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The European Commission Initiative on Breast Cancer (ECIBC): Plenary 2015

Improving breast cancer screening, diagnosis and care in Europe

9-11 December 2015, Baveno, Italy

Anke Bramesfeld, Massimo Ambrosio, Silvia Deandrea, Cristiano Gusmeroli, Jesús López Alcalde, Luciana Neamtiu, Liisa Pylkkänen, Zuleika Saz-Parkinson, Aslı Ulutürk, Donata Lerda

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The European Commission Initiative on Breast Cancer (ECIBC): **Plenary 2015**

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Joint Research Centre

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Thanks to the active participation of many experts and countries' delegates, the Plenary of the ECIBC managed to be a fruitful occasion not only for informing stakeholders but, most importantly, for gathering important inputs on the activities planned and carried out so far.

The ECIBC is coordinated by the JRC and supervised by DG SANTE: the continued support of the JRC hierarchy and of DG SANTE colleagues is essential and we wish, therefore, to take this occasion to, once more, forward our thanks to both teams and hierarchies.

Finally, we cannot be more thankful to some JRC colleagues: Brigitte Westritschnig and Chiara Margagliano for their invaluable support in the organisation of all ECIBC events and of the Plenaries in particular, and Manuel Florensa-Molist for designing and finishing all the dissemination material, including this report.

Picture 1: *Participants to the 2015 ECIBC Plenary.*

Abstract

The second plenary of the European Commission Initiative on Breast Cancer (ECIBC) took place from the 9 to the 11 December 2015 in Baveno, Italy. The purpose of the ECIBC Plenaries is to inform stakeholders on the activities of the ECIBC while at the same time seeking their feedback. The ECIBC was endorsed by members of the European Parliament during the Plenary through video messages by Anneli Jäätteenmäki, Vice-President European Parliament, and Alojz Peterle, President of the Member of Parliament's (MEP) Against Cancer.

The 2015 edition of the Plenary, entitled 'Improving breast cancer screening, diagnosis and care in Europe', included updates on the ECIBC, highly relevant keynote speeches, and presentations both on related projects and on the situation of breast cancer services in different countries.

In addition it focused, via dedicated parallel sessions, on four topics relevant for the ECIBC that, even if they have been debated for some years, are at present still largely under discussion:

- continuity of care;
- communication (and its assessment) in person-centred services;
- key outcomes for studies on breast cancer screening;
- volume-outcomes relation in breast cancer care.

Participation to the conference was only upon invitation. Ninety-seven persons from outside the JRC participated in this meeting, representing policy makers, patients, stakeholders, as well as representatives from other European Commission Directorates-General.

While the JRC staff provided and overview of the ECIBC progress, chairs of the two working groups, the Guidelines Development Group (GDG) and Quality Assurance Scheme Development Group (QASDG) presented interim outputs and plans of the two ECIBC pillars.

During the Event, the dates for 2016 Plenary were announced and the ECIBC web hub was launched. The web hub will constitute the interface of the project with all stakeholders, including citizens, enabling them to find useful information on the progress of the project in the development phase and, in future, the guidelines and requirements defining the quality benchmark to be achieved by breast cancer services throughout Europe.

Overall, participants judged the 2015 Plenary as meeting their expectations concerning the content and organisation of the event and provided valuable suggestions for aspects that may still be improved. In summary, the 2015 ECIBC Plenary succeeded both in informing stakeholders, while seeking their feedback and endorsement, and in further shaping the ECIBC pillars.

The ECIBC will continue to provide a platform for networking at the interface between research and policy. The ECIBC Plenaries aim at promoting a factual dialogue between science, clinicians, policy makers and administration, and, last but not least, patients in order to improve care for women confronted with breast cancer.

1. Introduction

The ECIBC Plenaries are set up to inform Member States and accessing countries, patients and other stakeholders, policy makers and the scientific and health-policy community about the aims, activities, and achievements of the ECIBC, while at the same time seeking their feedback and input. Furthermore, the Plenaries also aim to get policy makers and stakeholders, active in breast cancer care, linked and engaged with the ECIBC initiatives. The 2015 edition, focused on topics under the limelight in healthcare research, was structured in three parts:

1. Current state of ECIBC-projects. This included the JRC reporting on:

    - the voluntary European Quality Assurance Scheme for Breast Cancer Services (the *European QA scheme*)
    - the European guidelines for breast cancer screening and diagnosis (the *European Breast Guidelines*)
    - the platform of guidelines for all breast cancer processes (the Platform)
    - the web hub to host all ECIBC deliverables (launched during the first day of the Plenary)
    - surveys and research activities carried out at JRC to support the ECIBC (organisation of breast cancer services in Europe, conformity assessment for breast cancer services in Europe, a review of existing quality assurance schemes and other ongoing research).

2. Current key topics in breast cancer care research. This part of the meeting included presentations on:

    - The Concept of patient centred care in measuring the quality of health services
    - Dealing with evidence from qualitative research in guideline development
    - Clinical practice guidelines: International consensus on methodological standards
    - Other Projects on Cancer from EU-countries and abroad, covering CanCon, EU-TOPIA, US-Breast Centre Accreditation, and the European Network of Cancer Registries.

Additionally, parallel workshops were organised in order to address the following topics: 1. Continuity of care, 2. Communication in person-centred services, 3. Key outcomes for studies on breast cancer screening, and 4. Volume-outcome relation in breast cancer care.

3. The needs for ECIBC implementation covering:

- Country profiles on breast cancer care (posters and oral presentations)
- Equity of access to breast cancer screening programmes
- Experiences from patient advocacy
- Posters with National Accreditation Bodies activities in the field of breast cancer care

During the final wrap-up session, in addition to drawing conclusions on how the topics discussed could impact on the ECIBC, the dates of the 2016 edition of the ECIBC Plenary were announced (24th and 25th November 2016).

2. Organisation and participants

The second plenary of the ECIBC took place from the 9 December until 11th December 2015. Meeting venue was the Grand Hotel Dino in Baveno, Piedmont, Italy.

Participation to the conference was only upon invitation. As from 20th August 2015, the Plenary dates were announced to invitees via email and with a short description of the event's scope. The official invitations to participants were sent out on 5th November 2015 and the registration was open between 19th and 30th November 2015.

Members of the European Parliament, all ECIBC National Contacts, representatives of National Accreditation Bodies of European countries, the members of the two ECIBC working groups, Guideline Development Group (GDG) and the Quality Assurance Scheme Development Group (QASDG), cooperation partners of the ECIBC, representatives of European associations dealing with breast cancer screening, diagnosis and treatment, representatives of patient organisations, researchers and clinicians were invited.

97 persons from outside the JRC participated in the meeting, of whom 22 gave a presentation during either the plenary session or one of the parallel workshops.

The agenda and Plenary concept was made available via e-mail to all persons invited. After the event, and upon written consent, presentations and the list of participants were posted on the ECIBC web hub.

