and finally, a Press Pack containing information on EPAAC as well as a broad overview of cancer issues in general, to facilitate easier press coverage. Also alongside the Open Forum 2012, a conference on the 'State of the Art in Cancer Information' is planned by the Italian *Alleanza contro il cancro* (ACC) to take place as a side event one day after the conclusion of the Open Forum. Events during Open Forum 2012 are also planned by the European Cancer Leagues (ECL).

Quality control will be established using the PDCA model (Plan-Do-Check-Act) following the execution of the OF, in order to improve the next OF. An internal report will be written by the JA Partnership Secretariat to be submitted to the MT, JA AC and SC, noting the outcome of the event and reporting on any issues that may have arisen which are of importance for the next OF. In this way, the Secretariat will establish internal quality control and be accountable to the AC and the SC for the management of the event. External quality control, i.e. feedback from OF participants will be administered through questionnaires, which will be collected at the OF and analysed according to the following criteria: 50-70%- satisfactory, 70-80%- good,

80-90%- very good, 90-100%- excellent. Additionally, it is proposed that an online forum be created on the Virtual Partnership for comments and feedback, open only to the participants of the Open Forum. Risk management must also be provided and a list of all risks likely to be encountered along with their long- and short-term solutions created. This should be included in the complete OF detailed plan with complete agenda, to be delivered in Month 4.

The JA Partnership Secretariat will generally support the organisation and coordination of the Open Forum and will for each Open Forum meeting, Joint Action Advisory Committee meeting (JA AC) and EPAAC Steering Committee meetings, be responsible for: preparing the agenda of the event, coordinating invitations, liaising / communication with the speakers and participants, preparing the programmes, reports and conclusions and distributing reports and conclusions to the partnership and Virtual Partnership website. The Secretariat will generally provide expert and technical support to the work of the JA Management Team (JA MT) and JA Advisory Committee (JA SC) in coordinating the JA Partnership activities. It will support the organisation of all management team meetings and advisory committee meetings. It will liaise with JA partners, WPLs, and external stakeholders, ensure smooth internal exchange of information within the network (using tele-conferences, video-conference, e-mail, faxing, closed section of Virtual Partnership) and oversee external communication (Virtual Partnership website). It will facilitate exchange of information, foster relationships and synergies among different JA partners. One person will work full time to ensure this role. Collaborative project management tools and processes (e.g. document templates, mailing lists, databases, telephony, videoconferencing, web conferences, e-mail and faxing, electronic meetings) will be used to ensure smooth day-to-day running of the project. The main objective of the Secretariat is to promote and support good network structures and active involvement of a wide range of JA partners in the project.

The report of the 3 OFs will be included in deliverable 3due at M35.

Work package number 5

This Work Package has the overall aim of raising awareness about cancer promotion and prevention, especially among target groups in Europe, by disseminating the European Code Against Cancer using proven communication strategies and messages, and by engaging policy-makers at the European, national, and subnational levels. Actions will engage ECL cancer leagues and other dedicated partners in the joint effort to raise cancer prevention awareness and to reduce exposure to cancer risk factors, recognizing that "prevention offers the most cost-effective long-term strategy for the control of cancer", and that at least 33% and as much as 40% of all cancers are preventable. This work package on Prevention aims at effectively communicating the European Code Against Cancer (ECAC) messages, and to re-launch the successful European Week Against Cancer (EWAC) which took place across Europe between 1989 and 2005, which was a health promotion campaign originally organised as part of the European Commission's Europe Against Cancer Programme. ECL had coordinated the EWAC from 1999, and many ECL member leagues had been involved in the planning and implementation of the campaign from the start. The previous edition of European Week Against Cancer had assigned each year to a specific theme, and the programme itself has undergone some evaluations. This new edition will use the still-recognized Week with actions planned around promotion and prevention messages of the European Code Against Cancer, which has been underutlised and undercommunicated. Promotion will be focused on communicating the European Code Against Cancer (ECAC) messages. While much expertise and research went into the development of the Code, it has now been lost and forgotten. No recent literature is available on the Code. We will not duplicate or reinvent but gather how Member States are communicating promotion messages in an effective manner and use proven methods and strategies to communicate promotion and prevention messages related to ECAC. EWAC will be a vehicle for health promotion and prevention messages to be disseminated in Europe. EWAC will take place once a year, during the last week of May to also include 31 May designated as World No Tobacco Day. Each EWAC will be devoted to a theme, or set of themes, related to cancer

prevention in Europe and linked to the Code Against Cancer, and alongside each EWAC conference, a timely theme on tobacco control will be organised (e.g., pictorial warnings on cigarette packs, taxation, etc.) to coincide with World No Tobacco Day and to emphasise the importance of tobacco control in cancer prevention. ECL will work with other pan-European and global partners, to maximize resources and to reach out to as many European countries, regions, and cities as possible. Politically, it is aimed to engage the MAC II (MEPs Against Cancer II) group to support the efforts, with its new direction focusing on prevention and connecting the European, national, and subnational levels and with ECL providing the Secretariat for MAC II. It is expected that by providing a three-year kick-start of the European Week Against Cancer with an emphasis on promotion and prevention, actions will continue to take place as the EWAC would be well-recognized and noted each year with the help of ECL and other cancer leagues who would be encouraged to keep the EWAC alive, with ECL making this as a permanent part of its Strategy Plan. Annual conferences during the EWAC will showcase and share best practices and tools for raising cancer prevention awareness for European populations.

Work plan for each WP objective:
Actions for Objective 1: Raise awareness on the Prevention WP and the EPAAC and enlist support for our actions focusing on the importance of cancer prevention, among cancer societies, policy-makers, and pan-European partners with interests related to cancer and/or health.

