

JRC TECHNICAL REPORT



European Commission Initiative on Breast Cancer-ECIBC:

Organisation of project guiding and support meetings report-2014

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Abstract

The Joint Research Centre (JRC) coordinates the European Commission's Initiative on Breast Cancer (ECIBC). The ECBIC has two main tasks: 1) the development of a voluntary European quality assurance (QA) scheme for breast cancer services based on an EU legislative framework on accreditation covering all stages and aspects of care and 2) the set-up of the evidence base for such a QA scheme via (i) the development of the new European guidelines for breast cancer screening and diagnosis and (ii) a platform for evidence-based breast cancer guidelines covering stages other than screening and diagnosis (e.g. rehabilitation, follow-up, psychological support and palliative care).

Preparation for the ECIBC included literature searches, stakeholder meetings and consensus building workshops and a European-wide survey to gather information on the status and organisation of breast cancer screening and care. This report is a summary of the meetings held in 2014.

European Commission Initiative on Breast Cancer - ECIBC

Organisation of project guiding and support meetings report - 2014

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1 Executive summary

In December 2012, the Joint Research Centre (JRC), which is the European Commission's (EC) in-house science service, was assigned by the Directorate-General for Health and Consumers (now the Directorate-General for Health and Food Safety - DG SANTE) with the task of coordinating the *European Commission Initiative on Breast Cancer* henceforth shortened to ECIBC. This decision was taken partly in view of the legal constraints imposed by the EU's Financial Regulation, but also considering the JRC's independence from all national, private and commercial interests as well as its long-term experience in coordinating networks of national experts, stakeholders and Member State representatives. Further details can be retrieved in the following documents:

- <u>DG SANTE webpage: European Commission Initiative on Breast Cancer: description of working-</u> group structure
- JRC webpage: European Commission Initiative on Breast Cancer ECIBC

The JRC set up a dedicated team for coordinating the ECIBC; the Healthcare Quality team (HQ). ECIBC main tasks as defined by the DG SANTE document are:

- 1. To develop a new version of the European guidelines for breast cancer screening and diagnosis based on new knowledge and evidence;
- To develop a voluntary European quality assurance (QA) scheme for breast cancer services based on the EU legislative framework on accreditation, as defined in the Regulation of the European Parliament and by the Council of Europe setting out the requirements for accreditation and market surveillance.

With regard to guidelines covering stages other than screening and diagnosis, a platform for breast cancer guidelines is envisaged to host existing evidence-based, high-quality guidelines.

Other tasks, such as the development of the ECIBC web hub and the definition of a concept for training of professionals in breast cancer screening, were included. Moreover, tasks functional to the creation of the necessary knowledge platform were also assigned to initiative tasks and new tasks will be added, as needed.

In order to develop the tasks in a coordinated, consensus-based and sustainable way, the JRC set up a series of targeted meetings with a wide range of stakeholders involved in similar initiatives (past and current), including medical oncology professionals, accreditation bodies, patient organisations, methodologists, experts and concerned national authorities. The JRC also participated in external meetings and conferences in order to acquire the basic knowledge for starting the activities of the ECIBC and to inform stakeholders about the ECIBC's aim and tasks.

The present report is a summary of the 2014 meetings aimed at helping the preparation of the above

mentioned tasks. The meetings organised between 2011 and 2013 are described in the JRC report <u>European</u> <u>Commission Initiative on Breast Cancer – ECIBC: organisation of project guiding and support meetings – Meetings 2011 - 2013.</u>

2 Background

The ECIBC is coordinated by the JRC's Institute for Health and Consumer Protection (JRC-IHCP). This initiative responds to the *Council Conclusions on reducing the burden of cancer*¹ and it aims to mitigate the risks associated with inadequate quality of prevention and care. In this context, the tasks of the initiative can be summarised as (i) establishing a minimum set of evidence-based quality requirements for breast cancer care across Europe assessed and monitored via the accreditation legal framework (a voluntary European quality assurance scheme for breast cancer services) while (ii) developing the evidence underpinning the scheme, namely the new *European guidelines for breast cancer screening and diagnosis* (hereinafter mentioned as new *European Guidelines*) and a platform for existing guidelines for other stages of care. Its concept foresees that all aspects of breast cancer prevention and care, screening, diagnosis, treatment, survivorship - support - palliative care and management of recurrence (follow-up) are covered. In addition, the initiative will:

- iii. Develop a concept for training health professionals involved in digital mammography screening programmes; and
- iv. Develop a concept for the ECIBC web hub which should act as a host for all its deliverables in order to make them easily accessible to target users

These four tasks are strongly interlinked and their accomplishment will rely on inputs from relevant European and international stakeholders, experts and participating countries (Member States - MSs, plus Switzerland, Iceland, Montenegro, Norway, Serbia, Turkey). Therefore, a series of meetings targeting the widest possible audience of interested parties began in 2012. As these meetings were an important source of information and a platform for consensus for future stages of the project, the JRC will continue to invest ECIBC resources to disseminate the information related to the project and to identify and meet with stakeholders.

3 Scope

This report includes a description of the context and outcomes of the meetings held in 2014, the news about the ECIBC and the relevant stakeholders the JRC met during 2014. JRC staff involved in the

¹ COUNCIL OF THE EUROPEAN UNION - *Council Conclusions on reducing the burden of cancer* - 2876th EMPLOYMENT, SOCIAL POLICY, HEALTH AND CONSUMER AFFAIRS Council Meeting - Luxembourg, 10 June 2008

meetings included the IHCP Director, the Head of Unit for Public Health Policy Support (PHPS) and PHPS staff, in particular the Healthcare Quality (HQ) team. Only meetings and events which target the ECIBC are included in the present report.

Meetings involving the JRC and the main customer, DG SANTE, or other concerned DGs and EU bodies, like Directorate-General for Research and Innovation (DG RTD), Directorate-General for Enterprise and Industry (DG GROW) are cited but not fully described as they do not fall under the scope of this report.

4 Methods

The methods used for identifying relevant stakeholders have already been described in the report European Commission Initiative on Breast Cancer – ECIBC: organisation of project guiding and support meetings – Meetings 2011 - 2013.