Each session was moderated by the host, the JRC. Most of the sessions were held as plenaries, apart from four parallel workshops that were offered during the second day. Each of these parallel workshops was chaired by experts in the field together with a representative of the JRC Healthcare Quality Team. Rapporteurs reported on progress and outcomes of workshops during the third day. Key note speeches were held during the morning of the second and third day.

Annex 1 contains the biographies of speakers and *Annex 2* the list of the final 97 participants from outside the JRC.

All presentations are available at the link ECIBC web hub – Plenary 2015 page,[1] were a Flash Report of the Plenary 2015 is also available.

1. http://ecibc.jrc.ec.europa.eu/-/plenary-of-the-european-commission-initiative-on-breast-cancer-ecibc-improving-breast-cancer-screening-diagnosis-and-care-in-europe-.

3. Agenda and presentations

Each of the three days was characterised by an ECIBC-related thematic focus:

- The first day included welcome notes and reports on the current activities and projects of ECIBC.
- The second day comprised reports on national, European, and international activities and projects related and relevant to the ECIBC. The afternoon was dedicated to parallel workshops.
- During the third day, results from the parallel workshops were presented, last-minute presentations were held and an outlook on the event and on the ECIBC concluded the Plenary.

The final agenda (found in *Annex 2*) and presentations were as follows (see also the details available on the ECIBC web hub: ECIBC web hub – Plenary 2015 page[2]):

3.1. Day 1: ECIBC current state

3.1.1. Welcome & Opening

Video message: (Anneli Jäätteenmäki, Vice-President European Parliament) https://www.youtube.com/watch?v=3LIlRFWxAsE.
Video message: (Alojz Peterle, President of the MEPs Against Cancer, European Parliament) https://www.youtube.com/watch?v=W6UCgYyCyZk.
Welcome note (Krzysztof Maruszewski, JRC).

- *EC policies on (breast) cancer* (Michael Hübel, DG SANTE)

  The European Union has been active on cancer prevention and control since 1985. Cancer screening is a cornerstone of this approach. In the 2003 Coun-

2. http://ecibc.jrc.ec.europa.eu/-/plenary-of-the-european-commission-initiative-on-breast-cancer-ecibc-improving-breast-cancer-screening-diagnosis-and-care-in-europe-.

cil recommendations on cancer screening, the Council set out principles of best practice in the early detection of cancer, and invited all Member States to take common action to implement national population-based screening programmes for breast, cervical and colorectal cancer, with appropriate quality assurance. European Guidelines for quality assurance for breast, cervical and colorectal cancer screening have been developed as benchmarks on how to go about screening. Based on this work, DG Health and Food Safety have requested the Commission's Joint Research Centre to develop a new version of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis, and a voluntary European Quality Assurance scheme for Breast Cancer Services underpinned by accreditation and evidence-based guidelines – the European Commission Initiative on Breast Cancer.

- *Patients' expectations on EC-(breast) cancer policies* (Susan Knox, Europa Donna)

  EU policy provides the framework for improving and defining standards for breast cancer services in the EU and beyond. The EC 'European Guidelines for quality assurance in breast cancer screening and diagnosis' published in 2006 provided the basis for Europa Donna to advocate for the key priorities of screening and treatment in specialist breast units. Our short guide based on this document was translated into 17 languages and countries outside the EU are using it as well. ED has also worked on getting important Resolutions and Declarations on breast cancer passed by the European Parliament. For the last 10 years we have worked with the Commission on disseminating information and providing training concerning EU guidelines to member countries. This has led to the development of the ECIBC for which we have the highest expectations; Europa Donna views this as the culmination of our advocacy work for the last seven years.

Current state of the ECIBC project

- *ECIBC overview* (Donata Lerda, JRC)

  The European Commission (EC) launched the European Commission Initiative on Breast Cancer (ECIBC). It is a project to support European countries

with a harmonised and benchmarked policy for improving breast cancer care quality while reducing inequalities. Over the past 20 years, many guidelines have been made available at national/regional/local level, and quality assurance (QA) schemes have been developed and are running across EU. However, an evidence-based approach was not always applied and the auditing systems are diverse. The JRC, coordinator of ECIBC upon DG SANTE's mandate, with the invaluable collaboration of ECIBC National Contacts, patients' associations and experts, has mapped out how breast cancer services are organised in Europe, what ISO standards are applied in breast cancer care, what is the availability of breast cancer data, and what breast cancer QA schemes are present. The next steps are (i) to develop evidence-based guidelines, (ii) to set-up a modular, flexible and voluntary QA scheme underpinned by that evidence and by Regulation (EC) No 765/2008 on accreditation, including training requirements and a dedicated website.

- *Development of a voluntary European Quality Assurance Scheme for Breast Cancer Services* (Francesco Sardanelli, ECIBC-QASDG vice chair)

  The Quality assurance team developing the *European QA scheme* consists of the ECIBC coordination team, the secretariat, the QASDG, contributing non-QASDG members, such as the European Cooperation for Accreditation, scientific advisors, and external experts.

  The QASDG is presided by a chair and a vice chair, managed by a steering group and structured according to sub-groups dealing with the following subjects: Testing, Glossary, Organisation, Indicators and Certification.

  The QASDG working modalities are based on agreed rules of procedure that have already been approved. They foresee that

  - the *European QA scheme* is built on the basis of best available evidence and best professional practice, taking into account the legal and policy context,
  - evidence is gathered from the European Guidelines for Breast Cancer Screening and Diagnosis and the Platform of guidelines for processes of care other than screening and diagnosis,

- requirements will be established using the methodology of Delphi rounds, including, apart from the requirements stemming from the guidelines, also existing requirements obtained via calls,
- both the scope of the scheme (at the initial stage) and the final scheme, including specific requirements will be enhanced by a call for feedback,
- the scheme will be piloted before implementation.

The frame of the *European QA scheme* will be shaped by (a) the requirements applied by the national accreditation bodies to accredit the certification bodies that want to assess the quality of care of clinical processes and (b) the specific requirements for breast cancer services to attain the certification. In addition, national accreditation bodies will accredit laboratory and testing.

The next step is a public call for feedback on the *European QA scheme* scope, to be launched by February 2016.

- *Development of European guidelines for breast cancer screening and diagnosis* (Chris de Wolf, ECIBC-GDG co-chair)

The guideline development team consists of the ECIBC coordination team, the secretariat, the GDG, and contributing non-GDG members, such as the systematic review team, represented by the Iberoamerican Cochrane Centre, scientific advisors, and external experts.

The GDG is presided by both a chair and a vice chair responsible for the content and a chair and a vice chair responsible for ensuring a rigorous methodological approach. It is managed by a steering group and structured according to task forces dealing with the following subjects: Glossary, Guideline development methods, Citizens' and stakeholders' involvement, and Dissemination evaluation and chapters' subgroups (Screening, Diagnosis, Communication, Training, Interventions to reduce Inequalities, Monitoring and evaluation of screening and diagnosis).

The GDG working modalities are based on agreed rules of procedure that are being approved. It is also foreseen that:

- guideline recommendations will be selected following the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach,
- the group will be working in onsite meetings as well as by online cooperation using the Communication and Information Resource Centre for Administrations, Businesses and Citizens (CIRCABC) and the GRADE's software for Guidelines Development (GDT),
- the guidelines will be enhanced by calls for feedback both on their scope (at the initial stage) and on the final version.

