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REPORT FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS

Implementation of the Communication from the Commission, from 24 June 2009, on Action Against Cancer: European Partnership [COM (2009) 291 final] and Second Implementation Report on the Council Recommendation of 2 December 2003 on cancer screening (2003/878/EC)

EXECUTIVE SUMMARY

Cancer is a key public health concern across Member States and a central priority of EU health policy. In December 2003 the Council adopted the **Recommendation on cancer screening**[1]. In June 2009 the Commission adopted the **Communication on Action Against Cancer: European Partnership**[2]**.** This report summarises the main achievements in the fight against cancer in the EU in the framework of both initiatives towards the target to reduce cancer incidence by 15% by 2020.

- **Leadership:** The vast majority of Member States – 24 out of 28 - met the target of producing a National Cancer Control Plan (NCCP) before 2013.
- **Support to Member States**: through a Joint Action under the Health programme, guidance for Member States on establishing national cancer plans and on cancer care has been developed. A new Joint Action launched in 2014 will lead to a European Guide on Quality Improvement in Comprehensive Cancer Control. The Directive on the application of patients' rights in cross-border healthcare provides further opportunities for increased cooperation through European Reference Networks between healthcare providers and centres of expertise.
- **Prevention**: The fourth version of the *European Code Against Cancer* supported by the European Commission through administrative agreements with the International Agency for Research on Cancer will be launched soon.
- **Screening**: Based on current projections, well over 500 million screening examinations for breast, cervical and/or colorectal cancer will have been performed in publicly mandated programmes in the EU between 2010 and 2020. European Guidelines for quality assurance in screening and diagnosis have been produced for breast cancer (2006, supplements 2013), cervical cancer (2008, second edition 2014) and colorectal cancer (2010).
- **Quality assurance**: The Commission is developing a Quality Assurance scheme for Breast Cancer Services based on the European legislative framework.
- **Research**: During the last seven years, the EU has invested more than €1.4 billion in research efforts in relation to cancer. More than half of this budget - €770 million – has been invested in collaborative research projects to find new ways of fighting cancer and supporting patients.
- **Cancer information:** In 2012, the European Commission's Joint Research Centre was made responsible for coordinating the European Cancer Information System and acting as repository of European Union data and tools.
- **Coordination**: To improve the coordination of the range of cancer initiatives at EU level, the European Commission has established a European Union Group of Experts on Cancer Control in 2014.

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[1] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2003:327:0034:0038:EN:PDF

[2] http://ec.europa.eu/health/ph_information/dissemination/diseases/docs/com_2009_291.en.pdf

1. PREFACE

1.1 Introduction

On 2 December 2003 the Council unanimously adopted the **Recommendation on cancer screening**[3] (hereafter **the Council Recommendation**)which acknowledges both the significance of the burden of cancer and the evidence for effectiveness of breast, cervical and colorectal cancer screening. The Recommendation calls on Member States to take common action to implement national population-based cancer screening programmes with appropriate quality assurance, in accordance with European best practice guidelines. It further invites the European Commission to report on the implementation of cancer screening programmes, to consider the extent to which the proposed measures are working effectively, and to consider the need for further action. In 2008 a first Implementation report on the Recommendation[4] was published, covering the period 2003-2007.

On 10 April 2008, the European Parliament adopted a resolution on combating cancer in the enlarged EU, and Council conclusions on reducing the European burden of cancer were adopted on 10 June 2008. On this basis, the European Commission adopted on 24 June 2009 a **Communication on Action Against Cancer: European Partnership**[5] (hereafter **the Commission Communication**) to support the Member States in their efforts to tackle cancer by providing a framework for identifying and sharing information, capacity and expertise in cancer prevention and control, and by engaging relevant stakeholders across the European Union in a collective effort. According to point 3.1 of this Communication, a report on the work undertaken will be submitted by the Commission which will **constitute a basis for determining future EU action on cancer**.

1.2 The burden of cancer in the European Union

There were just over 2.6 million estimated new cases of cancer (excluding non-melanoma skin cancers) in the European Union (EU27) in 2012[6], 54% (1.4 million) occurring in men and 46% (1.2 million) in women.

The most common cancer sites were breast (364,000 estimated cases, 13.8% of all cancer cases), followed by prostate (359,000, 13.7%), colorectal (342,000, 13.0%), and lung cancer (309,000, 11.8%). These four cancers represented half (52.3%) of the estimated overall burden of cancer in the European Union in 2012.

The most common primary sites in men according to 2012 estimates were prostate (25.1% of the total), lung (211,000, 14.7%), colorectal (192,000, 13.4%) and bladder (96,000, 6.7%). In women, breast cancer was by far the most frequently diagnosed neoplasm *(364,000,* 30.4% of the total), followed by colorectal (151,000, 12.5%), lung (98,000, 8.2%) and uterus (64,000, 5.4%) cancers.

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[3] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2003:327:0034:0038:EN:PDF

[4] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2008:0882:FIN:EN:PDF

[5] http://ec.europa.eu/health/ph_information/dissemination/diseases/docs/com_2009_291.en.pdf

[6] Cancer incidence and mortality patterns in Europe: Estimates for 40 countries in 2012, European Journal on Cancer, February 2013.