The same structure of the interactions with the stakeholders as in the previous meetings report was kept:

- Attendance at conferences / workshops / trainings as participants
- Attendance at conferences / workshops / trainings as presenters
- Meetings with other EC institutions
- Bilateral meetings with selected external organisations or individual experts
- Attendance at events related to the CANCON (European Guide on Quality Improvement in Comprehensive Cancer Control) joint action

and two new paragraphs were added:

- ECIBC updates, and
- Meetings analysis.

5 Results

In support of the ECIBC, in 2014, the JRC organised 12 bilateral meetings with representatives of various organisations, associations, networks or EU projects. JRC staff (mainly HQ team members) attended 38 external meetings (seminars, conferences, trainings, workshops, working groups) and participated in five meetings within the CANCON joint action framework.

HQ team members gave 11 oral presentations, presented two posters and they attended one training course.

The stakeholders that JRC staff met in 2014 come from several fields such as accreditation, breast cancer services, cancer control, cancer data audit, certification, chronic diseases, clinical trials,

complementary and alternative medicine, composite indicators, cost-effectiveness, cross-border healthcare, development of recommendations, education, evidence-based medical research, guideline development and implementation, health systems, health technology assessment, mammographic screening, medical apps, medical devices, medical imaging, methodological research, *m*Health (mobile health), oncology, overdiagnosis, palliative care, patient safety, policy making, psycho-oncology, public health, quality assurance, quality of cancer care, quality of life, radiology, rehabilitation, research, risk assessment, safety-monitoring, satisfaction tools, scientific evaluation, survivorship, systematic reviews and training. These can be considered the keywords for the ECIBC that guided the identification of stakeholders.

5.1 List of stakeholders

Table 1 provides the list of European and international organisations/associations, professional societies and patients' associations approached by the JRC since 2011. Stakeholders listed in italics were first approached in 2014.

Table 1. Stakeholders (European and international organisations, professional societies, patients' associations) ordered by acronym

No	Name	Activity	Website
1.	BCN – Breast Centres Network	Breast Centres Network is the first international network of clinical centres exclusively dedicated to the diagnosis and treatment of breast cancer. It is a project of ESO (European School of Oncology) with the aim to promote and improve breast cancer care in Europe and throughout the world. The network includes <i>Breast Units</i> (<i>Multidisciplinary Breast Centres</i>) that fulfil minimum requirements to be considered referral centres.	http://www.breastcentresnetwork.org/
2.	CEN – European Committee for Standardization	CEN was officially created as an international non-profit association based in Brussels on 30 October 1975. Through its services it provides a platform for the development of European Standards and other technical specifications. CEN is a major provider of European Standards and technical specifications. It is the only recognized European organization according to Directive 98/34/EC for the planning, drafting and adoption of European Standards in all areas of economic activity with the exception of electrotechnology (CENELEC) and telecommunication (ETSI).	http://www.cen.eu/cen/pages/default.aspx
3.	DGS - German Society of Senology (Deutsche Gesellshaft für Senologie)	DGS started an accreditation system as a pilot project from the University-Hospital in Tübingen in 2002. The system is now completely implemented all over Germany; more than 93% of primary breast cancer patients are now diagnosed and treated in <i>Certified Breast Cancer Centres</i> .	http://www.senologie.org/

No	Name	Activity	Website
4.	DKG – German Cancer Society (Die Deutsche Krebsgesellschaft)	The German Cancer Society (DKG) is the largest scientific and professional oncology society in Germany, based in Berlin. Overall, the DKG has approximately 6 600 members. The DKG is a public health institution that works in formal cooperation with politicians, professional societies, service and product providers in healthcare markets, and patient claims for the benefit of cancer patients. It represents the Federal Republic of Germany in international organisations such as the International Union Against Cancer (UICC) and the European Union. The DKG is linked with all European cancer societies and is actively committed to the advancement of a common European health policy.	http://www.krebsgesellschaft.de/
5.	EA - European co- operation for Accreditation	The European co-operation for Accreditation (EA) is an association of national accreditation bodies in Europe that are officially recognised by their national governments to assess and verify—against international standards—organisations that carry out evaluation services such as certification, verification, inspection, testing and calibration (also known as conformity assessment services).	http://www.european-accreditation.org/
6.	EAPC - European Association of Palliative Care	The EAPC strives to develop and promote palliative care in Europe through information, education and research using multi-professional collaboration, while engaging with stakeholders at all levels.	http://www.eapcnet.eu/
7.	EAPM - European Alliance for Personalised Medicine	Founded in 2012, EAPM brings together Europe's leading healthcare experts, healthcare organisations and institutions, and patient advocates to improve patient care by accelerating the development, delivery and uptake of personalised healthcare including personalised medicine and diagnostics. EAPM works developing case studies, organising workshops, education, training and communication.	http://euapm.eu/

No	Name	Activity	Website
8.	ECCC - European Cancer Care Certification	European Cancer Care is an association which has been appointed by Eusoma to develop the voluntary certification process of breast centres.	http://www.cancercarecert.biostatistica.net/index.php
9.	ECCO - European CanCer Organisation	ECCO is a not-for-profit federation that exists to uphold the right of all European cancer patients to the best possible treatment and care, promoting interaction between all organisations involved in cancer at European level.	http://www.ecco-org.eu/
10.	ECL - Association of European Cancer Leagues	·	http://www.europeancancerleagues.org/
11.	ECN - European Cancer Network	ECN has the scope to integrate new Member States and applicant countries into the mainstream of European efforts toward continuous improvement of best practices in secondary cancer prevention. Assistance was provided for the implementation of evidence-based screening tests for breast, cervical and colorectal cancer recommended in the Commission proposal for a Council recommendation on cancer screening which is linked to European Cooperation on Development and Implementation of Cancer Screening and Prevention Guidelines (ECCG).	http://ec.europa.eu/eahc/projects/database.html?prjno=2004309
12.	ECP - European Cancer Prevention Organization	ECP was established in the early 1980s in order to foster action to prevent cancer.	http://ecpo.org/