Currently the GDG is collecting PICO questions to build the evidence basis for the guideline. The next step is a public call for feedback on the *European Breast Guidelines*' scope, to be launched by January 2016.

- *Guidelines platform and web hub* (Liisa Pylkkanen, JRC; Luciana Neamtiu, JRC)

While the ECIBC will use the future *European Guidelines for Breast Cancer Screening and Diagnosis* as the baseline for developing the *European QA scheme* for the screening and diagnosis processes, evidence for other care processes will come from national and international guidelines developed by other entities. Therefore, high-quality evidence-based guidelines will be collected in a Guidelines Platform. The goal of this platform is to provide healthcare providers and citizens with clear and objective guidance on all breast cancer services and promote informed decisions. The process to search, evaluate, update, and host these guidelines will be located in the ECIBC web hub. The web hub will be the interface of the ECIBC with the public.

- *Surveys and research activities: breast cancer screening and care in Europe, implemented breast cancer quality assurance schemes, and standards used in breast cancer care* (Silvia Deandrea, JRC; Aslı Ulutürk, JRC)

Developing a single European quality assurance scheme and guidelines applicable in all Member States, as foreseen by the ECIBC, is highly complex. In order to encompass different healthcare systems' settings and the related quality systems within each country, a series of research activities was carried-out covering Member States and associated countries. A first survey in 2012-2013

evaluated the structures of breast cancer services (http://ecibc.jrc.ec.europa.eu/-/report-lbna26591); a second survey in 2013-2014 assessed the use of ISO accreditation, certification and conformity assessment for breast cancer services under National Accreditation Bodies' governance (http://ecibc.jrc.ec.europa.eu/-/report-lbna27382); and a study reviewed existing quality assurance programs and healthcare accreditation of breast cancer services (http://ecibc.jrc.ec.europa.eu/-/report-lbna27382enn). Furthermore, a study, co-authored with the Fundación para el Fomento de la Investigación Sanitaria y Biomédica de la Comunitat Valenciana (FISABIO), collected data for breast cancer screening programmes general indicators and explored the equity of access to those programmes; related papers are being submitted for publication. Finally, data collected from a survey, co-organised with Europa Donna and Fatima Cardoso, are currently under evaluation: the survey looked at the implementation of the European Parliament Resolution on breast units. Information from all these research activities provides a comprehensive overview on the reality of breast cancer care in Europe and important background information for the development of the ECIBC objectives.

3.2. Day 2: Current topics in breast cancer care research

3.2.1. Keynote

- *The Concept of patient centred care and measuring the quality of health services* (Chris Graham, Picker Institute)

  Over the last two decades, the concept of person (or patient) centred care has become increasingly prominent in health services across the world. The aim of person centred care is to provide health services in a way that respects and responds to the knowledge, preferences, needs, and values of individual service users. At the core of the approach is the principle that users of health services should have a role in assessing the quality of care, by being given the opportunity to provide feedback about their own experiences. Measures of 'patient experience', including but not limited to patient surveys, are now widely used to assess the extent to which care is person-centred. This talk will trace the development of person-centred care and, alongside it, the increasing importance

Picture 2: *Audience to the 'Current state of the ECIBC project' session.*

of measuring and using patient experience. This will address the role of patient feedback in measuring and understanding service quality, with examples from cancer care and chronic disease settings.

3.2.2. Practice and challenges in assuring the quality of breast cancer care in Europe

The current status of breast cancer care was presented for *Hungary* (by Kitti Horváth, Chief Medical Officer's Office, Hungary), *Malta* (by Miriam Dalmas, Ministry for Energy and Health, Malta) and *Norway* (Solveig Hofvind, Cancer Registry of Norway). These countries do not only differ in their structural preconditions, with Hungary being a new Member State of 10 million inhabitants, Malta, a rather small state with about half a million inhabitants, and Norway a wealthy EFTA country, but also with regards to their organisation of breast cancer screening, care and quality assurance.

Breast cancer care and implemented quality assurance – A report on Hungary

Hungary is a middle-income Central-Eastern European country, which joined the EU in 2004. It currently has 9.87 million inhabitants. The cancer burden is rather heavy. Overall cancer mortality rate in 2013 was the highest among the EU28. Regarding breast cancer incidence, 34.7/100.00 new cases and 25.0/100.000 fatal cases were reported.

The Chief Medical Officers' Office, on behalf of the National Public Health and Medical Officers Services (ÁNTSZ) carries the task for organisation, coordination, monitoring and evaluation of breast cancer screening. For overall cancer care the National Cancer Institute bears the professional responsibility. Population-based organised breast screening facilities in Hungary are available since 2002; 42 Breast Screening Centres have been contracted by tender. Each centre has been connected with other elements of breast cancer care, forming a Breast Unit, as defined by the *European Guidelines* 4th edition (2006).

The National Screening Registry regularly receives feedback from the mammography units about all indicators. With appropriate interpretation of these data, quality assurance for breast cancer screening can be guaranteed.

Breast cancer care services in Malta

Aim: Patients diagnosed with breast cancer in Malta are navigated through several different cancer care services. These services are provided at different healthcare facilities and by different groups of professionals. This presentation will illustrate the breast cancer care services in Malta.

Background: The Republic of Malta consists of three main islands, Malta, Gozo and Comino, forming an archipelago in the Mediterranean Sea that has the highest population density in Europe combined with the lowest total population of any European Union (EU) Member State. In 2011, life expectancy at birth was 78.4 years for men (compared with 77.4 years for the EU as a whole) and 82.6 years for women (compared with 83.2 for the EU).

In 2013, there were 1687 new cancers registered in Malta. Of these, 309 were primary cancers of the female breast. There were 848 deaths attributed to cancer. These included 83 deaths attributed breast cancer. The 5-year relative survival from female breast cancer published in EUROCARE-5 stood at 81%.

Breast cancer care services: National population-based breast screening was introduced in 2009. Women aged 50-65 years are being invited for a mammographic screening every three years. A Breast Clinic at the main general hospital (Mater Dei Hospital – MDH) has been in operation since 2000. The clinic is led by two breast surgeons. These surgeons manage the vast majority of breast cancer cases diagnosed and treated in Malta. A multi-disciplinary team (MDT) meeting takes place every Thursday and during this meeting new cases referred by the screening programme or arising through the symptomatic route are discussed and a cancer care pathway is mapped for each patient. Individual patients may be re-discussed in more than one MDT session. In most cases, the imaging and pathological examinations and all surgical procedures are carried out at MDH. Oncology treatment (including all radiotherapy) is given at the Oncology Centre. A new Oncology Centre on MDH grounds was opened in the summer of 2015. A specialized palliative care unit operates from the Oncology Centre. Palliative care in the community is coordinated and provided by Hospice Malta which is a non-governmental organisation.

In Malta, comprehensive breast cancer care is offered in cancer centres. These centres have not been yet made subject to any specific legal or regulatory requirements or been included in a national or international accreditation or certification system. However, there is work in progress to introduce a system of quality assurance.