The estimated total number of cancer related deaths in the European Union (EU27) in 2012 was 1,263 million, of which 56% (708,000) in men and 44% (555,000) in women. Lung cancer, with an estimated 310,000 deaths (24.5% of the total) was the most frequent cause of death from cancer in Europe in 2012, followed by colorectal cancer (150,000 deaths, 11.9%), breast cancer (91,000, 7.2%) and stomach cancer (58,000, 4.6%). Lung cancer continued to be the most common cause of death from cancer in men (183,000, 25.9%) followed by colorectal (82,000, 11.6%) and prostate (71,000, 10%) cancers. Breast cancer was the leading cause of death in women (91,000, 16.3%), followed by colorectal (68,000, 12.3%), lung (81,000, 14.7%) and ovary (30,000, 5.4%) cancers.

Cancer survival varies widely between European countries despite major improvements in cancer diagnosis and treatment during the first decade of the 21st century. The number of adults surviving for at least 5 years after diagnosis has risen steadily over time in all the European Union, reflecting major advances in cancer management such as organised cancer screening programmes and improved treatments. However there continue to be big disparities between countries, and international survival differences are narrowing for only a few cancers such as breast, rectum, prostate, and melanoma of the skin[7].

1.3 The cost of cancer in the European Union

It is estimated that cancer cost the EU Member States €126 billion in 2009, with healthcare accounting for €51,0 billion (40%)[8]. Across the EU, the healthcare costs of cancer were estimated at the equivalent to €102 per citizen, but varied substantially from €16 per person in Bulgaria to €184 per person in Luxembourg.

Productivity losses due to early death were estimated to cost €42,6 billion and lost working days €9,43 billion. Informal care was estimated to cost €23,2 billion. Lung cancer had the highest estimated economic cost (€18,8 billion, 15% of overall cancer costs), followed by breast cancer (€15,0 billion, 12%), colorectal cancer (€13,1 billion, 10%), and prostate cancer (€8,43 billion, 7%). Researchers point out that these estimates are conservative, as some categories of healthcare costs, such as screening programmes, were not included due to the inability to obtain these data for all countries under study.

2. RESULTS OF ACTION UNDER COUNCIL RECOMMENDATION AND COMMISSION COMMUNICATION

2.1 National Cancer Control Programmes

Objectives for action: As a horizontal action, the Commission Communication sets the objective that by the end of the Partnership all Member States should have integrated National Cancer Control Programmes (NCCPs). Putting such plans in place should make a sustainable contribution to reducing the burden of cancer in the EU towards achieving the target of a 15% reduction by 2020 (510,000 fewer new cases).

NCCPs are public health programmes designed to ensure the centrally managed implementation and monitoring of evidence-based strategies for prevention, early

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[7] http://press.thelancet.com/EUROCARE1.pdf

[8] Economic burden of cancer across the European Union: a population-based cost analysis. The Lancet Oncology, Volume 14, Issue 12, Pages 1165 - 1174, November 2013

detection, diagnosis, treatment, rehabilitation, palliation and research. In 2009, the European Commission reinforced its long-term commitment to the fight against cancer by launching a European Partnership for Action Against Cancer (EPAAC) Joint Action. The overall aim of the EPAAC Joint Action (2009-2013) is to support Member States and other stakeholders in their efforts to tackle cancer more efficiently and as a framework for identifying and sharing information, capacity and expertise in cancer prevention and control, in order to achieve synergies and avoid scattered actions and the duplication of efforts. The partnership involved a wide range of stakeholders, all with specific experiences and expertise to enrich the evidence base. It included medical and scientific research institutions, industry representatives and non-governmental patient coalitions from all EU.

Implemented actions: The majority of Member States met the target of producing a NCCP before 2013. 24 of the 28 Member States had some type of NCCP or programme or strategy by 2013. The remaining four are underway for the finalisation of their respective NCCPs. The NCCPs present significant variations in terms of scope, of the topics included in the programme, the presence of indicators for their monitoring and/or evaluation, the duration of the plan/programme/strategy, the period of preparation and the involvement of patients.

EPAAC has provided three key deliverables useful for the further development and quality improvement of NCCPs:

- A report on the current state of NCCPs in the European Union[9]
- A Guide for the production of High Quality NCCPs in the European Union[10]
- Indicators for monitoring, evaluation and modification of NCCPs[11].

Significant efforts have been invested in all Member States to produce NCCPs and they constitute a key element for a sustainable contribution to reducing the burden of cancer in the EU because they mandate basic structures needed for cancer control and create a mechanism for accountability. They also represent a framework to introduce new guidelines, methods of care and cooperation mechanisms, which is conducive to advances in cancer care across the EU.

2.2 One third of cancers are preventable – the most cost-effective response

Objectives for action: The Commission Communication encourages the Partnership to adopt a horizontal approach on the basis of tackling major health determinants as an essential element to curb the increasing burden of cancer throughout the European Union. Cancer is caused by many factors and therefore its prevention shall address lifestyle, occupational and environmental causes. It has been estimated[12] that around one third of all cancers could be prevented by modifying or avoiding key risk factors. These factors

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[9] http://www.epaac.eu/from_heidi_wiki/Final_Report_on_National_Cancer_Control_Programmes.pdf

[10] http://www.epaac.eu/images/END/Final_Deliverables/WP_10_Annex_17_European_Guide_on_Quality_National_Cancer_Control_Programmes.pdf

[11] http://www.epaac.eu/from_heidi_wiki/Final_Report_on_National_Cancer_Control_Programmes.pdf

[12] http://www.who.int/cancer/prevention/en/

include smoking, being overweight, low fruit and vegetable intake, physical inactivity[13], alcohol consumption, occupational exposure to chemical carcinogens and sun exposure.