No	Name	Activity	Website
13.	ECPC - European Cancer Patient Coalition	Established in 2003, the European Cancer Patient Coalition is the voice of the European cancer patient community, uniquely representing the interests of all cancer patient groups. It was set up: to represent the views of cancer patients in the European healthcare debate; to enable and empower cancer patients by educating them about cancer and advocacy skills and to provide a forum for European cancer patients to exchange information and share concerns on cancer care policies in their countries and best practice experiences.	http://www.ecpc.org/
14.	EFOMP - European Federation of Organisations in Medical Physics	EFOMP is an umbrella organisation to all national member organisations (NMOs) having as their principal category of members medical physicists in Europe.	http://www.efomp.org/
15.	EMA - European Medicines Agency	EMA is a decentralised agency of the European Union. The Agency is responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union.	http://www.ema.europa.eu
16.	EONS - European Oncology Nursing Society	The European Oncology Nursing Society is a pan-European organisation dedicated to the support and development of cancer nurses.	http://www.cancernurse.eu/
17.	EORTC - European Organisation for Research and Treatment of Cancer	The aims of EORTC are to develop, conduct, coordinate, and stimulate translational and clinical research in Europe to improve the management of cancer and related problems by increasing survival but also patient quality of life.	http://www.eortc.org/
18.	ESMO – European Society for Medical Oncology	The European Society for Medical Oncology (ESMO) is a non-profit professional medical oncology society in Europe. ESMO offers post-graduate education and training in clinical cancer care and research, and produces evidence-based recommendations for basic standards of cancer care.	http://www.esmo.org/

No	Name	Activity	Website
19.	ESO - European School of Oncology	ESO has the aim of contributing to the reduction of deaths from cancer due to late diagnosis and/or inadequate treatment, by improving the skills of all health professionals dealing with cancer patients.	http://www.eso.net/
20.	ESR - European Society of Radiology	ESR is an apolitical, non-profit organisation, dedicated to promoting and coordinating the scientific, philanthropic, intellectual and professional activities of radiology in all European countries.	http://www.myesr.org/start/
21.	EUPHA - European Public Health Association	EUPHA is an umbrella organisation for public health associations and institutes in Europe. Founded in 1992, EUPHA is an international, multidisciplinary, scientific organisation, bringing together approximately 14 000 public health experts for professional exchange and collaboration throughout Europe. Its mission is to build capacity and knowledge in the field of public health, and to support practice and policy decisions through scientific evidence and producing and sharing knowledge with its members and partners in Europe. EUPHA activity is based on four pillars: Research, Policy, Practice, and Training and Education. In addition, 20 theme-specific sections are active.	http://www.eupha.org/
22.	EUREF - European Reference Organisation for Quality Assured Breast Screening and Diagnostic Services	EUREF is a pan-European organisation, widely drawn from different MSs and is operated on a non-profit making basis. EUREF commits itself to the development and dissemination of the European Guidelines, certification of breast services and mammography equipment, training and provides support and advice on such issues.	http://www.euref.org/

No	Name	Activity	Website
23.	Europa Donna – The European Breast Cancer Coalition	Europa Donna is an independent non-profit organisation whose members are affiliated groups from countries throughout Europe. It works to raise awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optimal treatment and increased funding for research. Europa Donna represents the interests of European women regarding breast cancer to local and national authorities as well as to institutions of the European Union.	http://www.europadonna.org/
24.	EUROPREV - European Network for Prevention and Health Promotion in Family Medicine and General Practice	EUROPREV aims to promote evidence-based disease prevention in general practice/family medicine in Europe.	http://www.europrev.org/
25.	EUSOBI - European Society of Breast Imaging	European Society of Breast Imaging (EUSOBI) is a society focused on breast imaging and creating unique medical and scientific standards in the field, it provides various training and fellowship programmes on breast imaging.	http://www.eusobi.org/
26.		EUSOMA is a multidisciplinary society committed to improving and harmonizing the standards of breast cancer care in Europe to make sure that all women have access to the best possible specialist breast diagnosis and treatment services.	http://www.eusoma.org/
27.	Fundación para el Fomento de la Investigación Sanitaria y Biomédica de la Comunidad Valenciana (FISABIO- CSISP)	FISABIO (the Foundation for the Promotion of Health and Biomedical Research of the Valencian Community) is a non-profit scientific and social institution, whose primary purpose is to encourage, promote and develop scientific, technical, health and biomedical research in the Valencian Community (Spain).	http://www.csisp.gva.es/

No	Name	Activity	Website
28.	G-I-N - Guidelines International network	G-I-N is a global network that supports evidence-based health care and improved health outcomes by reducing inappropriate variation throughout the world. G-I-N mission is to lead, strengthen and support collaboration and work within the guideline development, adaptation and implementation community.	http://www.g-i-n.net/
29.	GISMa – Gruppo Italiano Screening Mammografico	GISMA is the Italian multidisciplinary association that promotes the diffusion of population-based breast cancer screening programmes in Italy and monitors the quality of diagnosis and treatment offered in these programmes.	http://www.gisma.it/
30.	IACR - International Association of Cancer Registries	IACR is a professional society dedicated to fostering the aims and activities of cancer registries worldwide. It is primarily for population-based registries, which collect information on the occurrence and outcome of cancer in defined population groups.	http://www.iacr.com.fr/
31.	IARC - International Agency for Research on Cancer	IARC is the specialised cancer agency of the World Health Organization. The objective of the IARC is to promote international collaboration in cancer research.	http://www.iarc.fr/
32.	ICC - Italian Cochrane Centre	ICC is affiliated with the Cochrane Collaboration (CC). The objectives of the ICC are centred on supporting various activities of the Cochrane Collaboration within Italy.	http://www.cochrane.it/
33.	IPOS - International Psycho-Oncology Society	The International Psycho-Oncology Society (IPOS) was created to foster international multidisciplinary communication about clinical, educational and research issues that relate to psycho-oncology and primary psychosocial dimensions of cancer.	http://www.ipos-society.org/
34.	JCI - Joint Commission International	JCI works with health care organizations, governments, and international advocates to promote rigorous standards of care in three ways: accreditation, education, and advisory services.	http://www.jointcommissioninternational.or g/

No	Name	Activity	Website
35.	OECI - Organisation of European Cancer Institutes	· · · · · · · · · · · · · · · · · · ·	http://www.oeci.eu/
36.	Associazione	Senonetwork is the Italian network of breast cancer services. It has the goal of promoting the treatment of breast cancer diseases in Italy in devoted centres which respect the European standards.	·
37.	SIS – Senologic International Society	SIS is composed of non-profit associations, societies, scientific institutions, and groups, aiming to the promotion of knowledge in biology and medicine in human sciences, related to the breast, in order to establish an international federation, with the intention of advancing prevention, diagnosis and treatment of breast diseases, to spread senologic knowledge and to promote interaction with the community.	