Norway

Norway has a long standing, well established and refined system of public health registries. Data from different registries can be linked by personal identifiers. Thus comprehensive person-related routine data are available and can be used to evaluate and quality assure breast cancer screening, diagnosis and treatment.

3.2.3. Together for improving care for (breast) cancer: other projects on cancer from EU and abroad

- *CANCON* (Tit Albrecht, National Institute of Public Health, Slovenia)

  The Joint Action CANCON (Cancer Control) is focusing on the quality improvement in four important areas of cancer control: (i) development of comprehensive cancer care networks, (ii) community cancer care, (iii) survivorship issues, and (iv) guidance on several existing or potential screening programmes. In the latter, several challenges and new knowledge have shed new light on how screening programs should be organised. A work package on screening is exploring guidance on cervical, breast, colorectal, prostate, lung and stomach cancer. This should provide an up-to-date knowledge and advice to policymakers on how to act in the face of the challenges arising from these screening programmes. The listed core topics will each prepare a comprehensive chapter for the publication entitled European Guide for Quality Improvement in Cancer Control, which will be published at the end of the project and presented at the final conference, which will be one of the events of the Maltese Presidency to the Council of the European Union.

- *EU-TOPIA: Towards improved screening for breast, cervical and colorectal cancer in all of Europe* (Harry de Koning, Erasmus University)

  Breast, colorectal and cervical cancer cause 250 000 deaths each year, representing 20 % of EU-cancer mortality. Although important progress has been made in both detection and treatment, there is persisting inequity in progress to reduce its burden. The objective of EU-TOPIA is to systematically evaluate and quantify the harms and benefits of the running programs for breast, cervical, and colorectal cancer in all European countries, and identify ways to improve health outcomes and equity for citizens. We will first identify significant inequities in screening outcomes by assessing the key set of quality indicators for benefits and harms in each country. Using these indicators, outcomes and cost-effectiveness of existing cancer screening programs in 2015 will be estimated. For this, state-of-the-art models of the natural history of the cancers will be constructed, using country-specific data. Barriers hindering implementation of

optimal screening programs will be assessed, leading to road maps for improved screening. These road maps contain feasible changes, *e.g.*, to extend or reduce the program, to change the screen test used or change key quality indicators, to perform activities that reduce screening related harm or incorporate new developments in screening, and provide policymakers with evidence for increased, decreased or optimized use of screening. The project will lead to reduced inequity, reduced number of cancer deaths and over-diagnosed cases, and increase in life years gained and better cost-effectiveness by 2025.

- *Breast Center Quality Assessment Programs in US* (Cary Kaufmann, FACS)

  Breast Care provided by the multidisciplinary team makes it difficult to correlate results, whether good or bad, with interventions. In addition, there are relatively few evidence based quality metrics available to apply to centres wishing certification. Appropriate quality measures are those which are a) recognized by providers as being important, b) have variation in performance across centres, c) are feasible to extract performance data, and d) have a positive cost-benefit ratio. Another confounding problem is that quality measures must apply to the many varieties of breast centres, large and small, academic and community, urban and rural.

  In the US, two programs developed independently, each providing half of the quality equation. One program (NAPBC) focused on defining the structural components of care. They had to define structural requirements that were rigid enough to maintain high quality care but flexible enough to recognize the realities of the local community. The second quality program (NQMBC) focused on process measurements, or how well does the multidisciplinary team perform in each area of breast care. Although they measured specific performance levels, they had difficulty identifying benchmarks. Providing a single benchmark may be too high for many centres, while appearing too low and not providing improvement incentive for the better quality centres. The ideal breast centre certification combines both multidisciplinary structural requirements along with process of care assessment (including benchmarks) that recognize both the realities of local environment and the needs of individual patients.

- *European Network of Cancer Registries* (Nadya Dimitrova, Bulgarian National Cancer Registry)

  There are over 20 national and 82 regional cancer registries in Europe, covering 72% of the population of the EU. All of these registries have contributed, or have the potential to contribute, to the quality of breast cancer care in some way. Because definitions are standardized across Europe, registries can provide long-term descriptions of trends in breast cancer incidence, stage, treatment, survival and mortality by country, region or hospital. Registries linked to screening programme data can also identify and compare in detail (including molecular makers) symptomatic, screened and interval cancers, and allow international comparisons. Improving data collection through the establishment of links to clinical cancer registries and the wider availability of electronic data means registries have an increasing scope and timeliness of data which can be linked to measures of quality of care and screening history. They can also help estimate the cost-effectiveness of new technologies, and of interventions such as rapid referral clinics or specialist breast centres. The potential of cancer registries to contribute to breast cancer quality assessment is limited by a number of factors. Cancer registration in Europe remains heterogeneous for historical, economic and legal reasons, so the scope of data captured by registries is very variable. Some countries have complete population coverage, others have regional coverage, and a few have no effective population-based cancer registration. Some registries do not have access to death certificates, which makes survival calculation inaccurate. Many capture stage and treatment at diagnosis, but not all. Some can provide more detail, for instance on type of surgery, completeness of excision, molecular markers, comorbidity and follow-up data, and a few collect data on quality of life, for selected cohorts. Linkage of screening data to cancer registries is not being done in some countries for cost, legal or administrative reasons.

  The ENCR, with JRC, is working on improving the standardization and coverage of cancer registration in Europe. There is considerable potential for quality assurance and research through more widespread sharing of the more extensive data now collected by registries, clinical programmes and screening programmes, and the more detailed analysis of the data already collected.

3.2.4. Current topics from breast cancer care research: parallel workshops

The four workshops were dedicated to themes relevant for the development and implementation phases of ECIBC objectives, and particularly of the European QA scheme.

The results of the parallel sessions were presented by a rapporteur per session in the morning of 11th December.

3.2.4.1. Parallel workshop 1: *Continuity of care for breast cancer: what is it about and how can it be measured?*

Charles Shaw (chair), Anke Bramesfeld as JRC coordinator

For a successful treatment of breast cancer patients, both a multi-disciplinary approach and a structured network of various services are needed. Thereby assuring continuity of care between the various services (potentially governed by different entities) is a crucial issue for the quality of care. Continuity of care implies continuity in terms of disease management, transmission of patient's data/information, and relation of patient to service providers. This parallel session explored (i) which are the sensitive issues in assuring continuity in breast cancer care, and (ii) how quality of care can be assessed with respect to its continuity. It aimed at developing examples, options and ideas for assessing continuity of care in a reliable and valid way that allows for comparison of services. Based on the two presentations reported below, open discussion with participants looked at how the examples presented could be applied to other health systems and what assessment of continuity of care should look like, if applied on a European level. Both presentations report examples of how to measure continuity of care as a dimension of quality of care:

- *Integrated Care – what is important and how do we measure it?* (Jenny King, Picker Institute)

  This presentation looked at what is important from a user perspective in person-centred coordinated care including the things users believe should always happen for care to be coordinated. It looks then at a project aimed to produce

a robust user-reported measure that can capture the experience of older people with chronic conditions receiving health and/or social care services from different providers. The tool, under development by the International Foundation for Integrated Care, National Voices, the Nuffield Trust, the Picker Institute, and The King's Fund in England looks to assess coherence, coordination and quality of care.