1.1 Set up a WP Advisory Council (AC) to meet in December 2010, for the WP5 AC meeting to take place in month 1 (February 2011), when the ECL Executive Board will also meet, with AP and CP partners, coming from the following institutions:

(Associated Partners)
Italian Ministry of Health
Italian Cancer League (LILT)
Irish Cancer Society
Pharmaceutical Group of the European Union (PGEU)

(Collaborating Partners)
American Cancer Society (via audio conference)
Committee of the Regions, NAT
ECL Executive Board and other Member Leagues
Eurocare
European Cancer Patient Coalition (ECPC)
European Cervical Cancer Association (ECCA)
European Institute for Women's Health (EIWH)
European Network for Smoking Prevention (ENSP)
European Public Health Alliance (EPHA)
Federal Public Service for Health, Food Chain Safety and Environment, Belgium
Garnier International
IARC
International Association of Mutual Benefit Societies (AIM)
Lynn's Bowel Cancer Campaign
National Center of Public Health Protection, Bulgaria
Novartis
Pfizer
Smokefree Partnership (SFP)
The Health Promotion Foundation, Poland

UICC - Union for International Cancer Control
WHO EURO

The tasks of this Advisory Council will be to discuss how to measure baseline of cancer prevention awareness among public, to measure increased awareness and behavioural change at the population level and to agree on theme(s) of focus for EWAC, based on the European Code Against Cancer.

1.2 Consultant to conduct literature review, web search (month 1–February 2011) to identify existing campaign materials around Europe related to communicating the European Code Against Cancer, especially in relation to the last European Week Against Cancer campaigns.

1.3 Survey during month 1-2 (February to March) among ECL leagues and other organisations to:

i. identify materials used in communicating cancer prevention messages and the European Code Against Cancer
ii. identify prevention areas needing awareness-building ;
iii. engage survey expert or obtain expert advice to develop survey plan in month 1 (February 2011)
iv. implement survey plan and provide survey link with indications to provide baseline measure of cancer prevention awareness to be provided on ECL member league and perhaps other organisations' websites.

Actions for Objective 2: Re-launch a "prevention" version of the annual European Week Against Cancer (EWAC) which took place across Europe between 1989 and 2005 coordinated by ECL and cancer leagues, to take place in May of each year in the same week as World No Tobacco Day, with the theme of Health Promotion and Prevention, engaging policy-makers at the European, national and subnational levels.

2.1 The WP5 Prevention Advisory Council will agree on how the EWAC will be structured, including materials to be communicated and format and content of an event (conference).

2.1 A 1.5 day conference for kicking off EWAC will take place in May of each year in the same week as World No Tobacco Day, with the theme of Health Promotion and Prevention, engaging policy-makers at the European, national and subnational levels;

Actions for Objective 3: Optimise the use of existing simple but effective tools to communicate proven prevention strategies and campaigns, such as the European Code Against Cancer, in the development of media templates, toolkits and templates for adaption for use in Member States.

3.1 identify Consultant and interns to collect materials for the development of toolkits on agreed themes and target audiences for each year. The themes will be selected and defined by the WP5 Advisory Council when it convenes in Month 1 (February 2011) at the latest.

Based on the advice of the Advisory Council, a Cancer Prevention toolkit with templates will be developed for each year by the Consultant(s), ECL Director (who has experience developing health education toolkits) and with guidance from the American Cancer Society, in line with the themes chosen for that year's European Week Against Cancer.

3.2 The toolkits would be ready at least one month before each EWAC conference. The toolkits would be disseminated among the Member States for translation into their own contexts and

languages. They can be made available by 1) providing print samples at meetings and 2) making them downloadable on the ECL and partners' websites.

At least one toolkit will be developed each year. Depending on time and resources, several toolkits could be defined for specific target audiences and disseminated to reach those audiences:

- Politicians, via the MEPs (Members of the European Parliament) and national MPs
- Children and youth, via primary and elementary school-based settings identified via cancer leagues and other partners
- Women, via organisations dedicated to women's cancer issues
- Roma, immigrant, and other underserved populations, via leagues with connections to Roma and immigrant populations

Actions for Objective 4: Target vulnerable population groups, such as women, children, Roma populations. Target population groups could be women and children. For e.g., by engaging young people in their communities (such as ministries of education, local governments, schools) and via their platforms (such as the internet and social digital media channels) and by focusing on the special issues relevant to women (such as tobacco use and lung cancer).

The Advisory Council meeting in Month 1 (February 2011) will include on the agenda 1) identify what are the vulnerable population groups deserving special attention for WP5 actions and 2) how to reach and address these vulnerable population groups.

Agreed actions could include, for e.g., engaging young people in their communities (such as ministries of education, local governments, schools) and via their platforms (such as the internet and social digital media channels) and by focusing on the special issues relevant to women (such as tobacco use and lung cancer) and for Roma and other underserved populations.

Actions for Objective 5: Engage ECL leagues, Partnership partners and other networks to widely disseminate tools and other Work Package deliverables.

Communicate regularly with ECL member leagues and WP5 partners and their networks, committing them to help make available the actions of WP5, along with the templates and toolkits developed each year.

Final Product of WP5: The final product of the WP will be a report on perception and self-reported behaviour change of Europeans after the three EWAC campaigns, with recommendations on continuation or discontinuation of EWAC and/or other cancer prevention campaign activities.
In order to be practical and economically-realistic, baseline measurements will utilise European surveys already conducted prior to the EWACs. An attempt will also be made to have interns survey Belgian residents prior to the first EWAC conference taking place in Brussels 2011.
The dissemination channels (electronic, printed, etc) will be provided by ECL member leagues and all partners involved in the dissemination of ECAC messages over the last years. The main channels to reach European populations will be cancer league site visitors, journalists, general public through social media.

A report on baseline measurement results of cancer prevention awareness among EU populations (surveys' results, literature search) will be ready at M6. A report on perception and self reported behaviour changes of EU as result of the 3 EWAC campaigns with recommendations on continuation (or not) of the EWAC campaigns (or other prevention activities) will be ready at M36.

The deliverable of this WP (D4) will be evidence based cancer prevention toolkits and templates to be adapted for use by each MS. It is due at M27.