A key element of the European response is the **European Code Against Cancer**[14]. It passes across two clear messages:

- certain cancers may be avoided – and health in general can be improved – by adopting healthier lifestyles; and
- cancers may be cured, or the prospects of cure greatly increased, if they are detected at an early stage.

Addressing the public at large in a citizen-friendly format, the Code is a key communication tool in the prevention of cancer and should constitute the major tool for disseminating preventive measures and contributing to change the perception of cancer.

***Implemented actions**:* Health promotion on the basis of major health determinants has been a longstanding priority for the European Commission, and has included strategies for nutrition, overweight and obesity-related health issues[15], and alcohol-related harm[16]. The Commission has developed an ambitious tobacco control policy[17] aimed at discouraging children and young people from taking up smoking and at harmonising the internal market of tobacco products, and at supporting national efforts to protect citizens against exposure to second-hand smoke, taking into account the need to tailor health promotion to specific population and target groups.

In the occupational field, the evaluation of the EU Health and Safety Strategy 2007-2012[18] showed that it achieved relevant goals and identified the need to continue to focus in prevention of occupational diseases, cancer being of major importance, in the framework of coordinated actions with other EU Health and Environment Strategies. For that purpose, the Commission has adopted a new EU Strategic Framework on Health and Safety at Work 2014-2020[19].

Moreover, **Directive 2004/37/EC of the European Parliament and of the Council, of 29 April 2004, on the protection of workers from the risks related to exposure to carcinogens or mutagens at work**[20] sets out a number of preventive measures to eliminate or minimise work-related exposures to chemical carcinogens and mutagens. In addition, the list of substances classified as carcinogens or mutagens is being updated in line with scientific evidence in Part 3 of Annex VI to Regulation No 1272/2008 (CLP) on classification, labelling and packaging of substances and mixtures[21].

More specifically the EPAAC Joint Action re-launched the **European Week Against Cancer**[22] to convey the health promotion messages from the European Code Against Cancer.

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[13] This objective would converge with the EU policy objectives defined in the Council Recommendation of 26 November 2013 on promoting health-enhancing physical activity across sectors, OJ C 354, 4.12.2013, pp. 1-5.

[14] http://www.cancercode.eu/

[15] http://ec.europa.eu/health/nutrition_physical_activity/policy/strategy_en.htm

[16] http://eur-lex.europa.eu/LexUriServ/site/en/com/2006/com2006_0625en01.pdf

[17] http://ec.europa.eu/health/tobacco/introduction/index_en.htm

[18] http://ec.europa.eu/social/BlobServlet?docId=10965&langId=en

[19] http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52014DC0332

[20] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32004L0037:en:NOT

[21] http://eur-lex.europa.eu/legal-content/EN/ALL/?uri=OJ:L:2008:353:TOC

[22] http://www.europeancancerleagues.org/ewac/european-week-against-cancer-2013.html

The 4th edition of the **European Code Against Cancer** (first version 1987, second version 1994, third version 2003), supported by the European Commission through administrative agreements with the **International Agency for Research on Cancer (IARC)**, has been initiated and work is ongoing.

2.3 Screening and early detection of cancers

Objectives for action: The Council **Recommendation** recommends population-based screening for breast, cervical and colorectal cancers on the basis of the available evidence of effectiveness, subject to implementation of appropriate quality assurance systems. The WHO has endorsed in 2011 these recommendations for its 53 Member States in the European Region[23].

Organized cervical cancer screening has been undertaken since 1963 in some Member States. Breast cancer screening programmes began to be implemented in the late 1980s. Colorectal cancer screening programmes, however, have only been established in the 2000s and still cover a small part of Europe.

According to the first implementation report on the Council recommendation, the annual volume of screening examinations in the EU at the time was considerable; however, this volume was less than half of the minimum annual number of examinations that would be expected if the screening tests specified in the Recommendation were available to all EU citizens of appropriate age (approximately 125 million examinations per year). Furthermore, less than half of the volume of examinations at the time (41%) was performed in population-based programmes which provided the organisational framework for implementing comprehensive quality assurance as required by the Recommendation.

Implemented actions: Based on current projections, it has been a substantial improvement in screening coverage in the EU in the last years. Over 500 million screening examinations for breast, cervical and/or colorectal cancer will be performed in publicly mandated programmes in the EU alone between 2010 and 2020. The three cancers covered by the Recommendation (breast, cervical and colorectal cancer) account for almost one-fifth, or 400,000, of the 1.8 million cancer deaths in the European Region (IARC 2008).

First data from the European health interview survey (EHIS) Wave I[24] on breast, cervical and colorectal cancer screening[25] were published in December 2010. According to this data[26] the percentage of women who have ever undergone a mammography, aged between 50 and 69, among the countries studied, France has the highest proportion (92.9 %), followed by Spain (92.3 %), Austria and Germany (90 %), Belgium (89.5 %) and Hungary (86.9 %); Bulgaria (19.5%) and Romania (13.5%) having the lowest.