Table 2 provides the list of international projects and networks contacted by the JRC since 2011. Stakeholders listed in italics were first approached in 2014.

Table 2. Stakeholders (international projects and networks)

No	Name	Activity	Funding
1.	Guide on Quality	Purpose of this <i>Joint Action</i> is to address comprehensive cancer care across the member states and to set the guiding principles for its achievement.	European Commission – Joint Action
2.	COMET - Core Outcome Measures in Effectiveness Trials	brings together people interested in the development and application of agreed	MRC Hub for Trials Methodology Research (HTMR) Network European Commission under the Seventh Framework Programme. NHS National Institute for Health Research (NIHR)
3.	Communication	project (running from January 2011 to 2015) whose objective is to improve the	European Commission under the Seventh Framework Programme

No	Name	Activity	Funding
4.	ECCG - European Cooperation on Development and Implementation of Cancer Screening and Prevention Guidelines		European Commission
5.		The ECHO project is an international effort to bring together the hospital databases of several European countries and make the data available via an online summary tool.	European Commission under the Seventh Framework Programme
6.	ENCR - European Network of Cancer Registries		European Commission
7.		EPAAC is a partnership that brings together the efforts of different stakeholders into a joint response to prevent and control cancer. In its initial phase, until early 2014, the work of the partnership will be taken forward through a <i>Joint Action</i> . It encompasses 36 associated partners from across Europe and over 100 collaborating partners.	European Commission – Joint Action

No	Name	Activity	Funding
8.	EUnetHTA	EUnetHTA is a network of government appointed organisations (from EU Member States, EU-accession countries, plus EEA and EFTA countries) and a large number of relevant regional agencies and not-for-profit organisations that produce or contribute to health technology assessment HTA in Europe	European Commission – Joint Action
9.	EURECCA - European Registration of Cancer Care		European Society of Surgical Oncology (ESSO); European CanCer Organisation (ECCO)
10.	•	EUREGHA is a network of 13 European Regional and Local Health Authorities focused on public health, which aim is to promote collaboration amongst regions and local authorities, more specifically regional and local health authorities in Europe, within the framework of the policies relating to public health and healthcare, as well as to establish focused collaboration with the institutions of the European Union and with the international and public organisations related to public health and healthcare throughout the world.	European Regions: Lower Austria (AT); Catalunya (ES); East of England (UK); Flanders (BE); Skåne (SE); Västra Gotäland (SE); Veneto (IT); North West of England (UK); Podlaskie (PL)

No	Name	Activity	Funding
11.	EUROCAN - EurocanPlatform	EUROCAN brings together 28 European cancer Institutions and organisations to work together in a unique collaboration. The centres share infrastructures and collaborate on projects to help advance cancer research and treatment. The aim of the project is to improve outcomes for cancer patients and reduce mortality. This is being achieved by focusing on three key areas of research: prevention, early detection and improved treatments.	European Commission
12.	EUROCARE - Survival of cancer patients in Europe		Italian Ministry of Health, Compagnia di San Paolo, CARIPLO Foundation

No	Name	Activity	Funding
13.	•	The Commission Patient Safety and Quality of Care Working Group brings together representatives from all 27 EU countries, EFTA countries, international organisations and EU bodies. The Group assists in developing the EU patient safety and quality agenda	http://ec.europa.eu/health/patient_safety/policy/index_en.htm

The individual stakeholders usually have one or more professional affiliations. A non-exhaustive list of public and private institutions contacted / met by the JRC (through one or more of their representatives or employees) is reported in *Table 3*. Institutions listed in italics were first approached in 2014.

Table 3. Public and private institutions indirectly contacted through one or more of their representatives

No	Name	Country
1.	Accredia	Italy
2.	Ambulatorio di omeopatia, Centro di riferimento regionale toscano, Ospedale Campo di Marte, Azienda USL 2 Lucca	Italy
3.	Azienda Sanitaria Locale (ASL) di Milano	Italy
4.	Breast Centre - Humanitas Cancer Centre (BCH)	Italy
5.	Champalimaud Foundation	Portugal
6.	CERMET	Italy
7.	Centre fribourgeois de dépistage du cancer du sein	Switzerland
8.	The Christie NHS Foundation Trust	United Kingdom
9.	Croatian National Institute of Public Health	Croatia
10.	Danish Health and Medicines Authority - Hospital Services and Emergency Management	Denmark
11.	Deutsche Akkreditierungsstelle GmbH (DAkkS)	Germany
12.	Direção-Geral da Saúde	Portugal
13.	Emilia-Romagna Local Health Unit	Italy
14.	Swiss cancer screening, Fédération suisse des programmes de dépistage du cancer	Switzerland
15.	Fakultní nemocnice Olomouc	Czech Republic
16.	Gesundheit Österreich GmbH	Austria
17.	Gynaecological department (women's clinic) Bürgerspital	Switzerland

No	Name	Country
18.	Iberoamerican Cochrane Centre	Spain
19.	Institut Català d'Oncologia	Spain
20.	Institute for Health Research - Lancaster University	United Kingdom
21.	Institute of Oncology Ljubljana	Slovenia
22.	Institute for Oncology Veneto	Italy
23.	Institute of Public Health of the Republic of Slovenia	Slovenia
24.	Karolinska University Hospital	Sweden
25.	Kleijnen Systematic Reviews Ltd (KSR)	United Kingdom
26.	Kooperationsgemeinschaft Mammographie GbR	Germany
27.	Lazio Regional Health Authority	Italy
28.	London Breast Institute	United Kingdom
29.	Mammografi Sverige - Unilabs AB	Sweden
30.	Mario Negri Institute	Italy
31.	Mass Screening Registry Finland	Finland
32.	Ministero de Sanidad y Politica Social	Spain
33.	Ministry for Health, the Elderly and Community Care	Malta
34.	Ministry of Health	Cyprus
35.	Ministry of Health	Italy
36.	Ministry of Health	Poland