Work package number 6

The WP will improve implementation of the Council Recommendation on Cancer Screening by alleviating key barriers, to make screening of appropriate quality, as recommended by the Council of the EU, accessible to all citizens who may benefit. Further added value will be created by promoting synergy between cancer screening and other areas of early detection. A network of European Schools of Screening Management will be initiated which is dedicated to capacity building for implementation and improvement of population-based cancer screening programmes. The innovation is that comparable courses do not exist in Europe. A two-week course curriculum will be developed by experts from internationally recognized centers of excellence in 2011. An audit of one regional or national cervical cancer screening programme will be conducted in the planning process. The course will be piloted in 2012, by training at least 15 competitively selected participants from national and regional screening management units. A criterium of selection will be the likelihood that the participant will constructively work on implementation or improvement of cancer screening programmes in the next few years. This, along with with networking in order to develop certification, will promote sustainability of the results. The literature of inequalities in participation and compliance in screening programmes will be reviewed, and a survey addressed to the national or regional screening managers assessing the existence of inequalities in screening compliance and what kind of interventions have developed to reduce inequalities. Experience gained will be exchanged between regions to improve implementation of population-based breast, colorectal and cervical screening programmes. Health checks and periodic health examinations aim for prevention and early diagnosis of diseases in people who do not yet present symptoms. For many of these checks the evidence base is lacking, and many other established quality criteria for screening are not met. The experience in the Netherlands in developing quality criteria for health checks will be exchanged with other member states and initial consensus on pan-European quality criteria will be developed. The WP will establish links with the European Science Advisory Network for Health, European Network for Health Technology Assessment, and with the European Network on Cancer Screening and Prevention Programmes.

Work plan for each WP objective:

Actions for objective 1: To establish an intensive comprehensive training course in management of cancer screening programmes

1. Recruitment of experts in cervical cancer screening for audit: The work package leader will recruit the experts from the cervical cancer group in the European Cancer Network (ECN). The audit may also be performed by the work package leader who is an expert in the field and another expert from the Finnish cervical cancer screening programme, particularly if this is necessary to save time and expenses.

2. Conduct audit of a recently established population-based cervical screening programme completed: The audit will be performed by M10 according to criteria based on the EU Guidelines for quality assurance in cervical cancer screening. The audit is planned for a regional programme in Poland (Kielce) during the first year of the project.

3. Recruitment of experts for designing and conducting pilot course on implementation of population-based cancer screening programmes taking audit results into account. The number of experts is limited by the budget (4 to max. 8) depending on travel costs. Experts will be nominated by the project managment and by the other members of the senior management team recruited from leading

screening programme managers, trainers and scientists in Europe. They will be recruited from the European Cancer Network in which the European cancer screening networks have been consolidated. The experts will be recruited by M6.

4. Comprehensive, intensive 2-week pilot course on implementation of population-based cancer screening programmes: The curriculum will cover the generic scope of the EU cancer screening guidelines, i.e. the entire process of screening from invitation to follow-up diagnosis and treatment, as well as the overarching topics of quality assurance (documentation, monitoring, evaluation, training, implementation, communication). The project management will suggest a curriculum to be reviewed by the senior management team. The curriculum will be ready by M12 and will take into account experience in university post graduate training on screening evaluation and international courses on cancer epidemiology and cancer registration organized by IARC, as well as experience in implementation of population-based cancer screening programmes.

Actions for objective 2: To identify inequalities in cancer screening programmes

1. The Centro Superior de Investigación en Salud Pública (CSISP) will perform literature review on screening inequalities, to be completed by M3 and the descriptive report identifying the most important factors that have been associated to the inequalities in participation and adherence to the screening programs, M14;
2. CSISP will develop a small open-ended survey on inequalities in participation to screening programs by M15. They will identify, through ECN and EUREGHA, the survey respondents, 1-2 key persons from the screening programmes in each European country
3. CSISP will conduct the survey through email and telephone, with national and regional screening managers from each EU country as respondents by M21
4. CSISP will conduct a teleconference with 5 participants from WP6and 10 experts on cancer screening inequalities identified during the literature review. The objective of the TC would be to obtain recommendations on reducing screening inequalities, by M25.
5. CSISP will integrate the survey results and expert recommendations in a report by M34.

Actions for objective 3: To facilitate expert advice to regions seeking to implement or improve cancer screening programmes as recommended by the Council of the EU

1. EUREGHA composed of the Northwest England Health Office, VAZG and Veneto will organize 3 workshops on screening results; methodology; obstacles, improvement in colorectal, breast and cervical cancer screening programmes with the purpose of identifying how best to improve the implementation of existing programmes and to address setting up programmes, M14, M24 and M33. Those workshops will be hosted by one of the three regions each time. The participants are mainly the experts of national and regional population based cancer programmes. The content will focus on best practices for screening, raising awareness and the obstacles of implementation.

2. EUREGHA will set up a working group on cancer in order to support the JA but also to create synergies and exchange information on the work of the partnership. Membership of the working group is based on expressions of interest, according to call for interest drafted by EUREGHA. The

working group aims to broaden the cooperation with and amongst the members and is likely to meet at least once a year with its experts, M1

3. The workshops will have their own reports. However, each workshop will follow up on the outcome of the previous workshop. The work of the CSISP will be integrated in the workshops. The regions referred to in question one are the participants at each of the workshops and subsequently will be responsible for the drafting of reports. There shall be two proceedings reports to be undertaken between the three workshops. These reports (M18 and M36) will monitor the progress that occurs between and after workshops.

Actions for objective 4: To develop a pan-European consensus on quality criteria for health checks
Rationale: The Netherlands is at the moment in the process of preparing a national document on quality criteria for health check, under auspices of the Ministry of Health. This document is one of the source documents to be considered by the project team. Apart from the Netherlands also the UK, Ireland, Germany and Belgium have already expressed interest to participate in the project team. Many countries participating in the EPAAC have expressed interest to participate in the workshops

1. NEN will organize a kick-off meeting to plan the CEN Workshop (CEN Workshop Agreement-CWAs are consensus-based specifications, drawn up in an open Workshop environment. A CEN Workshop Agreement is a more flexible and timelier alternative to the traditional European Standard (EN), but one which still possesses the authority derived from the openness of participation and agreement inherent in the operations of CEN and its national members.) They will prepare the workshop business plan, select the project team, Workshop chair and designate the secretariat, M6.

2. The project team will distribute a survey on relevant source materials from the respective countries/organisations. In a preparatory meeting, the project team will also **r**eview source materials and prepare the first draft for workshop considerations, M9.