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[23] http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/policy/screening-and-early-detection

[24] EHIS wave 2 is being conducted in all EU Member States between 2013 and 2015 under Commission Regulation (EU) No 141/2013: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2013:047:0020:0048:EN:PDF.

[25] http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=hlth_ehis_hc2&lang=en
http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=hlth_ehis_hc3&lang=en
http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=hlth_ehis_hc4&lang=en

[26] http://epp.eurostat.ec.europa.eu/statistics_explained/index.php/Breast_cancer_screening_statistics

The adoption of **European guidelines on best practice** was identified in the **Recommendation** as the most important activity to implement screening programmes in order to facilitate the further development of best practice for high quality cancer screening programmes on a national and, where appropriate, at regional level. Already in 2006, the ***4th edition of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis***[27] was produced. Since the publication of the last implementation report, work on guidelines has continued to be a priority:

- In 2008 the European Commission in cooperation with IARC and the European Cervical Cancer Screening Network (ECCSN) produced the ***2nd edition of the European Guidelines for Quality Assurance of Cervical Cancer Screening and Diagnosis***[28]**.** These guidelines include extensive updates on technical details and documentation, as well as assessment of new technologies, e.g.: liquid-based cytology, automated interpretation of Pap smears and testing for human papillomaviruses. The scope of the guidelines has also been extended to include comprehensive instructions prepared by a multi-disciplinary team of experts for general practitioners, gynecologists and cytopathologists.

- In 2010 the European Commission in cooperation with IARC produced the ***First edition of the European Guidelines for Quality Assurance in Colorectal Cancer Screening and Diagnosis***[29]. The EU Guidelines on colorectal cancer screening aim to raise quality standards by providing guiding principles and evidence-based recommendations on quality assurance which should be followed when implementing colorectal screening programmes in the EU Member States. They cover the entire screening process - from invitation and organisation, through to diagnosis and management of lesions detected. They focus on elements essential to *screening*, but also include principles which are equally important in *diagnosis*: training, multidisciplinary teamwork, monitoring and evaluation, cost-effectiveness, minimising adverse effects, and timeliness of further investigations.

- In 2013 the European Commission in cooperation with IARC, EUREF, the European Working Group on Breast Screening Pathology, and the Joint Action EPAAC published the ***Supplements to the 4th edition of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis***[30]**.** The first supplement (Digital mammography update) responds to the rapid technological development that has accompanied a wide increase in the use of digital imaging in mammography screening and diagnosis since the fourth edition was published. The second supplement deals with several topics in the quality assurance of pathology in breast cancer screening and diagnosis in which problems and practical solutions as well as new techniques and other advances have emerged in recent years.

- In 2014 the European Commission in cooperation with IARC and the European Cervical Cancer Screening Network (ECCSN) intends to deliver the ***2nd edition of the European Guidelines for Quality Assurance of Cervical Cancer Screening***

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[27] http://ec.europa.eu/health/archive/ph_projects/2002/cancer/fp_cancer_2002_ext_guid_01.pdf

[28] http://bookshop.europa.eu/is-bin/INTERSHOP.enfinity/WFS/EU-Bookshop-Site/en_GB/-/EUR/ViewPublication-Start?PublicationKey=ND7007117

[29] http://bookshop.europa.eu/is-bin/INTERSHOP.enfinity/WFS/EU-Bookshop-Site/en_GB/-/EUR/ViewPublication-Start?PublicationKey=ND3210390

[30] http://bookshop.europa.eu/en/european-guidelines-for-quality-assurance-in-breast-cancer-screening-and-diagnosis-pbND0213386/

and Diagnosis – Supplements covering primary HPV testing in cervical cancer screening and organization of human papillomavirus (HPV) testing and conventional cytology in cervical cancer screening.

One of the objectives of the EPAAC Joint Action was to establish an intensive **comprehensive training course in management of cancer screening programmes**. For expert support in designing and piloting the intensive training course, a network of European Schools of Screening Management (ESSM) was initiated[31].

The EU Health Programme has also supported the **AURORA project[32]** to identify a common and feasible strategy on how to promote Cervical Cancer Screening in the new EU Member States targeting women 30-69 years old and ensuring the coverage of hard to reach groups, assist the new EU Member States in the implementation of evidence-based screening for cervical cancer and promote a European exchange of information and expertise.

For the purpose of mapping cancer services delivering screening and care across European countries, **the European Commission Joint Research Centre (JRC) launched a survey in 2012 on breast cancer services in European countries[33]**. According to the results of this survey, 22 countries hold screening programmes for breast cancer, among which 21 are organised according to the definitions given in the guidelines. 15 out of 25 countries hold screening programmes for colorectal cancer, and other four are in a transition phase toward an organised programme. 19 out of 25 countries hold screening programmes for cervical cancer and some are converting current non-systematic activities into a population-based, quality assured programme.

2.4 Accreditation of breast cancer services in the European Union

Objectives for action*:* The Commission Communication states the intention of the Commission to develop a voluntary European pilot **accreditation scheme for breast cancer screening and follow-up, building on the new European guidelines in breast cancer screening and diagnosis** (and their previous editions as the most longstanding and developed guidelines in the area).