- *Continuity of care* (Simone Wesselmann, German Cancer Society)

  Continuity of care, from the patients' perspective, is a core element of good care. It comprises three major points: (1) one care provider for the patient with breast cancer who is a stable contact person through the complete care pathway (2) communication between care providers and (3) cooperation between care providers. The European QA scheme follows a patient-centred approach and therefore requirements must be defined which reflect the three aspects and focus on multidisciplinary, inter-professional communication and cooperation of care providers in a certified network along the treatment pathway of breast cancer patients. Additionally, the requirements must be uniquely defined and (if applicable) measurable in order to be used by care providers for quality assurance and improvement.

The discussion following these two presentations highlighted the contribution of the different professions involved in breast cancer care to the realisation of coordinated and continuous care. The more complex breast cancer centres/services are, the greater the need of a secure, interoperable and sustainable system for transmission of data; the same applies to complex decentralised/networked structures.

3.2.4.2. Parallel workshop 2: *Communication in person-centred services*

Luzia Travado (chair), Liisa Pylkkanen as JRC coordinator

All information concerning breast cancer, should be delivered to both patients and healthy women (*e.g.* in screening) in an honest, clear and easily understandable way, and if applicable, visual information and decision-aids may be used. All patients should be given choices and enough time to decide on treatment options,

Picture 3: *Panel of parallel workshop 1.*

participation in trials and tissue donation. Communication training is an essential tool for healthcare professionals to be able to correctly interact with patients. Furthermore, the continuity of communication needs to be ensured throughout the entire patient journey – keeping the person in the centre. This parallel session focussed on three main topics: (i) which are the sensitive issues in the continuity of person-centred communication in breast cancer care (*e.g.* problems), (ii) how the continuity of communication can be improved (*e.g.* tools), and (iii) how the continuity and person-centredness of communication can be measured (*e.g.* indicators). In particular, examples and possibilities for assessing person-centred communication in breast cancer services in order to facilitate development of recommendations and enable comparison of the quality of breast cancer services were presented. The three presentations focussed on how the continuity and patient-centredness in communication can be improved and measured.

- *Psychosocial support and communication needs of breast cancer patients* (Luzia Travado, Champalimaud Clinical Centre, Lisboa)

  Good and effective communication is considered a key component of good medical practice, and a core competence that can be trained. Therefore, it is necessary to systematically train healthcare providers in breast cancer care in communication skills. Communication skills training (CST) should be therefore offered in undergraduate and postgraduate curricula for physicians, nurses, and other allied healthcare professionals in cancer care and in continued professional development programmes in psychosocial oncology in all cancer settings.

  However, much remains to be done, for instance, in establishing requirements for clinical practice (and for the *European QA scheme*) related to communication.

- *How continuous communication can be ensured throughout the patient journey* (Yvonne Wengström, Karolinska Institute and University Hospital, Stockholm)

  Professor Yvonne Wengström discussed the continuity and assessment of person-centred communication.

  She highlighted that person-centred care is responsive to consumer needs, values and preferences, is integrated and coordinated, relieves physical discomfort, provides emotional support, allows involvement of significant others and supports the provision of information, communication and education to enable individuals to understand and make informed decisions about their care.

  She also emphasized that the health care professionals need to communicate in a manner that patients could understand and provide accurate information according to patients' preferred information level.

  The enabler of person-centred communication is patient-physician communication. The key dimensions in person-centred communication are information, involvement in care and empowerment – including physical and emotional support.

- *Patients' perspective* (Kathi Apostolidis, European Cancer Patient Coalition)

  Kathi Apostolidis presented how communication in cancer care too often is only disease-centred and not patient-centred. Thereby important issues related to the patients' wellbeing as well as those related to the integration of cancer care into the patients' daily life are not addressed.

The following discussion highlighted the need of a more holistic view of patients as persons in order to be able to meet communication needs. When talking to patients, more than just the information on disease and treatment needs to be delivered.

3.2.4.3. Parallel workshop 3: *Key outcomes for studies on breast cancer screening*

Roberto D'Amico (chair), Jesús López Alcalde as JRC coordinator

The third parallel session discussed a core set of desirable and undesirable outcomes to be assessed in breast cancer screening studies in order to facilitate an informed decision making. Two presentations prepared the discussion on this key topic:

- *Contribution 1* (Mireille Broeders, Radboud University Medical Centre)

  Continuous monitoring and evaluation of a screening programme is necessary to ensure that it is as effective as expected. Screening outcomes, both desirable and undesirable, become available throughout the screening process and afterwards. In general, a distinction can be made between evaluating the performance of the screening programme and its impact on health indicators, such as mortality. Performance indicators reflect the provision and quality of the activities constituting the screening process without directly reflecting the reduction in mortality. Evaluating the long-term benefits and harms of screening for breast cancer takes many years and requires the application of complex epidemiological and statistical methodologies. Ascertainment of impact of the programme further demands that follow-up of screened and non-screened cohorts continues over extended periods of time and that adequate links exist

between programme data and other relevant data sources. A frequently used but challenging alternative is to identify and monitor early surrogate measures, such as the rate of advanced cancers, that can possibly predict outcome.

- *Contribution 2* (Bettina Borisch, University of Geneva)

  The study and evaluation of outcomes for breast cancer screening (programmes) is important for the individual as well as for the public health institutions that run screening programmes. EU member countries and their respective health care systems may value outcomes differently and the single citizen has again another demand as to the quality and outcomes of screening. The citizens as well as the 'national' questions that may need further outcome studies were presented.

The discussion that followed highlighted that it is not just a question of choosing the right outcome parameters for screening but more so it is important how the information provided by outcome parameters on screening is forwarded in an understandable way to citizens.

3.2.4.4. Parallel workshop 4: *Volume-outcome relation in breast cancer care*

Ina Kopp (chair), Silvia Deandrea as JRC coordinator

In spite of the consistent results shown for several other diseases (*i.e.* AIDS, abdominal aortic aneurysm coronary angioplasty, myocardial infarction, knee arthroplasty, coronary artery bypass, etc.), the extent of the association between the volume of activity and the outcomes for breast cancer care is not always straightforward. This is due to the fact that results depend, among other factors, on the definition of caseload (whole hospital, centre, surgeon, etc.), the outcome chosen (mortality, proxies, etc.), and the set threshold. Selection bias and a different case-mix also deserve careful statistical adjustment. The objectives of this session were (i) to explore the existing evidence on the association between caseload and outcome for breast cancer, and (ii) to discuss the most appropriate and feasible outcomes to be measured for this purpose.

Contributions from experts from different countries may stimulate a discussion on how healthcare policies introducing (or not) thresholds in the number of cases treated affected the organisation of cancer care and the access to the services. Two presentations, both reporting examples of the assessment of the impact on volumes on outcomes in (breast) cancer care, were offered as a starting point for discussion.