3. NEN, with assistance from RIVM / Netherlands Ministry of Health, will hold a CEN Workshop Agreement (CWA) which aims to reach a consensus on pan-European quality criteria for health checks. Participation in a workshop will be open to anyone, and the opportunity to participate will be widely advertised in advance by its proposers and by CEN and its member bodies), M17

4. The workshop project team / NEN will publish the draft workshop agreement to allow for inclusion of final comments and ensure consensus is reached on the content. The final, public draft of the workshop agreement will be published 30 days after the draft agreements are published, M22.

5. After the comment phase of 60 days, the final workshop agreement will be published, M24.

The deliverable related to this Wp (D5) is an intensive comprehensive training course in management of cancer screening programmes.

Work package number 7

Work plan for each WP objective:

Actions for Objective 1: To identify and assess best practices across European health services, promoting the exchange of experiences focusing on innovative organizational approaches, including patient's perspective.
1.1: To set criteria for identifying and assessing best practices, focusing on organizational approaches: multidisciplinary care and national and regional networks (Month 9). Methods: Review of published experiences, mapping of existing regional networks and workshop with experts.
The literature search regarding multidisciplinary care and networks in cancer care will be ready on Month 12 with the following keywords: Multidisciplinary care, team, networks, cooperative group, organization, and patient journey; databases to search in Medline and Cochrane database. The workshop with expected attendance will be 30 experts with published experience and representatives of the Scientific societies involved in cancer care in EU. The final product will be*:* Identification and assessment of best practices on organizational approaches in cancer care (ICO, NCOD, IPOS, EAPC, BMH, ECCO, Lombardia, ECPC).

1.2: To improve treatment, symptom assessment and follow-up of palliative care through a standardised assessment methodology (PRO) and evidence based guidelines (M18). Expert's agreement on key symptom assessment, implementation of standardized agreement in palliative care units and template for evidence based guidelines. Experts will be selected via membership lists of the EAPC RN and ESMO/ECCO with published research on the topic. The expected number of experts will be 30 with specific background in symptom assessment in palliative care. The product will be: Standardised assessment methodology of key symptoms and follow up for palliative care; Template for CG in Palliative care (NTNU, EAPC).

1.3: To disseminate and assess the standards of care for children with cancer (M16). International conference to increase policy awareness on standards of care for paediatric oncology will be organized. (M36) A conference is planned to take place on 20-21 October 2011 in Poland and will engage at least 70 participants from across Europe, consisting primarily of representatives from European paediatric and haematology units and Ministries of Health and Parent's Organizations. The National Consultant of Paediatric Oncology and Haematology in Poland was requested to lead this project in coordination with the Ministry of Health on reflection of his breadth of experience and expertise in this area. The event is organised in conjunction with SIOP Europe, the European Society for Paediatric Oncology, who have been working on creating standards of care through the pan-European SIOPE Board. The organisation's scientific expertise as the only pan-European organisation for paediatric oncology is essential to this task. Discussions at this high-level, multi-stakeholder event are likely to include: Different experiences of EU Member States on a range of services currently available for the care and treatment of children and adolescents with cancer in paediatric oncology and haematology departments and units across Europe; presentation of principles, through an intensive consultation process with the paediatric oncology community in Europe, of the organization of the complex care net of for children and young people with tumours and severe haematological diseases in different Member States; National and/or regional cancer registries; challenges concerning the staffing of paediatric oncology departments and current professional education opportunities; the primary elements required for the complex care and treatment of children and young people with cancer; the social care aspects of treating children and adolescents with cancer, in particular the requirement of continuous education throughout treatment; the role and importance of parent and patient organisations in the creation of the European Standards of Care for Children with Cancer and methods and tools to integrate the European Standards of Care for Children with Cancer guidelines in each individual country. Survey to Paediatric Oncology/ Haematology Treatment Centres**:** Following the collated data from a survey instigated by the SIOP Europe Board in 2008 on the state of care standards for centres treating children and *adolescents with cancer in Europe, it was agreed that* consensus on standards should be formed by a multi-stakeholder group of experts. The European Partnership for Action against Cancer will allow these standards to be disseminated across Europe and the SIOPE Board are keen to measure the effectiveness and interest in implementation of the standards in order to gauge any progress made since the original survey was carried out. The survey is expected to be carried out from M30 – M36 of the European Partnership against Cancer, allowing a period of

time for the standards to be disseminated to all relevant stakeholders. Most likely to consist of qualitative questions*, this panel study of the paediatric and adolescent units originally surveyed will be in electronic format.* Product will be*:* Standards of care for children with cancer in Europe (SIOPE, PMoH) and Report on the survey to Paediatric Oncology Units (SIOPE and PMoH).

1.4: To assess evidence and use of Complementary and alternative medicine (CAM) in cancer care and to propose criteria for dissemination of appropriate information (M24). Assessment of dissemination of CAM, review of the evidence (workshop) and mapping of the EU CAM in cancer care (survey). Two workshops are planned: the first with experts from a small number of centres with published experience in CAM in cancer (London, Locarno, Wien, Copenhagen, Firenze and Berlin) will define the criteria for literature search, survey definition as well as criteria for definition of the mapping the EU CAM in cancer care (M12). Survey to Cancer Units of Hospitals across EU to identify clinical activities related to integrative medicine. A map of the activities will be defined (M20). Workshop reviewing the evidence of the literature via Medline with the CAM therapies (herbal medicine, anthroposophy, homeopathy and acupuncture) will be reviewed. Also, interactions with chemotherapy will be analyzed. SIGN criteria will be used in grading literature. Experts form different EU centres (n=30) with published experience and representatives of scientific societies involved in cancer care will be invited to the final workshop in order to discuss the report. The final product will be: Use of CAM in cancer care, with evidence reviewed (RTI).

Actions for Objective 2: To develop, review and harmonize Clinical Guidelines (CG)

2.1: To develop new nutritional evidence based CG for cancer patients (M24). The methodology will be to contact Experts, patient groups and scientific societies with expertise in nutritional cancer care. Panels of experts will be appointed to address specific topics which will represent chapters of the CG (i.e., nutritional support during active treatment, nutritional support in the palliative phase, etc…). The literature will be searched via Medline following a strategy consisting in the assessment of clinical trials published in international journals and involving patients with cancer receiving nutritional support or describing the clinical effects of malnutrition on cancer patients' outcome. Literature search and writing of the first draft of the CG will be accomplished during the first 12 months of the project (M12). In M24 of the project, the draft will be circulated among experts worldwide and comments/criticisms received will be incorporated in the CG. The methodology to develop the guideline will be the Delphi procedure. Nutritional CG for cancer will be then circulated among cancer centres in Europe, and their implementation will be assessed via online survey. Product will be: Nutritional CG for cancer (ESPEN).