This follows the approach of the **Recommendation** to promote evidence-based cancer screening through a systematic population-based approach with quality assurance. This was followed by **Council Conclusions on reducing the burden of cancer** in 2008[34] inviting the Commission to explore the potential for developing a European pilot accreditation scheme for breast cancer screening and follow-up, based on the European Quality Assurance guidelines.

Implemented actions: In December 2012, the JRC was assigned with the following tasks:

- To develop a new edition of the European Guidelines for Breast Cancer Screening and Diagnosis, and

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[31] http://www.epaac.eu/from_heidi_wiki/ESSM_firstannouncement0619.pdf

[32] http://www.aurora-project.eu/en/web/cervical-cancer-screening-608

[33] http://bookshop.europa.eu/en/report-of-a-european-survey-on-the-organisation-of-breast-cancer-care-services-pbLBNA26593

[34] http://www.eu2008.si/en/News_and_Documents/Council_Conclusions/June/0609_EPSCO-cancer.pdf

- To develop a quality assurance scheme for Breast Cancer Services based on the European legislative framework on accreditation as defined in the Regulation (EC) No 765/2008 of the European Parliament and of the Council of 9 July 2008 setting out the requirements for accreditation and market surveillance relating to the marketing of products[35].

This project, which is still underway, is aimed at establishing a minimum set of quality requirements for breast cancer health-care across the EU based on a new ***edition of the European Guidelines for Breast Cancer Screening and Diagnosis*** which should be available in 2016. In addition a ***European Platform of Guidelines*** will be developed by JRC to host existing guidelines for other stages of breast cancer care beyond screening and diagnosis, covering treatment, rehabilitation, follow-up – including surveillance and, where necessary, pain management, and aspects such as psychological support and palliative care, which are essential for a patient-centred concept of quality.

2.5 Applying best healthcare approaches in practice - identification and dissemination of good practice

Objectives for action*:* The Communication foresees a reduction in inequalities in cancer mortality by reducing the disparity between the best and worst performing Member States in 70% by 2020[36]. This is supported by the development of guidelines for models of best practice in cancer-related care, taking into account national, regional and local contexts.

Implemented actions*:* The EPAAC has developed several initiatives in the area of health care included producing a comprehensive picture of the cancer care landscape in Europe:

- *To identify best practices in European health services, promoting innovative network approaches to exchange experiences:* a **Policy statement on *multidisciplinary cancer care*[37]** to define the core elements that all tumour-based multidisciplinary teams should include was developed. In addition, a ***computer-based symptom management and decision support*** system for symptom management within palliative care was established.

- *To develop paediatric cancer care guidelines:* The Joint Action worked closely with the European Society for Paediatric Oncology (SIOP) on the promotion of guidelines on improving paediatric oncology. Recently, a survey to Member States was carried out to evaluate the implementation of these guidelines using the results of a similar 2008 study by SIOP as a baseline measurement. The results of this comparison are expected in 2014.

- *Evidence and use of complementary and alternative medicine in cancer:* A survey of the European structures and centres providing complementary and alternative medicine within the framework of integrative oncology is ongoing.

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[35] http://eur-lex.europa.eu/Notice.do?val=477184:cs&lang=en&list=511806:cs,480690:cs,477184:cs,&pos=3&page=1&nbl=3&pgs=10&hwords=

[36] http://www.oecd.org/health/cancer-care.htm

[37] http://www.ejcancer.com/article/S0959-8049(13)01007-1/abstract

- *To develop, review and harmonise the content and implementation of clinical guidelines:* Joint action partners focused on two areas in their work on developing clinical guidelines for cancer care: nutrition and rare cancers. On nutrition, the guidelines arising from the work on nutrition have been disseminated by the JRC to European cancer centres[38].

- *To implement a training strategy to improve psychosocial and communication skills among health care providers:* A number of partner organisations contributed to a mapping exercise on health system resources in psychosocial oncology care, communication skills among health care professionals and psycho-oncology training activities, as well as the existing gaps in need versus capacity. The results indicate that in 20 of the 26 countries that answered the survey, psychosocial oncology care is included in the NCCP, but only 10 have a specific budget for it[39].

In order to give continuity to the efforts to improve cancer control, especially in the field of healthcare, the Commission launched in 2014 a **new three year Joint Action on cancer control,** funded from the Second EU Health Programme. Its main objective is to deliver a **European Guide on Quality Improvement in Comprehensive Cancer Control** as well as a Member States Platform, which will provide space for discussions on cancer topics.

It is foreseen that the Guide and the position papers which will be developed include both good practice and evidence-based recommendations, help to foster quality improvement in cancer control and care at national levels and to contribute to decreasing inequalities. The Guide is due to address the topics of evidence-based and quality-based cancer screening programmes, Comprehensive Cancer Network organisation, Community-based cancer care and Survivorship. Member States will receive guidance on implementation of various aspects of high-quality screening programmes in line with the European guidelines for quality assurance in cervical, breast and colorectal cancer screening and guidance on other potential screening programmes (e.g. lung, prostate). Member States are to be provided with a model of a Comprehensive Cancer Network, which they can subsequently adapt to their own contexts.