- *The Italian National Outcomes Programme (PNE)* (Marina Davoli, Outcome Evaluation Programme – National Agency for Health Services)

  Hospital or physician volume represents a measurable variable with a relevant impact on effectiveness of health care. Since 2009, the National Outcomes Programme (PNE) evaluates outcomes of care of the Italian hospitals; nowadays it represents an official tool to assess the National Health System (NHS).

  There is clear evidence from the scientific literature of an association between volume of breast cancer surgery, 30 days intra hospital mortality, five years survival and rate of conservative surgery. Although the systematic review of the literature does not permit to identify predefined volume thresholds, the EUSOMA guidelines identify a minimum threshold of 150 for a breast unit and 50 for single surgeon.

  In Italy in 2014 there are 467 hospitals performing more than 10 breast cancer surgeries, among these only 123 (26%) perform more than 150 surgeries corresponding to 70% of operated women. The biggest hospitals often have more than one ward in which surgery is subdivided; the proportion of women having surgery in high volume wards (more than 135) is 62% in 2014, as compared with 54% in 2010; we also observed a great geographical variability.

  In June 2014 the Ministry has approved a national guideline for the organization of the breast units and some regions are reorganizing the breast cancer network of hospitals to comply with different standards including the volume of care. However, the available data from PNE show that it is still very high the proportion of women having breast cancer surgery in proper sites.

- *Retrospective analysis on case numbers and process quality in breast surgery in Germany* (Günter Heller, Federal Institute for Quality Assurance and Transparency in Healthcare (IQTIG))

  Background: Numerous studies from around the world have shown a positive association between case numbers and the quality of medical care. The evidence to date suggests that conformity to guidelines for the treatment of patients with breast cancer is better in German hospitals that have higher case numbers.

  Methods: We used data obtained by an external programme for quality assurance in inpatient care (*externe stationäre Qualitätssicherung*, *esQS*) for the years 2013 and 2014 to investigate seven process indicators in the area of breast surgery, including histologic confirmation of the diagnosis before definitive treatment, axillary dissection as recommended by the guidelines, and an appropriate temporal interval between diagnosis and operation. Case numbers were categorised with the aid of various threshold values. Moreover, subgroup analyses were carried out for patients under age 65, patients in good general health, patients without lymph-node involvement, and patients with a tumour size pT0 or pT1 or an overall tumour size less than 5 cm.

  Results: Data on 153 475 patients from 939 hospitals were analysed. Six of seven indicators had values that were better overall, to a statistically significant extent, in hospitals with higher case numbers. Although this relationship was not consistently seen, the worst results were generally found in the category with the lowest case numbers. Similar, though less striking, results were obtained in the subgroup analyses. An exception to the general finding was that, in hospitals with higher case numbers, the interval between diagnosis and operation was more often longer than three weeks.

  Conclusion: Guideline adherence is higher in hospitals that treat more cases. The present study does not address the question whether this, in turn, affects morbidity or mortality. To improve process quality in peripheral hospitals, the quality assurance programme should be continued.

The chair and Silvia Deandrea from the JRC explored and discussed with the participants the methodology and clinical issues arising from the presentations and if the *European QA scheme* on breast cancer should or should not take into account the volume of activity of the centres seeking certification.

3.3. Day 3: The way forward

3.3.1. Keynote

- *Dealing with evidence from qualitative research in guideline development* (Özge Tunçalp, Department of Reproductive Health and Research, WHO)

  There is growing recognition that guidelines questions sometimes fail to reflect the priorities of key stakeholders and that issues related to the acceptability and feasibility of the recommended interventions are not necessarily addressed through effectiveness reviews. Qualitative syntheses are increasingly conducted, but methods to assess how much confidence to place in synthesis findings, which is an essential consideration for guideline development, are poorly developed. The Confidence in the Evidence from Reviews of Qualitative research (CERQual) approach provides a transparent approach to assess how much confidence to place in findings from a qualitative evidence synthesis. Like the GRADE approach (Grading of Recommendations Assessment, Development and Evaluation), currently used for effectiveness evidence, this approach facilitates the use of qualitative evidence to inform decisions and shape policies. Department of Reproductive Health and Research of the World Health Organization, as part of the GRADE-CERQual Project Group, has been developing guidelines conducting and incorporating evidence from qualitative syntheses.

3.3.2. Report from the parallel workshops

Four rapporteurs shortly summarised to the audience the main points discussed during the parallel workshops and as reported in this report in the respective *3.2.4.* paragraphs. The rapporteurs where: Luigi Cataliotti for the Parallel workshop 1: *Continuity of care for breast cancer: what is it about and how can it be measured?*, Luzia Travado for the Parallel workshop 2: *Communication in person-centred services*, Holger

Schünemann for the Parallel workshop 3: *Key outcomes for studies on breast cancer screening*, and Robert Mansel for the Parallel workshop 4: *Volume-outcome relation in breast cancer care*.

1. *Continuity of care for breast cancer: what is it about and how can it be measured?*

Continuity of care relates to person centred coordinated care and should be understood as one of the key features of quality of care. Especially in the complex treatment processes of long term care, that not only require medical but also psychosocial interventions, continuity of care is of key relevance. Continuity of care relates to the continuity of information across treatment processes and facilities, continuity of the management of treatment and continuity of relationship, notably the relationship between healthcare professionals and patients.

The assessment of continuity of care needs the patient perspective. Continuity of care becomes particularly relevant when transitions in care are planned, such as discharge to outpatient care, but also if transferred to other services, when outpatient care and care in the home environment is set up and in unplanned situations such as emergency admissions to hospital. The quality of continuity of care from the patient's perspective, which should be regarded as the ultimate judgement of its realisation, needs to be assessed through patient questionnaires.

From the facilities' perspective, continuity of care can be seen in the successful integration of different health and social care providers. Even if care is provided by different facilities and institutions, requesting them to present their quality of services together as unique/networked provider is already a first step to scrutinize their processes of continuity of management and information. Further quality indicators related to continuity of care can focus on specific processes and structures that are essential for implementing continuity of care, such as case discussions or pre- and post-treatment multidisciplinary conferences.

2. *Communication in person-centred services*

The way by which healthcare professionals communicate with patients impacts on the quality of the provider-patient relationship, patient's adjustment to dis-

ease and treatment, clinical outcomes, and the patients' satisfaction, but also the clinician's satisfaction and well-being and the healthcare economy. Healthcare professionals need to be trained in effective and patient centred communication. Such training can be integrated in undergraduate and postgraduate curricula for physicians, nurses and other allied healthcare professionals in cancer care. It also can be part of continued professional development programmes in psychosocial oncology in all cancer settings.

Patient centred communication differs from disease centred communication by taking into account patients' preferences and state of mind. Today's patients differ from those 15 years ago as they have more access to information, notably through the internet but also a desire for refined honest and clear information relating not only to disease and symptoms, but also to treatment alternatives, effects of treatment, risks, impact on quality of life and self-help opportunities. Benefits and harms of all interventions should be communicated honestly, clearly and effectively, patients' preferences and values need to be considered in communication and decision making. Finally citizens/patients should be given enough time to make an informed decision.