2.2.: To promote harmonization of CG focused on rare cancers (M24). To map existing networks of rare cancer tumours and patient groups (survey), to explore agreements and discrepancies and to review current clinical practice (workshop). Clinical practice guidelines on rare adult solid cancers across the EU will be mapped centrally with the information provided by ECCO and ESMO. Clinical leaders of these CG will be invited to a workshop. Ways to collaborate on a regular basis will be discussed in the workshop. Web-based tools will be developed, to guarantee sustainability of the process for the future. A preparatory work on major inconsistencies, if any, will be carried out, and the results discussed in the workshop. At the minimum this will result in awareness of such inconsistencies. At best, this will result in progressive harmonization of the content of the recommendations in the CG. Products: Map of the networks for rare cancers in European Health care systems, as well as patients associations (INCa, ESMO, ECPC) and Report on feasibility to harmonize Clinical Guidelines at EU level (INCa, ESMO, ECCO, ECPC)..

2.3: To review experiences on implementing CG, with a focus on inequalities (M20). To review successful implementation and barriers of CG in cancer care, with a focus on addressing health inequalities (workshop).). The literature on implementation of CG in cancer care will be reviewed, and key themes on barriers to CG

implementation identified. A particular focus will be to identify any examples of implementation of CG that addresses health inequalities, for example in access to healthcare. The evidence will be discussed and disseminated through an EU level expert and stakeholder workshop The results of the workshop will be published as a report. Product: Report on implementing clinical guidelines in cancer care with a focus on addressing health inequalities (EONS, EHMA) (M22).

2.4: To develop a guide for effective implementation of CG and self-assessment tool for organizations (M30). Methodology: EONS Putting Evidence into Practice (PEP) project is the European translation of existing USA clinical guidelines for cancer symptom management for nurses http://www.ons.org/Research/PEP. These guidelines and assessment toolkits provide evidence for assessment and management for use by nurses and practitioners at a local health service level. EONS has developed a partnership with the USA team, negotiating a licence and supporting tool development via provision of expertise, translation and implementation. The guidelines will be evaluated and modified into a European format by a panel of European clinical experts provided by EONS, translated into 8 European languages and disseminated to nurses. This EU project supports workshops on how to implement better cancer symptom management using CG and will be conducted in 3 countries linked with discussion of barriers and difficulties of using CGs as well as exemplars of implementing change through guidelines. Product: Guide for effective implementation of clinical guidelines in cancer care (EHMA and EONS).

Actions for Objective 3: To implement a training strategy to improve psychosocial and communication skills among health care providers

3.1: Mapping of needs and resources in communication skills and psychosocial care (M18). Web based survey to map the needs and resources and report with experts input description of the survey: web based survey aimed at national health institutions, organizations and scientific societies responsible for cancer care and education with a detailed assessment of the need and resources involved in psycho-oncology as well as in communications skills training needs and activities developed in EU countries. Product: Mapping of needs and resources in communication skills and psychosocial care (NCOD, HOPE, IPOS, ECPC, EOHSP).

3.2: To implement three training pilot workshops for improving communication skills and pychosocial care (M36). To develop a training tool in communication skills and psychosocial care tested in three selected countries with low resources in this area. Development of the training tool in a workshop with IPOS experts to design a pilot educational programme, based on the detected needs in objective 3.1. Three countries with high needs identified will be contacted through country representatives in the Partnership in order to agree to implement a pilot training programme. Product: Report on the outcomes of the training workshops in communication skills and psychosocial care (NCOD, IPOS).

The deliverable of this WP (D6) will be a report on "Mapping the landscape of cancer care in Europe", due at M34.

Work package number 8

In spite of the impressive pace of cancer research, translating basic discoveries into new and more effective prevention tools, treatments and diagnostics remains complex and difficult to manage. Knowledge breakthroughs take years, if not decades, to be translated into improved outcomes for patients and this requires organization, communication and cooperation among scientists, clinicians, healthcare professionals, science policy makers, industry, patients and society at large.
Today, priorities and funding for cancer research are frequently set at the national or local level in the European Union's 27 Member States and as a result there is tremendous heterogeneity between approaches and financial resources. Moreover, organisations that provide funding for research, including national

medical research councils, charities, European institutions, and private sources, add to this confusion with their differing requirements, goals, and restrictions. Lack of coordination translates into duplication of research efforts, which leads to waste of time and resources, and severely limits Europe overall progress in the fight against cancer.
Thus, it is urgent to improve collaboration in cancer research across Europe and to identify gaps within the cancer research continuum where coordination is essential. Previous work conducted by the Eurocan+Plus project recommended that Europe should aim at building bridges between research domains to achieve significant impact and encourage innovation. Following these recommendations, this WP will addresses existing limitations by bringing together MS/AC, NGOs including patient organisations and healthcare professionals, industry and other stakeholders in the cancer research continuum, with the aim of developing a concerted approach to achieve coordination of one third of research from all funding sources by 2013 within selected areas of cancer research.