The Commission is also keen to support eHealth solutions in particular through its eHealth Network and eHealth Action Plan, as eHealth has the potential to deliver more personalised targeted, effective and efficient cancer care and can help reduce errors. Such benefits have been demonstrated when using telemedicine for managing disease as well as for health promotion. In another field of action on healthcare provision, the Commission is exploring technical and financial solutions for the supply of medical isotopes, following episodes of shortages in supply across Europe. Following the Council Conclusions "*Towards the Secure Supply of Radioisotopes for Medical Use in the European Union*" adopted on 6 December 2010[40], a European Observatory was established to help to address issues concerning the supply chain which directly impacts on healthcare needs.

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[38] https://ec.europa.eu/jrc/en/news/making-diet-count-cancer-prevention

[39] http://www.epaac.eu/healthcare

[40] http://ec.europa.eu/energy/nuclear/radiation_protection/medical/doc/2012_council_radioisotopes.pdf

2.6 Rare cancers

Objectives for action: The Communication stresses the need to tackle inequalities in cancer mortality amenable to healthcare by reducing the disparity between the best and worst performing Member States. The case of rare cancers is mentioned as an area of EU added-value based on future cooperation on European Reference Networks, for example in the field of rare diseases, which include many rare cancers.

In principle, rare tumours should be defined the same way as rare diseases. These are defined as those conditions whose prevalence is lower than 5 per 10,000 in the European population. Annually rare cancer diagnoses represent about 22% of all cancers diagnosed. In contrast to cancer in adults, virtually all the cancers in children are rare but severe. Approximately 40,000 children are diagnosed with cancer every year in the EU. These tumours pose special burdens on patients, requiring diagnostic and treatment expertise that may not be readily available close to their residence. Patients sometimes have to travel long distances to access appropriate pathologic diagnosis and multidisciplinary treatment, and they have few options for a second opinion.

Implemented actions: EU policy in the field of rare diseases seeks to help address the challenges related to addressing rare tumours. This is based on the 2008 **Commission Communication on Rare Diseases: Europe's challenges**[41], and the 2009 **Council Recommendation on an action in the field of rare diseases**[42]. European Union action in this field is aimed at improving patients' access to appropriate and timely diagnoses, information and care. In this area, European action can be more effective than Member States acting individually.

Moreover the **Directive on the application of patients' rights in cross-border healthcare[43]** clarifies patients' rights to access safe and good quality treatment across EU borders, and be reimbursed for it. It provides a basis for increased cooperation between national health authorities through several actions. Some provisions are addressing rare diseases. In particular Article 12 foresees enhanced cooperation of Member States and gives the Commission the mandate to support Member States in developing European Reference Networks (ERNs) between healthcare providers and centres of expertise in EU countries for low prevalence, complex or rare diseases.

Two Decisions[44] [45] adopted in March 2014 establish the criteria for the ERNs and its members as well as the process to assess, evaluate and approve them. Only networks approved according to these legal requirements will receive formal EU recognition and will be awarded the EU ERN logo, a registered trademark owned by the European Union.

Based on the EU rare diseases framework, the European Commission has supported several initiatives under the Health Programme as follows:

- In 2012, the project **RARECARENET (Information Network on Rare Cancers)[46]**, which built upon some of previous activities of the Project

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[41] http://ec.europa.eu/health/ph_threats/non_com/docs/rare_com_en.pdf
[42] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF
[43] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:en:PDF
[44] http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=OJ:JOL_2014_147_R_0006
[45] http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=OJ:JOL_2014_147_R_0007
[46] http://www.rarecarenet.eu/rarecarenet/

RARECARE (Surveillance of Rare Cancers in Europe)[47] which provided estimations for incidence, survival, prevalence and mortality for all rare cancers. The project aims (i) to provide updated indicators of rare cancer burden, (ii) to collect and disseminate information on the health care pathways for rare cancers, (iii) to identify the criteria for centres of expertise for rare cancers, (iv) to produce and disseminate information on diagnosis and management of rare cancers, (v) to develop a clinical database on very rare cancers, (vi) to provide new knowledge on these diseases and their clinical management, and (vii) to develop and disseminate information for patients including a list of patients' associations dedicated to rare cancers.

- In 2013, the **European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment (ExPO-r-NeT)**, to support the provision of healthcare to children and young people with cancer in a Member State other than the Member State of affiliation, when the expertise with certain cancer conditions is rare and case volume low, contributing to provide cross-border best care to rare childhood cancer populations.

Moreover **Rare Cancers Europe**[48]**,** a multi-stakeholder initiative addressing specific challenges posed by rare cancers was formed.

2.7 Cooperation and coordination in cancer research

Objectives for action*:* The Commission Communication asks to develop a coordinated approach to cancer research across the EU, aiming to achieve coordination of one third of research from all funding sources by 2013.

Implemented actions: The EU plays a very important role as cancer research funder. During the last seven years, through its 7th Framework for Research (2007 – 2013), the Commission has invested more than €1.4 billion in international collaborative research, frontier research, mobility programmes, public-private partnerships and coordination of national research efforts in relation to cancer. More than half this budget - €770 million – has been used to encourage leading players from across Europe and abroad to join forces in 'collaborative research projects', to find new ways of fighting cancer and supporting patients. These projects are helping to understand better how the various cancer types emerge, and how to diagnose them earlier and treat them with more success.