Indicators related to communication can be those measuring structure, such as the availability of courses for communication. Outcome indicators would be patient reported outcomes (PROMS), thus requiring patient questionnaires.

3. *Key outcomes for studies on breast cancer screening*

The effectiveness of screening is defined considering the balance between benefits, such as reducing mortality and morbidity, and harms, such as those related to overdiagnosis and overtreatment. The evidence for these originates from randomised controlled trials (RCT) and observational studies. When estimating the balance of benefits and harms of screening interventions using available studies, these need to be comparable in terms of considering the same screening setting, and the same screening scenario. Benefits and harms need to be measured using the same outcome. In addition, the cultural context of screening needs to be considered. When choosing the endpoints/outcomes for scrutinizing screening, they should represent what is important from a patient's perspective, not what is

reported by the single studies. Ideal measures of benefit and harms in screening include quality adjusted life years (QALY) or disability adjusted life years (DALY). There is no consensus on how outcomes should be defined. A systematic way to do it would be using Delphi methodology, thus letting multidisciplinary panels assess and rate all possible outcomes for their importance and by this method rank them. The outcomes defined through this process can then be subject to PICOs. A recommendation for screening should be based on a precise definition of the question/problem, its benefits and harms, and the quality of the evidence for benefits and harms. However, it must also consider underlying values, available resources, equity issues, acceptability and feasibility.

4. *Volume-outcome relation in breast cancer care*

The discussion touched several hot topics related to the question of volume–outcome relation in breast-cancer care. Can a volume-outcome relation be considered for cancer care, which is a rather diverse process, and for breast cancer care in particular? Breast cancer care includes a multitude of treatment processes, including diagnostics, surgery, chemo- and radiotherapy, rehabilitation etc. To what extent does volume-outcome relation apply to all these processes? In particular, the volume-outcome relation for diagnostics needs to be distinguished from that for treatment.

When considering the impact of volume on outcomes, meaningful outcomes should be considered, taking into account citizen/patient values. Possible outcomes include mortality, relapse, and quality of life. However, in particular relevant outcomes, such as relapse or survival take quite some time to evolve and are influenced by multiple factors beyond the treatment quality. Bias and confounding variables need to be taken into account, and outcomes should be risk-adjusted as well as possible.

Further in the discussion on volume-outcome relation, the unit needs to be defined to which the volume-outcome relation refers to: a hospital, a hospital unit, a ward, a physician's workload. Finally, before recommending specific volume outcomes, their practical implementation and policy context needs to be considered.

Picture 4: *Presentation of the results the parallel workshop 3.*

3.3.3. Last minute presentations

There were three last minute presentations:

- Ana Molina, FISABIO, Spain reported about a study on equity of access to breast cancer screening programmes in 27 European countries. Most of the countries periodically monitor participation to screening according to diverse socioeconomic variables; 17 countries report about interventions to tackle social inequalities in participation, mostly by a general approach. She concluded that more focused interventions are needed to overcome social inequalities in participation in breast cancer screening programmes.

- Elizabeth Benns, Independent Cancer Patients' Voice, UK reported on her experience as a patient representative participating in the auditor team of breast cancer care facilities.

- Ina Kopp, Guidelines International Network, Institute for Medical Knowledge Management, Germany provided feedback on ECIBC activities that were presented in the plenary from an 'outsider' and methodology expert point of view. She called on the ECIBC to be very transparent, for instance by publishing on the web hub not only the documents, the objectives, and the working groups' members' profiles, but the methodological approach as well. She judged ISO accreditation in the field of medical treatment as risky, however less problematic in the field of testing/examination processes. All in all she valued the open discussion occurring in the ECIBC Plenaries as a good way to ensure that inputs from stakeholders and experts to optimise ECIBC development and implementation chances are received and understood.

3.3.4. Closing words

During the Plenary, GDG and QASDG meetings took place and the GDG co-chair and QASDG chair reported to the audience the main points agreed during those short meetings.

Chris de Wolf (GDG co-chair) reported that the GDG agreed on how to proceed with the six chapters of the guidelines (1. Screening, 2. Diagnosis, 3. Communication, 4. Training of professionals, 5. Interventions to reduce inequalities, and 6. Monitoring and evaluation) in order to set the PICO (Population, Intervention, Comparison, Outcomes) questions that will be covered by the European Guidelines for Breast Cancer Screening and Mammography applying the GRADE method. He also explained that these new guidelines will not be focussed on quality assurance as this aspect will be addressed by the *European QA scheme* and their short name was agreed to be *European Breast Guidelines*. He finally announced that during the GDG meetings, great progress in the preparation of the Guidelines scope to be submitted to the call for feedback was obtained (the call was in fact launched the 18/12/2015).

Robert Mansel (QASDG chair) described to the audience how the work of the QASDG was agreed to be organised, by subgroups (Testing-Imaging, Pathology, Medical Physics, Molecular/Genetic Testing, Competence, Organisation, Scope and Modules, Certification Processes, Indicators, Research) and task forces in col-

laboration with the GDG (screening and diagnosis [GDG] with testing activities, such as medical imaging, clinical pathology, medical physics, molecular/genetic testing [QASDG], training [GDG] with competence [QASDG], monitoring [GDG] with indicators [QASDG], glossary [GDG] with quality concepts and key-words [QASDG]). He reported that the organisation of the sub-group activities was prioritised as functional to the development of the QA scheme scope to be submitted to the call for feed-back, which was planned to be launched at the beginning of 2016 (the call was in fact launched the 17/02/2016).

Donata Lerda (JRC) closed the conference inviting participants to visit the newly launched ECIBC web hub and to join the ECIBC Plenary 2016 (24th and 25th November 2016, again in the Lake Maggiore district).

Central findings of the plenary meetings refer to:

- The importance of keeping the transparent and inclusive character of the ECIBC. The web hub is the key channel in this respect. It aims to serve as an interface between the ECIBC and citizens and stakeholders. With the launch of the web hub, the first important milestone of the ECIBC has been reached.
- The need to publically share the methodologies applied and the expected timeline to better prepare the acceptance and implementation of the *European QA scheme* and of the *European Breast Guidelines*. All along its development phase, information and documents on the ECIBC will be made publicly available on the web hub.
- The importance of combining a rigorous and methodological sound approach with the flexibility required to adapt both the scheme and the guidelines to the different healthcare systems in Europe, respecting their diversity.
- The ECIBC welcomes contributions and inputs. Besides the annual Plenaries, calls for feedback on the scope of the *European QA scheme* and of the *European Breast Guidelines* are organised for the end of 2015-beginning of 2016; the final versions, expected for 2018, will be as well submitted to a call for feedback. These calls represent a key moment for the project to receive inputs from stakeholders and the public, ensuring that most of the possible obstacles for implementation can be ironed down before the roll-out phase.