No	Name	Country
37.	Ministry of Health of the Republic of Lithuania	Lithuania
38.	Ministry of Health, Welfare and Sport	The Netherlands
39.	Ministry of Social Affairs	Estonia
40.	Ministère des affaires sociales et de la santé	France
41.	National Cancer Control Programme	Ireland
42.	National Cancer Institute Milano (Istituto Nazionale Tumori – INT)	Italy
43.	National Health Service (NHS)	United Kingdom
44.	The Netherlands Cancer Institute	The Netherlands
45.	Onkologický ústav sv. Alžbety, s.r.o.	Slovakia
46.	Oslo University Hospital	Norway
47.	Piedmont Reference Centre for Epidemiology and Cancer Prevention (CPO Piemonte)	Italy
48.	Polytechnic University of Milan	Italy
49.	Public Association for Healthy People	Hungary
50.	Radboud University Medical Centre Nijmegen	The Netherlands
51.	Riga East University Hospital	Latvia
52.	The Royal Marsden, Downs Road	United Kingdom
53.	Scientific Institute of Public Health	Belgium
54.	Specialized Hospital for Active Treatment in Oncology	Bulgaria
55.	Syöpäjärjestöt - Cancer Society of Finland	Finland
56.	Swiss Accreditation Service (SAS)	Switzerland

No	Name	Country
57.	Tuscan Network for Integrative Medicine	Italy
58.	Tübingen University	Germany
59.	United Kingdom Accreditation Service (UKAS)	United Kingdom
60.	Università di Modena e Reggio Emilia	Italy
61.	University College Hospital, London	United Kingdom
62.	Vivantes Center for Breast Diseases	Germany

5.2 Description of events

5.2.1 Attendance at conferences / workshops / trainings as participants

JRC-IHCP staff attended 38 events in 2014.

Relevant events are listed in *Table 4*.

Table 4. Attendance at conferences / workshops / trainings as participants

No	Date	Event	Organiser	Title	Place	Impact
1.	15-16/01/2014	Training	European Centre for Disease Prevention and Control (ECDC)	Workshop on evidence-based tools and methods	Brussels (BE)	The workshop focussed on systematic reviews and evidence base methodology for developing reports, guidelines and other documents.
2.	30/01/2014	Workshop	The Italian Group for Mammography Screening (GISMa) and the National Screening Monitoring Centre (ONS) in cooperation with the Italian Cochrane Centre, the Italian Association of Epidemiology, Partecipasalute, Società Italiana di Radiologia Medica (SIRM), EUROPA DONNA and Società Italiana di Medicina Generale (SIMG)	European estimates of the mammography screening balance sheet of benefits and harms: challenges for communication and research	Bologna (IT)	The ECIBC would be the perfect platform for the development of a common standard for overdiagnosis assessment. Experience of the Informed Choice About Cancer Screening project should be taken into account in the guidelines and QA scheme development.
3.	14/02/2014	Working group	Directorate-General for Health and Consumers (now Directorate- General for Health and Food Safety – DG SANTE)	Patient Safety and Quality of Care Working Group	Brussels (BE)	A representative of Healthcare Quality Team attended the meeting in order to participate in the discussion regarding standardisation in healthcare.
4.	18/02/2014	Event	Organisation of European Cancer Institutes (OECI) European Cancer Patient Coalition (ECPC)	Event on 'How uniform is cancer care in Europe?'	Brussels (BE)	The event covered several areas of interest for the ECIBC. Issues such as cancer prevention, inequalities in cancer care, need to ensure continuity of MACs activity through the next EP elections, link between MACs and patients associations were raised.

No	Date	Event	Organiser	Title	Place	Impact
5.	13/03/2014	Working group	Directorate-General for Health and Consumers (now Directorate- General for Health and Food Safety - DG SANTE)	Patient Safety and Quality of Care Working Group	Brussels (BE)	The working group meeting focussed on the presentation of the draft reports: Reporting and learning systems for patient safety incidents across Europe and Education and training in patient safety across Europe. The reports and the findings from the Commission survey can be used as background information for ECIBC concerning patient safety issues.
6.	3/04/2014	Debate	Progress Educational Trust (PET)	Relative risk: breast cancer and genetics	London (UK)	The debate focused on the needs of the women with a high risk of developing breast cancer.
7.	3-4/04/2014	Summit	Directorate-General for Health and Consumers (now Directorate- General for Health and Food Safety - DG SANTE)	EU Summit on Chronic Diseases	Brussels (BE)	The event had a political profile. During the meeting information was gathered from all stakeholders in order to address chronic diseases effectively, in view of an ageing population and the subsequent economic pressure imposed on the national healthcare and social systems.

No	Date	Event	Organiser	Title	Place	Impact
8.	4/04/2014	International conference	CERGAS Bocconi and SDA Bocconi School of Management in collaboration with Helsinn Group	mHealth for Improving Quality of Life Enhancing Cancer Supportive Care	Milano (IT)	There is the need of developing new apps, with an effective positive impact on cancer patient outcomes (e.g. apps considered as a medical prescription, like drugs or other interventions); on the other side, some problems are emerging in this market: • lack of supporting evidence: almost no randomised controlled trials on the effectiveness of their use • no requirements for a transparent declaration of the sources of data and credentials of developers • - lack of a regulatory frame: almost anyone can produce and sell an health app.
9.	14/04/2014	Workshop	Italian Ministry of Health	European Union Network on Patient Safety and Quality of Care exchange mechanisms	Rome (IT)	Presentation of the ECIBC at the same event where European standardisation in healthcare initiatives were discussed has been shown to be a disadvantage, because people confuse the two topics and, negative concerns regarding CEN and related healthcare initiatives have been automatically associated with the ECIBC. Planned, targeted communication initiatives with experts involved in PaSQ should be a priority.