Work plan of the WP:
The following actions will be taken:

1. Questionnaires aimed at MS/AC, NGOs including patient organisations and healthcare professionals, and industry will be prepared and distributed in order to identify and prioritize areas for research coordination. The questionnaires will make use of the classification system of the Common Scientific Outline (CSO, http://cancerportfolio.org/cso.jsp) which would help compare research priorities of the respondents by using the same validated and controlled vocabulary. The questionnaires, which will be prepared in collaboration with all the associated partners, will take into consideration available information from previous and ongoing national and EU initiatives to create synergies and avoid redundancy. The most appropriate methodology for questionnaire analysis will be discussed and agreed upon by all partners (for example, the use of a matrix approach on important overarching themes or priority listing through consensus workshops following a 'collection of research priorities').
2. The results of the questionnaires will be discussed at the meeting to be held in Rome (month 11) in preparation of the first Research Forum. The consolidated elaboration of questionnaires results will be then presented at the Research Forum in Brussels (month 14) were researchers, MS/AC, funding organisations, programme managers, and other stakeholders will identify common areas of research priorities and will discuss proposals on main areas that could potentially be coordinated. The WP will pro-actively work towards engaging as many MS/AC and funders as possible in order to secure a critical number of areas that will be followed up and serve as pilot projects.
3. Based on the outcome of the Research Forum, and particularly on the mobilisation of the MS/AC and funders, a road map for implementing research coordination in selected areas will be prepared during a follow up meeting in Paris (month 17).
4. The road map will be further discussed at a workshop that will take place in Madrid (month 21). In this workshop MS/AC, funding bodies, researchers and other stakeholders will discuss key challenges posed by the identified cancer priorities to be undertaken in collaboration, and will work on the preparation of pilot projects in the selected areas.
5. A follow up meeting in Valencia (month 30) will gather those MS/AC and funding organisations willing to participate to the pilot projects. The aim is to prepare the launch of the coordinated action in selected area(s) of cancer research.
6. The general outcome will be presented at a second Research Forum that will take place in Amsterdam (month 33). The pilot projects will be presented as well as possible paths to achieve and sustain future coordination in key areas of cancer research.

Throughout the duration of the project, associated partners will be in contact through monthly teleconferences and email. Collaborating partners will be also involved in the discussions when appropriate.

The sustainability of research coordination in the selected areas will be key to their success, and as a result

we will strive to look at existing and novel funding instruments that may secure the continuity of the research coordination. To this end, from the early stages of development of the work, we will pro-actively engage all partners in policy issues that address long-term financial mechanisms at the Commission, Member States and the European Parliament level. Moreover, we will identify areas of common interest that may generate public/private partnership.
The deliverable related to this WP (D7) "Identification and prioritization of areas for research coordination and subsequent practical implementation" will be due at M36.

Work package number 9

European funded projects, such as EUROCHIP and EUROCOURSE, have identified the priority information needed to support policy action on cancer control. Such information is however still far from being available at a Europe-wide level. The **main objective** of this Work Package is to build a comprehensive cancer information system for the European Union.
The WP will bring together the main actors involved in the provision and the use of cancer information: national and regional governmental institutions, cancer registries, research institutes, international institutes, European networks, patient associations, media and citizens representatives. During the first year, the health information needs will be reviewed according to three main areas: data collection, data analysis, and information diffusion and dissemination. A thematic map will be built of ongoing activities on cancer information to identify overlaps and points of weaknesses. Following this first activity and through the entire time frame, the WP activity will be aimed to support actions that can satisfy the most critical needs. During the second year a conference will be organized in Italy within the Open Forum, aimed to reach an agreement on the priorities identified and to propose the main objectives of the subsequent 2014-2020 programme.
Aims of the WP:

1. To map the main sources of cancer data in Europe and to identify the priority topics to be supported by the Partnership.
2. To unify under a common platform cancer burden indicators (incidence, mortality, survival and prevalence) provided by existing European activities.
3. To promote a European task force aimed to discuss the need for data on cancer costs and to produce an inventory of relevant available information.
4. To initiate a development of a standardised approach to the routine collection of data on survivorship using population based cancer registries.
5. To develop an inventory of statistical methods to analyse population based cancer data.

Work plan for each WP objective:

Actions for Objective 1: To map the main sources of cancer data in Europe and to identify the priority topics to be supported by the Partnership
The health information useful to support policy action on cancer control has been identified by EU projects, but presently it is not sufficiently available at a Europe-wide level. The main scope of WP9 is to contribute building a shared, advanced and comprehensive cancer information system for European Union.
Cancer registries are the most important population based source of data, and many efforts have been spent to monitor and improve the quality and the coverage of the information they provide. To comply with this aim, the main issues to be taken in account are: geographical coverage, data quality, establishment and spread of best practice, collection of clinical data on stage and treatment, provision of up-to-date data, long-term follow-up, needs and obstacles to registration activities, particularly regarding sustainability and privacy legislation. The activities of cancer registries in Europe have been coordinated since 1989 within the European Network of Cancer Registries (ENCR).
WP9 is not planning to duplicate already funded activities, but to maintain a close coordination with ongoing activities on this topic in order: i) to report the Partnership on the progresses made; ii) to optimise the use of

cancer registries data for pursuing the other Partnership objectives; iii) to integrate cancer registry data with other sources of information, such as health care system, demographic, socio-economic data. Other sources of data exist in Europe, potentially able to provide relevant information, per se or cross-analysed with cancer registriy data. Statistical Institutes provide data on population structure by age, sex and geographical area, population projections in the future, and general and cause specific mortality. They also collect data on socio-economic variables in European countries and regions that are associated with outcome of health care activity. Administrative sources can potentially provide data on cancer care infrastructures (eg. density of general and specialized doctors, density of imaging machines, number of radiotherapy units, etc), and on drugs and other resources provided for cancer care.
Cancer Institutes often maintain data bases that could provide very detailed, even if not always population-based clinical information.
WP9 will map the existence within Europe of these various data sources, and will check on the availability and the quality of these data. A European map of cancer information will be built, using the indicators identified by EUROCHIP and ECHI. The map will identify areas of data availability and data needs. INT will act as the focal point for this task, carrying out a systematic research of the information presently available, identifying strengths and weaknesses, and drafting a document that will be discussed and approved by all partners in a joint meeting. During the second year, a meeting, organized in collaboration with ACC and with the participation of all partners, will provide proposals and recommendation for the next programme of Community action (2014-2020) in the field of Cancer Information. ACC will be charged to organize this meeting