Europe is one of the world's leading regions for cancer research. Most of this research is funded and carried out within individual countries. To help coordinate and connect the many and various national efforts, the EU funds initiatives such as the mapping of national cancer funds via the **TRANSCAN network**[49]; optimises and links national and regional cancer registries via the **EUROCOURSE network**[50]; and facilitates expert exchanges and helps transfer best practice from one country to another.

Implemented Moreover, the EPAAC launched work on cancer research with three specific objectives:

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[47] http://www.rarecare.eu/aims/aims.asp

[48] http://www.rarecancerseurope.org/

[49] http://www.transcanfp7.eu/transcan/index.php

[50] http://www.eurocourse.org/

- To identify and prioritise areas in cancer research that will benefit from coordination and cross-border collaboration;

- To identify mechanisms for a concerted approach for coordination of one third of cancer research from all funding sources by 2013;

- To develop research coordination pilot projects in selected areas.

In this context, the following pilot projects were developed: European cancer research coordination in early phase clinical research; a European platform for cancer outcomes Research; and a European knowledge hub for epidemiology and public health research on cancer: research coordination and knowledge sharing.

It was clear from the start that no single methodology could be applied for coordination of all areas of cancer research between all countries. The challenge was thus to tailor coordination methodologies to specific research topics and to the needs of interested parties, using consensual principles for coordination.

2.8 Providing the comparable information necessary for policy and action

Objectives for action*:* The Commission Communication asks to ensure accurate and comparable data on cancer incidence, prevalence, morbidity, cure, survival and mortality in the EU by 2013. To this aim, the need is recognized for a **European cancer information system (ECIS),** bringing together institutions and resources dealing with cancer information and data to provide the knowledge necessary to optimize cancer control activities. ECIS should coordinate and guide the entire process of data collection, quality control, management, analysis, and diffusion.

In order to improve comparability of epidemiological cancer data, two of the first projects supported by the European Commission in the framework of the Europe Against Cancer programme in 1987 were the establishment of the **European Network of Cancer Registries (ENCR)**[51] and the **EUROCARE** ***(Europe Cancer REgistry-based study on survival and care of cancer patients)***[52]**.** The ENCR promotes collaboration between cancer registries, defines data collection standards, provides training for cancer registry personnel and regularly disseminates information on incidence and mortality from cancer in the European Union and the whole of Europe[53].

Dissemination of cancer comparable information is also sustained by the European wide databases of cancer as causes of death maintained by **EUROSTAT**[54], which is in charge of collecting and homogenizing statistics on cancer mortality by age, sex, nationality and region; moreover, the **ENCR** data[55] constitute a comprehensive system of information on the cancer burden in Europe (mainly incidence and mortality), complemented by **EUROCARE** data for survival, prevalence and patterns of care.

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[51] http://www.encr.eu/

[52] http://www.eurocare.it/

[53] http://unstats.un.org/unsd/methods/m49/m49regin.htm#europe

[54] Eurostat data collection on causes of death is now conducted under the Commission Regulation (EU) No 328/2011: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:090:0022:0024:EN:PDF.

[55] http://eco.iarc.fr/Default.aspx

Finally, and in order to create a comparable system of cancer indicators, the **EUROCHIP (European Cancer Health Indicators) Project**[56] funded by the EU Health Programme has developed indicators to monitor cancer. Within the **EUROCOURSE Project,** the **European Cancer Observatory (ECO)** website was developed as a centralized gateway for automated cancer registry data management and dissemination. General health related data, necessary for an appropriate interpretation of cancer indicators, are organized within the **EU health websites**[57]. General and health specific economic data are collected in the **OECD health database**[58]**.** Finally, the European scientific community is in the forefront of methodological research in population-based epidemiology and public health, from analysis and projection of incidence and mortality trends, to survival analysis, prevalence estimation, planning and conduction of high resolution studies, and for the study of social and economic inequalities on health.

Implemented actions*:* The EPAAC Joint Action prioritised three main objectives to contribute to the development of the European Cancer Information System:

- To map the main sources of cancer data in Europe and to identify the priority topics to be supported by the Partnership;

- To unify under a common platform cancer burden indicators (incidence, mortality, survival and prevalence) provided by existing European activities;

- To create a Task force on population-based cancer cost investigation in Europe.

In 2009, the EPAAC Joint Action was mandated to deliver, by 2013, a proposal laying the basis for a future European Cancer Information System, in consensus with all cancer stakeholders (data providers, health professionals, governments, citizens, patients and researchers).

In 2012, the JRC was made responsible for assisting the discussion on an ECIS and acting as repository of European Union data and tools. The report "***Developing a European Cancer Information System: a proposal from the European Partnership for Action Against Cancer (EPAAC)"***[59] which was produced as an outcome of the EPAAC serves as basis for the work of the Joint Research Centre (JRC).

The Joint Research Centre (JRC) will ensure the sustainability of ECIS and coordinate its further development. It is working in close collaboration with all major stakeholders in the cancer data domain, supporting the European Network of Cancer Registries (ENCR) for which the JRC took over the Secretariat in 2012, and collaborating with the International Agency for Research of Cancer (IARC) and other scientific networks and projects at European level such as EUROCARE, CONCORD (Global surveillance of cancer survival)[60], the Joint Action PARENT (Cross-border Patient Registries Initiative)[61] and other groups, to define the best effective options on all the major ECIS functions, such as data quality control, statistical analysis, diffusion and dissemination of cancer information, etc.