No	Date	Event	Organiser	Title	Place	Impact
10.	14-15/05/2014	Workshop	SenoNetwork	The 4th Pavia Update on Breast Cancer	Pavia (IT)	As most breast centres seeking certification in the context of the ECIBC will be reference hubs for high risk women, requirements and indicators for this subpopulation should be included in the scheme. The lack of consistency in the existing guidelines and the growing availability of a large number of new studies should also be taken into account.
11.	16/05/2014	Workshop	Deutsche Krebsgesellschaft (DKG) Union for International Cancer Control (UICC)	1st European Round Table Meeting to discuss quality of cancer care 'Improving Cancer Care in Europe – Which Institutional Health Structures are Beneficial and Why?'	Berlin (DE)	The degree of acceptance of guidelines can be increased if the entities are involved from the beginning and by offering them a model for future work. For the ECIBC, the invitation of all these stakeholders providing input for draft and final versions of the guidelines and for the QA scheme might not be considered enough to buy them in.
12.	2-4/06/2014	Conference	DECIDE Project Team	Participation of the JRC at the DECIDE International Conference	Edinburgh (UK)	DECIDE is a key partner for the European Commission Initiative on Breast Cancer

N	Date	Event	Organiser	Title	Place	Impact
11	12/06/2014	Conference	Patient Safety and Quality of Care (PaSQ) Working Group	Sharing Good Practices to Improve Quality of Care and Patient Safety in the EU	Madrid (ES)	Some of the experiences shared might be useful for the ECIBC: Professional skills accreditation programme for the Andalusian public health system, Javier Ferrero Alvárez-Rementería, ACSA (Andalucía, Spain The Italian national observatory on good practices for patient safety, Gianni Caracci, AGENAS (Italy) Expert standards in nursing, Petra Blumenberg, DNQP (Germany)
1	26-27/06/2014	Congress	GISMa (Gruppo Italiano per lo Screening Mammografico - Italian Society for Mammography Screening)	Italian Society for Mammography Screening Annual Conference 2014	Salerno (IT)	Steps should be taken towards unifying cancer care, taking into consideration the differences in the composition of the population and the different levels of economic resources. Prediction of Cancer at Screening (PROCAS) study provides a promising approach to personalised screening.

No	Date	Event	Organiser	Title	Place	Impact
15.	30/06/2014	Workshop	Polytechnic University of Milan (Italy)	Doing Research in Healthcare with Administrative Databases	Milan (Italy)	The project <i>Programma Regionale di Valutazione degli Esiti degli interventi sanitari</i> (P.ReVal.E) developed and computed some composite indicators for measuring the adherence to the clinical guidelines for diabetes and chronic pulmonary obstructive disease. It would be of interest to collaborate with them in order to develop the composite indicators for the quality assurance scheme within the European Commission Initiative on Breast Cancer (ECIBC). Other projects presented at the workshop might be of interest for the development of the ECIBC QA scheme and will require further documentation.
16.	11/09/2014	Workshop	WHO Collaborating Centre for Cancer Early Detection and Screening	Early Detection and Screening Programmes in Mediterranean Countries	Turin (IT)	The EUROMED project targets topics overlapping with the ECIBC (survey on the implementation of breast cancer screening programmes, web hub, quality assurance, etc.) for non-EU countries (with the exception of Croatia, which is now EU); some of them are involved in the ECIBC with the nomination of a national contact: Montenegro, Serbia, Turkey. Material produced by EUROMED might be used as a resource complementing information obtained from EU countries. The Healthcare Quality Team should consider approaching the European Society for Breast Imaging (EUSOBI) as a relevant stakeholder.

No	Date	Event	Organiser	Title	Place	Impact
17.	15-17/09/2014	Conference	Centre for Evidence-Based Medicine at the University of Oxford in partnership with the BMJ, The Dartmouth Institute for Health Policy and Clinical Practice and Bond University—Australia	Preventing Overdiagnosis 2014	Oxford (UK)	Overdiagnosis is still a debatable and complex subject. Efforts have been made to estimate the problem, to discuss it and to reduce it. It can be seen from three different points of view: the patient, the clinician and the payer. The European Commission Initiative on Breast Cancer should take into account the issue.
18.	18/09/2014	Seminar	Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, in collaboration with INGM, FAST and "Donne e tecnologie"	'Le app in medicina: regole, best practices e responsabilità' (The apps in medicine: rules, best practices and responsibilities)	Milan (IT)	 The seminar highlighted three main topics: Legal aspects to be considered (privacy, medical device, responsibility) to develop and release applications for mobile smartphones. Give clear and complete information on results presented and calculations performed (official paper, trusted website, etc.). There is a real demand for apps to support health professionals and patients.
19.	23-24/09/2014	High level meeting	Directorate-General for Health and Consumers (now Directorate- General for Health and Food Safety - DG SANTE)Public Health Programme Management and Diseases	1st Meeting of the Commission Expert Group on Cancer Control	Milan (IT)	JRC may suggest to DG SANTE some topics for funding of the next Health Programme (e.g., randomised control trials on alternative and complementary medicine)
20.	13/10/2014	Workshop	Senonetwork	Senonetwork: incontro centri di senologia 1.0	Milan (IT)	The heterogeneity of quality assurance schemes, data collection procedures and databases reinforces the need of the two JRC reports foreseen in 2015 on those topics.

No	Date	Event	Organiser	Title	Place	Impact
21.	30-31/10/2014	Conference	EUnetHTA	HTA 2.0 Europe – Teaming Up for Value	Rome (IT)	EUnetHTA is a key stakeholder for the ECIBC, in particular for the development of the new European guidelines on breast cancer for screening and diagnosis and for the platform of guidelines. The JRC should ask EUnetHTA which team could apply the 'HTA Core model' to evaluate the effects of breast cancer screening programmes.
22.	3-4/11/2014	Conference	Italian Presidency of the Council of European Union	Conference on Quality, Safety and Cost-Effectiveness	Rome (IT)	The conference addressed several topics relevant to PHPS activities. The new Council Conclusions on patient safety promoted during the Italian Presidency will be published very soon. The 2014 edition of the 'Esiti' ('Outcomes') programme in Italy has been recently published and presented. The JRC should contact the project representative in order to investigate how 'Esiti' data could be used to analyse the relationship between volume and outcomes in breast cancer.