Actions for Objective 2: To unify under a common platform cancer burden indicators (incidence, mortality, survival and prevalence) provided by existing European activities.
The availability of the main **cancer burden indicators** (incidence, survival, prevalence and mortality) is presently very heterogeneous in Europe. Incidence rates are provided from population-based cancer registries data and are then centralized and regularly published by IARC. Survival rates are currently provided at the European level, by region, country and registry area, by the EUROCARE network and related projects (HAEMACARE, RARECARE). Prevalence can be in principle obtained from cancer registries data. While prevalence data are available from Nordic countries and theoretical estimates of 1-yr and 5-yr prevalence will be provided in Globocan 2008, the most recent European comparative and observation-based data are those pertaining to 1992, provided by the EUROPREVAL project. Mortality data are collected at the national level by official death certificates. Cancer mortality statistics by country and registry area are organized and diffused by IARC. No coordination exists for consistent provision of these indicators as regards definitions, periods of reference, pace of updating, data sources and methods of analysis. High Resolution studies with detailed clinical information collected on representative samples of cases collected by cancer registries are in course or planned in several European countries (such as France, Italy, Spain, UK).
WP9 will bring together all the existing partners working at the pan-European level on cancer burden indicators to coordinate the analysis and provision of incidence, mortality, survival and prevalence rates estimated in European populations. Updated incidence and mortality data will be made available in the framework of current activities being undertaken by IARC/ENCR. Data from HAEMACARE and RARECARE will also be considered. Population survival, and sample high resolution data on stage and treatment from cancer registries, will be available by INT (FP), with ISS through the programme of the EUROCARE projects. Prevalence data will be provided, mainly from EUROPREVAL with the contribution of other sources of data, and this task will be developed by ISS (FP), in collaboration with IARC, INT.

A working group will be convened, including IARC (responsible for incidence and mortality statistics), INT and ISS (responsible for survival, high resolution studies and prevalence statistics), and ENCR, to agree common definitions for cancer sites, geographical areas, age classes and time periods. All these indicators

will be disseminated through the EU web portal and the Partnership web-site, using the facilities developed so far with the European funds. IARC will be responsible for dissemination of these standardized results.

The high resolution studies are a necessary complement of survival statistics. These studies are aimed to explain the differences in cancer survival across areas and overtime, through the collection of more detailed information than that routinely available to cancer registries on tumour stage at diagnosis, clinical characteristics, diagnostic examinations, treatment and clinical follow-up, using representative samples of incident cases. Between-country coordination of high resolution studies will be made to provide supplementary data useful for the interpretation of survival differences as well as indicators of standard care for cancer (eg. proportion of patients treated in accordance with guidelines). This task will be developed by INT, with the collaboration of ISS, ENCR and other stakeholders (clinical networks, oncological institutes)

Actions for Objective 3: Task force on population-based cancer cost investigation in Europe

Cancer incidence is increasing and fortunately prognosis is also tending to improve. Basic, pharmaceutical, clinical, diagnostic costs are increasing faster than the available resources of most countries. Consequently costs are a fundamental aspect of cancer control. However population-based cancer cost analysis are rarely performed at European level. Standardized and comparable data are scarce. The Joint Action will organize, at European level, a task force to discuss and reach consensus on comparability of available data and on common methodology to collect cancer cost data. The task force will include cancer experts, epidemiologists, health planners, economist and stakeholders. Task force will produce:

a) inventory of ongoing, reported and published population-based studies on cancer costs in order to evaluate the comparability of available data across Europe. Studies considered can be at aggregated level (considering cancer cost estimates nationally) or at individual level (collecting data on cancer costs in samples of cases preferably from cancer registry datasets);
b) discussion on best methodology to be applied in order to collect comparable data on cancer costs at population level across Europe;
c) regression analysis between socioeconomic indicators and cancer outcomes in order to study correlation between economy and cancer outcomes;
d) discussion on which deprivation index (derived from national census data) can be used in various European countries to estimate cancer survival by social class.

Associated partner involved in the Task Force are INT, OECI, ERI3 INSERM, INRC, VEC. Moreover the task force will collaborate with OECD and IARC.

Actions for Objective 4: To initiate a development of a standardised approach to the routine collection of data on survivorship using population based cancer registries.

Survivorship covers the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. Survivorship research focuses on the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase. Survivorship research addresses quality of life of cancer survivors and their families and caregivers, including social, familiar, sexual and emotional aspects. Information useful to study survivorship also includes issues related to the ability to get health care and follow up treatment, to late effects of treatment. A standardised approach to the routine collection of survivorship data using population based cancer registries in various European countries will be studied, taking into account existent European experience and proposals. This task will be carried out by INT (Focal point), in collaboration with patients' organizations (FAVO, ECPC), international and national networks (OECI, ACC) and stakeholders.

Actions for Objective 5: To develop an inventory of statistical methods to analyse population based cancer data.

Sound statistical analysis is important for the full exploitation of population based cancer data. Many excellence experiences exist in Europe for the various fields of statistical analysis, such as trend and

projections analysis, national estimates of incidence in countries with limited registry coverage, survival analysis, prevalence estimates, cross- analysis between incidence and survival indicators and Health Care System and socio-economic indicators, and so on. Such experiences are sparse in many countries, are generally funded by national programmes, and usually work independently. The establishment of a European network on data analysis will allow to better coordinate the efforts, to provide scientists with wide pan-European datasets, and to start build a European capacity for statistical analysis, projections and forecasting epidemiological cancer indicators.
A panel of experts in population based data analyses, projections and forecasting will be identified by ISS and IARC in consultation with ENCR and other subjects. ISS will be the focal point of this action, in collaboration with with ENCR, FRANCIM, IARC, IKNE, INT

A report on data availability in 27 MS (+ other countries) will be ready at M12; a report on harmonisation of cancer burden indicators will be ready at M24; a report on the inventory of statistical methods to analyse population based cancer data will be ready at M24; a report on methodology to estimate cancer costs in Europe will be ready at M30; a report on methodology for the routine collection of survivorship population-based data will be ready at M32.
The deliverable linked with this WP (D8) "reports on cancer incidence, mortality, survival, prevalence and cancer costs in Europe" will be due at M36.