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[56] http://www.tumori.net/eurochip/

[57] http://epp.eurostat.ec.europa.eu/portal/page/portal/health/introduction

[58] http://www.oecd.org/health/health-systems/oecdhealthdata.htm

[59] http://www.epaac.eu/cancer-data-and-information

[60] http://www.lshtm.ac.uk/eph/ncde/cancersurvival/research/concord/concord_2.html

[61] http://www.patientregistries.eu/

Today, more than 200 cancer registries are connected under the ENCR in Europe. Data collection systems in the different countries reflect the specific organisation of national health systems, and barriers persist in data access, so it is difficult to move from the national to the European scale as not all indicators are comparable across the EU. Registries presently provide most epidemiological data on cancer, yet they are underfunded, mostly understaffed, or launched without proper planning.

2.9 Working together in Partnership

***Objectives for action**:* The Communication defines the role of the European Commission to ensure the cooperative and action-oriented approach of the Partnership, and to make certain that the proposed actions and activities are appropriate for action at EU level.

***Implemented actions**:* Joint actions are activities, under the Health Programme, carried out by the European Union and Member States. For the period of duration of the Partnership, the consultative structures of the EPAAC Joint Action have permitted an extensive exchange of views and a constructive cooperation between the European Commission and the Member States.

To increase the visibility and to improve the coordination of the range of cancer initiatives at EU level, the European Commission has established **a European Commission Group of Experts on Cancer Control**[62].

This responds to demands from Member States and stakeholders for improved coordination in the light of the expanding cancer work. In addition, sharing knowledge and information can help resolve some of the difficulties that Member States are facing in cancer control and will facilitate cooperation with relevant stakeholders.

3. CONCLUSIONS

EU action on cancer based on the Commission Communication has strengthened cooperation between the European Union, Member States and relevant stakeholders and has created European added value in relevant areas (NCCP, screening, cancer information system, rare cancers, etc.) as well as a practical basis to continue and expand mechanisms for cooperation. This cooperation in strategic areas has provided a framework which made a sustainable contribution to reduce the burden of cancer in the EU and towards maintaining the target of a 15% reduction by 2020. According to the last available data, in the period 2000-2010, the incidence of the most frequently occurring forms of cancers (i.e. breast, lung, prostate and colorectal) decreased by about 10%.

In order to take forward this cooperation, this Report has described some of the next steps:

- **The 3rd EU Health Programme** offers opportunities to promote public health action on cancer.

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[62] http:// **Commission Decision 2014 C/167 05, of 3 June 2014,** ec.europa.eu/health/major_chronic_diseases/docs/com2014_c167_05_en.pdf

- **Horizon 2020**, in particular its Health, demographic change and wellbeing objective, offers opportunities to pursue research on cancer and other major chronic diseases.

- The Commission continues to support the development of high quality **National Cancer Plans** in the European Union.

- **There is a need to** support the dissemination of the 4th edition of the European Code Against Cancer as a **key tool for the prevention and promotion activities against cancer in the EU**.

- It will be important to make the **new Tobacco Products Directive** fully operational by ensuring full use of its delegated and implementing powers as well as supporting its implementation by Member States in order to reduce smoking throughout the EU and contributing to reduce the incidence of cancer.

- There is a need to enhance cooperation between the fields of **Public Health, Environment and Occupational Health** in order to tackle the avoidable causes of cancer from a broader perspective.

- The Commission is supporting the new ***edition of the European Guidelines for Breast Cancer Screening and Diagnosis, a*** **European platform for high quality, evidence-based breast cancer guidelines** covering other stages and aspects of care, and a **voluntary European Quality Assurance scheme for Breast Cancer Services**.

- Having launched the **Joint Action CANCON (European Guide on Quality Improvement in Comprehensive Cancer Control),** the main deliverable being the **European Guide on Quality Improvement in Comprehensive Cancer Control.**

- **Stakeholders should consider using the Directive on the application of patients' rights in cross-border healthcare** for the creation of European Reference Networks, including on rare tumours. The Commission intends to organise calls for Networks in 2014 and 2015.

- The **situation of cancer screening** has clearly improved in the last years and especially since the adoption of the Council Recommendation. However the European Commission services consider that work in the area of implementation and updating of screening programmes and networking between centres and experts, remains as a priority public health objective, at the EU, national and regional level, in the coming years.

- In addition, in order to support an equal treatment for patients suffering from rare tumours, there would be added value in considering a specific **Action on Rare Cancers**.

- It will be important to develop the **European cancer information system (ECIS),** to provide the knowledge necessary to optimize cancer control activities.

- The Commission is developing a coordinated approach to **cancer research activities** across the EU.

- There is a need for wider uptake of **eHealth** for efficient disease management and to strengthen effective prevention practices.

The recommendations of Members States and stakeholders, in the framework of the **European Commission Group of Experts on Cancer Control,** will also be taken into account.

The European Commission maintains, as stated in the Communication the objective to reduce the burden of cancer in the EU, and that the target of a 15% reduction of cancer incidence by 2020 (510,000 new cases) is an achievable result.