No	Date	Event	Organiser	Title	Place	Impact
23.	4/11/2014	Event	Quaestor of the European Parliament European Society of Radiology (ESR)	European Society of Radiology (ESR) Launch Event on the 'Call for a European Action Plan for Medical Imaging'	Brussels (Belgium)	The ESR developed a 'European Action Plan for Medical Imaging' (http://www.myesr.org/html/img/pool/EN_Backgr ound_doc_final.pdf) to improve quality of care and patient safety. The aim of the 'European Action Plan for Medical Imaging' is to call on the European institutions to focus on reforms necessary to achieve and strengthen innovative and sustainable health systems and to emphasise issues of key importance to imaging. It also targets harmonisation at European level in the areas of: quality & safety, education & training, research, e-health.
24.	4/11/2014	Event	European Voice	European Voice Health Check Annual Forum: EU Healthcare 2014-2019: what's on the agenda?	Brussels (Belgium)	The event (http://www.development-institute.com/en/sitededie/41/healthcheck_foru m/event) was directed at key policy makers, international business leaders and industry specialists. The following topics were discussed: • Latest regulations affecting the healthcare sector post-European elections opportunities; • Challenges and priorities facing health in Europe for the next 5 years; • Ideas with policy makers and industry leaders on solutions to make healthcare innovative, cost-effective and sustainable.

No	Date	Event	Organiser	Title	Place	Impact
25	19 – 20/11/2014	Workshop	COMET	Core Outcome Measures in Effectiveness Trials (COMET IV) meeting	Rome (Italy)	COMET: its support is key for a number of activities of the ECIBC: • Guidelines on breast cancer screening and diagnosis • Alternative therapies in oncology Core Outcomes in Women's Health (CROWN) Initiative (http://www.crown-initiative.org/): key stakeholder for the guidelines on breast cancer screening and diagnosis.

5.2.2 Attendance at conferences / workshops / trainings as presenters

Table 5 presents the list of events held in 2014 where the JRC gave presentations related to the ECIBC.

Table 5. Attendance at conferences / workshops / trainings as presenters

No	Date	Organiser	Event	Location	Presentation
1.	5-7/02/2014	International Breast Disease Centers (IBDC)	4 th International Congress of Breast Disease Centers 2014	Paris (FR)	The EU vision
2.	11/02/2014	European Parliament	Lunch Meeting on Advanced Breast Cancer	Brussels (BE)	JRC contribution to improvement of patient outcomes: a Europe-wide and evidence-based initiative on breast cancer
3.	18-21/03/2014	European CanCer Organisation (ECCO)	European Breast Cancer Conference (EBCC9)	Glasgow (UK)	The Joint Research Centre position EU voluntary accreditation scheme for breast cancer services and revision / integration of the European guidelines The EU dual project for breast cancer services: ongoing and planned activities for screening
4.	17/06/2014	EUROPA DONNA Italy	'TUMORE AL SENO - Dalla prevenzione alla cura di qualità - Il ruolo del volontariato' (Breast cancer - From prevention to quality of treatment - the role of voluntary)	Milan (IT)	L'iniziativa della Commissione Europea per il tumore al seno: un servizio per le donne Europee

No	Date	Organiser	Event	Location	Presentation
5.	23-24/06/2014	European science open forum (ESOF)	ESOF 2014	Copenhagen (DK)	Cancer screening: indications, benefits and myths
6.	24-28/06/2014	International Association of Cancer Registries (IACR) and North American Association of Central Cancer Registries (NAACCR)	Annual Conference of the International Association of Cancer Registries (IACR) and the North American Association of Central Cancer Registries (NAACCR)	Ottawa (Canada)	European voluntary accreditation scheme for breast cancer services: an important step for cancer data standardization
7.	18-19/09/2014	European Organisation for Research and Treatment of Cancer (EORTC)	EORTC Quality of Life Group Autumn Meeting	Venice (IT)	A general presentation about the healthcare team and the ECIBC
8.	27-28/09/2014	European Society for Medical Oncology (ESMO)	ESMO 2014 Conference	Madrid (ES)	Communication to patients and from patients: what should be included in a European quality assurance scheme?
9.	13/10/2014	ASL Varese Progetto Mattone Internazionale	'La progettazione europea nell'ambito di Horizon 2020 e del 3rd European Health Programme 2014- 2020	Induno Olona (IT)	JRC e Commissione Europea: progetti sulla salute pubblica

No	Date	Organiser	Event	Location	Presentation
10.	21-24/10/2014	International Psycho- oncology Society	Conference	Lisbon (PT)	Poster: The European Commission Initiative on Breast Cancer: a project focusing on women
11.	12/11/2014	Progetto Mattone Internazionale	Workshop	Rome (Italy)	Ensure overall quality of care when crossing borders: European web hub on breast cancer
12.	12-14/11/2014	European Network of Cancer Registries (ENCR)	Conference	Ispra (IT)	Poster: The European Commission's Initiative on Breast Cancer: a challenge for standardisation of breast cancer data
13.	20 – 21/11/2014	European Cancer Prevention Organization	Annual Meeting	Hasselt (BE)	Breast cancer screening and early detection: the European Commission Initiative on Breast Cancer - ECIBC

5.2.3 Meetings with EC institutions

The HQ team participated in the *Patient Safety and Quality of Care Working Group* meetings coordinated by DG SANTE on a regular basis. The JRC also had meetings with DG SANTE, DG GROW, DG RTD and EMA. These events are not described as they do not fall under the scope of this report.

5.2.4 Attendance at events related to the CANCON joint action

In 2014, the JRC participated in several events organised within the framework of the CANCON joint action. A presentation entitled *Potential areas of collaboration of the Joint Research Centre with CANCON WP9* was given at the CANCON WP9 (Cancer Screening) kick-off meeting.

Table 6. JRC participation at CANCON events

No	Period	Meeting	Location
1.	11-13/03/2014	Participation of the JRC at the CANCON kick-off meeting	Luxembourg (LU)
2.	22-23/05/2014	Participation of the JRC at the CANCON WP9 (Cancer Screening) kick-off meeting	Helsinki (FI)
3.	06/06/2014	Participation of the JRC at the CANCON Stakeholders Forum	Brussels (BE)
4.	23/09/2014	Participation of the JRC at the CANCON Guide Coordination Committee meeting	Milan (IT)
5.	24/09/2014	Participation of the JRC at the CANCON Joint Action Steering Committee meeting	Milan (IT)
6.	24/09/2014	Participation of the JRC at the CANCON WP5 – MS Open Forum meeting	Milan (IT)

5.2.7 Bilateral meetings with organisations or individual experts

In 2104, 12 bilateral meetings including videoconferences, teleconferences and on-site meetings were organised with some of the stakeholders included in *Tables 1 to 3*.