Work package number 10

A National Cancer Plan (NCP*) is a public health programme designed to reduce the number of cancer cases and deaths and improve quality of life of cancer patients, through the systematic and equitable implementation of evidence-based strategies for: prevention, early detection, diagnosis, treatment, rehabilitation, palliation and research to search for innovative solutions and evaluate outcomes. It is designed with the aim of making the best use of available resources. During the design of a comprehensive NCP an evaluation of the various ways to control cancer is undertaken and the plan will then incorporate and promote the implementation of those measures that are considered to be the most cost-effective and beneficial for the maximum number of persons in the population and according to the specific situation of the nation and the resources (present and planned) at its disposal.
A NCP:
- promotes the development of care management guidelines,
- places emphasis on the prevention of cancers or early detection of cancer cases so as to increase the possibility of cure and better control and faster return to pre-diagnosis life, and
- plans for the provision of services that will seek to offer as much comfort as possible to patients and their carers with advanced or incurable disease. A well-conceived, well-managed national cancer control programme:
- lowers cancer incidence and mortality
- improves the life of cancer patients, no matter what resource constraints a country faces.
NCPs are also an effective tool for the communication of the decisions and the plans identified and chosen by a Member State and the evidence supporting and influencing them in a transparent fashion both to public within the Member State and also with and between other members of the European Union.
Controlling cancer in Europe will require the investment of substantial resources and the effective coordination of national policies. In a study published by WHO in 2004 it was shown that there are notable 'performance gaps' in the cancer control programmes operating in different countries in Europe. Europe is still characterised by unacceptable inequalities in cancer control both between and within Member States. These can be exemplified by the widely-diverging cancer survival rates published in the EUROCARE studies.
Since the beginning of the 21st century a number of EU Member States have started to develop, publish and implement NCPs. The Communication from the Commission of 2009 on Action against Cancer pledges that

by the end of the Partnership, i.e. by 2013 all Member States will have adopted integrated cancer plans.
However, several EU Member States are still in the process of developing their first ever plans and some others have not yet started such a project. Nonetheless, to date, only a small number of Member States are already in the process of evaluating their first cancer plans and re-issuing a revised plan to cater for the next few years. Notwithstanding this apparent progress, inconsistencies and heterogeneity also abound with regards to the content of these national plans. A recent systematic assessment of the National Cancer Control Plans available in Europe in 2009 showed that despite the growing number of plans in Europe (19 in the 31 countries studied), significant differences remain between them. A major source of concern is the fact that in many cases, elements crucial to a health systems approach and to the efficacy of the plans such as financing, resource allocation or governance were missing or inadequate.
WP 10 is aiming at establishing the state-of-play in the development of NCPs in the EU, at conducting an analysis of the content and an evaluation the effectiveness of the extant plans and ultimately at facilitating the transfer of knowledge and expertise obtained on the design, challenges encountered, implementation and outcomes of NCPs between the EU Member States.

Work plan of the WP:
Initially, a questionnaire will be circulated that will: screen the present state-of-the-art of the NCPs in the member states (MS), explore MS's own positions on their own NCPs and review structures of the existing NCPs. Circulation of the questionnaire is supposed to take place in the first week of January 2011.
Questionnaires from all MS, Norway and Iceland will be analysed based on their adherence to the WHO guidelines for NCPs, inclusion of structural and process indicators and based on the MS' self-assessment of the situation. In the second step, structures of all NCPs will be reviewed. A summary report will follow up on that work.
In the evaluation of the content of the NCPs the following will be screened and analysed:

1. Adherence to the WHO guidelines on NCPs
2. Inclusion of process and outcome indicators in the NCP
3. Milestones for intermediate evaluation and progress reporting
4. Presence of economic evaluation of each step and each component of the NCP and a solid financial plan to support the implementation of the NCP

Benefits of the NCPs should be based on:

1. process and outcome indicators (intermediate indicators such as attendance rates at screening programmes can be taken into account)
2. improved access to cancer care (shorter waiting lists, shorter time from diagnosis to treatment, etc.)
3. comprehensiveness of measures and their assessment
4. self-assessment within the MS

WP10 should also help in determining which topics/areas/components/chapters of a NCP are necessary as these should then represent a template, which should serve for assessment at the national level as well as internationally, principally obviously within the EU and EEA. Priority areas should serve as the core of a NCP, possibly leaving some other areas as options, but this should be left to the project to determine. Discussions within the Working Group and the Steering Committee should be oriented towards receiving feedback, suggestions and guidance. Outcome indicators for the NCPs should be: organisational improvements in cancer management – e.g. introduction of reference centres, adoption of guidelines, etc., new organised screening programmes successfully introduced – based on their structural approach but also based on the adherence to the screening programme, improved access – shorter waiting lists, shorter times from diagnosis to treatment. Guidelines for NCPs should be prepared within this WP, taking into account 'best cases' as guidance for those: who have achieved less than optimal results, those who lack a comprehensive NCP and those who would like to restructure it. Guidelines should include approach to all the

key areas of cancer management and the modes of introducing the different interventions. At the end guidelines should include a structured template that would serve as guidance in checking own NCP against (not really a recipe for setting up an own NCP from scratch!). WP10 will define specific indicators to be evaluated for the assessment of NCPs. These indicators should serve both at the national as well as for an international comparison and be used as a basic evaluation/assessment set.

Work on NCPs will be organised on three levels and two special working bodies will be established and constitute the structure for 2 of these levels. Work, that will be done by partners from the WP 10 (Belgium, Ireland, Italy, Malta and Slovenia) on the so called first level (preparation of the background documents, questionnaires, analyses etc.) will be reviewed and completed by the organisations on the second level (Working Group on NCPs). Finally, on the third working level, Steering Committee of the Partnership will review the work done on second level and adopt the final decisions.
Working Group (WG) for the NCPs will include representatives of:
- all Member States,
- Iceland and Norway,
- WHO Europe,
- EUREGHA (European Local and Regional Health Authorities) and
- EOHSP (European Observatory on Health Systems and Policies)

. **Steering Committee (SC) of the Partnership**, as the cover body will include:
- representatives of the European Commission,
- members of the Working Group,
- members of the SC of the Joint Action EPAAC and
- representatives of IARC (International Agency for Research on Cancer), the EOHSP, ECPC (European Cancer Patient Coalition), a representative of an industry association and
- individual renowned experts.

* documents covering health system and security in the field of cancer even if named differently

An overview of the current states regarding NCPs in MSs Norway and Iceland will be ready at M12.

The deliverable linked to this WP (D10) "Prepared guidelines and specific indicators for NCPs" will be due at M36.