5.3 ECIBC updates

Preparatory activities performed for the ECIBC in 2014 included literature searches, outsourcing of supporting services for the ECIBC tasks (Information Technology services for the concept and development of the web-hub and services for the development and piloting of the European QA scheme), stakeholder meetings, participation in external events and publishing of the reports: 'Report of a European survey on the organisation of breast cancer care services - Supporting information for the European Commission initiative on breast cancer' and 'European Commission initiative on Breast Cancer-ECIBC: Organisation of project guiding and support meetings - Meetings 2011-2013'.

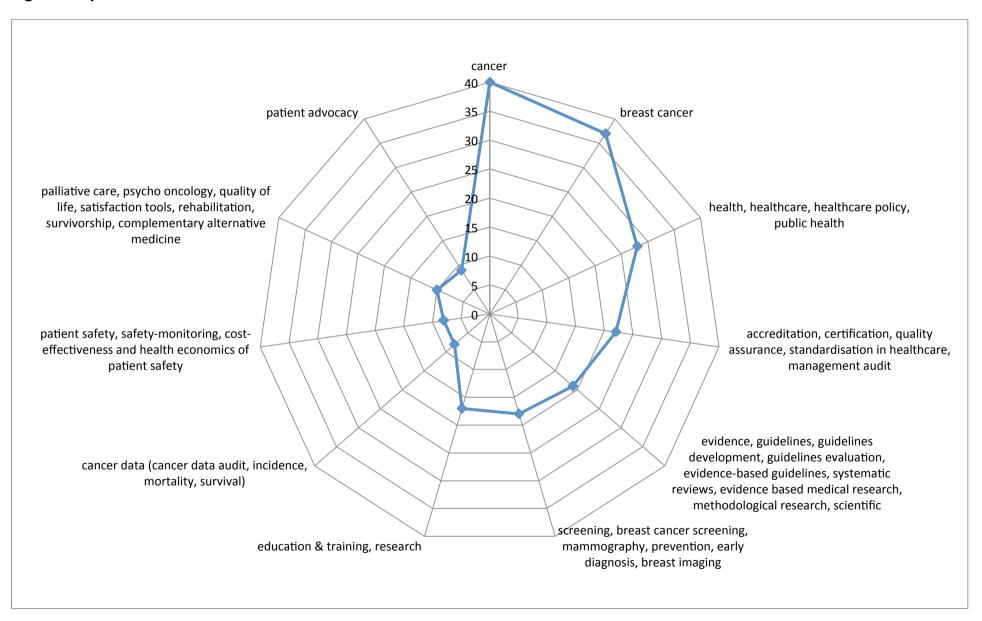
Another important step for the ECIBC was the publication on DG SANTE website of the calls for expression of interest in for participation in the working groups:

- Guidelines Development Group (GDG) to support the Commission in developing a new version of the European Guidelines for Breast Cancer Screening and Diagnosis based on new knowledge and evidence:
- Quality Assurance Scheme Development Group (QASDG) to support the Commission in developing
 a voluntary European quality assurance (QA) scheme for breast cancer services based on the EU
 legislative framework on accreditation and on the guidelines.

5.4 Meetings analysis

An analysis, taking into account the stakeholders profiles, was performed in order to identify areas where improvements in the collaboration and networking in support of the ECIBC should be made. ECIBC-defined keywords were assigned for each meeting. Besides the ECIBC keywords (cancer, breast cancer, health, healthcare, accreditation, quality assurance, certification, evidence, guidelines, guidelines development, guidelines evaluation, evidence-based guidelines, screening, breast cancer screening, mammography, prevention, early diagnosis, breast imaging, public health), several others were identified based on each meeting's context (e.g., education & training, research, cancer data, patient safety, patient advocacy) and were included in the analysis. Then, the keywords were grouped into clusters. The majority of the meetings focused on cancer, breast cancer, accreditation, certification and quality assurance. Topics like education, training and research in the context of the ECIBC also arose during the meetings. In addition, general subjects such as patient safety and patient advocacy were topics of discussion as well. A diagram showing the results of the analysis can be seen in Figure 1. In the diagram, the numbers reflect the frequency of the keywords allocated to the meetings and not the total number of meetings. Based on these numbers, decisions concerning networking and collaboration priorities can be made.

Figure 1. Synthetic overview on area of interest for the ECIBC



6 Conclusions

- The aim of both bilateral meetings and participation in external events was to give visibility to the
 ECIBC and to involve stakeholders as much as possible. The meetings include different type of
 stakeholders, such as professional organisations, patients' organisations, scientific networks,
 accreditation/certification bodies, policy makers, research, training and educational organisations.
- In 2014, the bilateral meetings were organised with entities working in the area of accreditation, cancer data audit, cancer screening, certification, clinical trials, complementary and alternative medicine, composite indicators, education, evidence-based medical research, guideline development, guideline implementation, health technology assessment, mammographic screening, medical imaging, methodological research, public health, quality of life, quality of treatment, radiology, research, risk assessment, safety monitoring, satisfaction tools, scientific evaluation and training.
- Now the ECIBC is known at European level and the majority of the stakeholders have a positive
 attitude towards the project. However, i) the JRC should continue to present updates about the
 ECIBC during future European and international events and ii) continue meeting stakeholders in
 order to facilitate their involvement in the project.

7 Future perspectives

In addition to the working groups' meetings organisation, the JRC will continue scan the horizon for detecting new projects relevant for the ECIBC, plan meetings with stakeholders, based on Figure 1 and to attend relevant external events.

While ECIBC's activities are ongoing, a report similar to this is planned on an annual basis in order to maintain transparency on how the JRC collaborates with stakeholders and to acknowledge their contribution to the ECIBC. The JRC plans to develop a strategy for encouraging participation in the piloting / implementation phase of the QA scheme, in order to ensure that adhesion to the QA scheme (and to the Guidelines) will be extensive and impactful.

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We also wish to acknowledge the contribution and support of all the stakeholders we met and contacted thus far; without their inputs we would not have been able to design the ECIBC appropriately. We count on their continued support for being able to provide Europe the expected healthcare quality tools (guidelines and associated QA scheme) for addressing inequalities in breast cancer care.

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