4. Conclusions

The second ECIBC plenary set out to inform stakeholders on the current state of the ECIBC projects and to engage them in the discussion on burning topics connected to the quality of care for breast cancer, hence relevant for the ECIBC. The plenary was a wide success, as the general positive feedback from participants suggests. In detail the plenary succeeded in:

- Explaining the methodology, scope and current state of development of both the *European QA scheme* and the *European Breast Guidelines*. Many of the free-text comments of the evaluation forms referred to the information on ECIBC as having been very meaningful to participants.
- Seeking feedback from stakeholders on the ECIBC, in particularly on the *European QA Scheme* and the *European Breast Guidelines*. Thereby, stakeholders made explicit that the methodology used to develop both the *European QA Scheme* and the *European Breast Guidelines* needs to be better detailed to the public, possibly directly on the homepage of the ECIBC web hub, at least during the ECIBC development phase.
- Communicating the framework under which the *European QA Scheme* will work together with countries and National Accreditation Bodies (NAB) to ensure that what is being developed will be feasible and that countries' uptake will induce a significant impact on citizens, and women in particular. This was achieved via presentations on the ECIBC, countries and NABs posters and presentations aimed at ensuring a transparent communication about the accreditation framework applied for the *European QA Scheme*.
- Receiving input for the ECIBC on subjects highly relevant to quality of care and measurement of quality of care. The parallel workshops on continuity of care, on communication in person-centred services, on key outcomes for studies on breast cancer screening and on the volume-outcome relation in breast cancer care were key for collecting meaningful ideas and inputs.
- Receiving input for key themes for ECIBC: the keynote lectures (one on the concept of patient centred care and one about using qualitative research for guideline development) certainly provided important indications on the way

forward considering two important aspects, the first more relevant for the content, the second for the methodology, but closely interlinked. They helped in clarifying that the ECIBC needs to focus on patient experience rather than patient satisfaction and that for patient centred guidelines, qualitative research is essential.

On the basis of the experience from the ECIBC Plenary 2015, the ECIBC Plenary 2016 will again report on the state and progress of the ECIBC projects during 2016.

Furthermore, the ECIBC Plenary 2016 will again ask countries and National Accreditation Bodies to present themselves, interact with each other, engage in commenting and contributing to the *European QA scheme*, and contextualise their preparedness to the piloting and running of the *European QA scheme*. This means, that the JRC will do its best to increasingly engage these key 'implementing' actors, also by having more countries' and NABs' presentations.

As the keynotes were highly appreciated and so stimulating, the Plenary 2016 will also invite keynote speakers to provide new and different insights, potentially more focussed on the implementation needs. The ECIBC 2016 will continue to provide a platform for networking at the interface between research and policy to improve care for women confronted with breast cancer.

Finally, as the 2015 ECIBC plenary succeeded in grasping the interest of the European Parliament, through video messages by the Vice-President of the European Parliament and of the President of the Member of Parliament's Against Cancer group, the 2016 ECIBC plenary aims to engage a greater number of policy representatives.

Picture 5: *Participants to the 2015 ECIBC Plenary.*

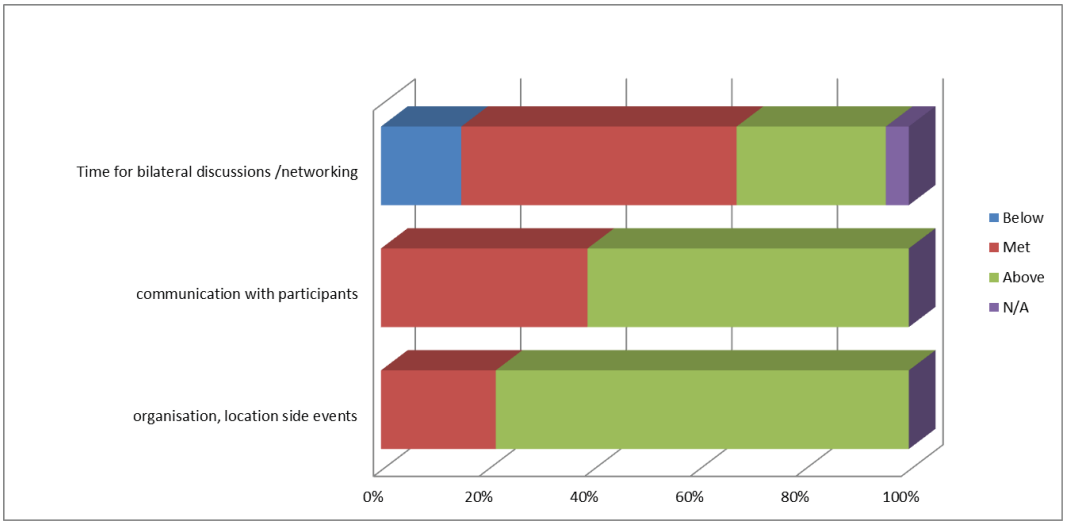


Figure 1: *Overall evaluation of ECIBC plenary, n= 46.*

5. Evaluation of the event

46 participants of the ECIBC plenary filled out the feedback questionnaire (corresponding to approximately 50% participation). In general responses were overwhelmingly positive. The content and the quality of the presentations met or even exceeded the expectations of more than 90% of the respondents for the plenary sessions at Day 1 (Current state of ECIBC-projects) and Day 2 (Current topics in breast cancer care plenary). At Day 3 (The way forward), after two very intense days, still 86% found that their expectations were met or exceeded.

Most of the comments and feedback were related to discussion time not being felt sufficient (by about 20% of respondents at Days 1 and 2 and by 15% at Day 3). In line with this, 15% of respondents felt that time for bilateral discussion and networking was not enough, while general communication with participants was judged as good. While this is an encouraging message, showing the great interest risen by the topic and favoured by the event's design, it is certainly a message to be taken home for carefully balancing presentations with discussion time at the next ECIBC Plenary. The location (Hotel Dino in Baveno) exceeded expectations of most of the participants, therefore the JRC will pay the due attention also to the logistical aspects.

In an open section of the questionnaire, respondents listed what they felt had been most meaningful to them at the conference. Most often respondents listed the country profiles, both as presentations and as posters, as having been most meaningful to them. These country profiles presented the actual status of breast cancer care and its quality assurance in the countries (and are key for understanding which are the implementation needs and potentials for the ECIBC). Similarly, National Accreditation Bodies' posters on their activities related to breast cancer care were appreciated. The updating on the ECIBC projects, namely reporting on the development of the European Breast Guidelines as well as the activities related to European QA scheme were also felt to be most meaningful to many. Both keynotes, the one on patient centredness and the one on how to use qualitative research as evidence for guideline development, received a positive feedback.

List of pictures and figures

Annex 1: Speakers

Tit Albreht, M.D. (1961), Slovenian, Ph.D. in Health Services Research at the University of Amsterdam, Head of the Centre for Health Care, National Institute of Public Health of Slovenia, Senior Researcher in the field of health services research, health policy and health systems, member of the Scientific Committee of EUPHA, member of the Slovenian Preventive Medicine Society, member of the Health Council of the Ministry of Health of Slovenia. He is an Associate Professor of Public Health at the Department of Public Health of the Medical Faculty in Ljubljana. He acts as a reviewer of several scientific journals and of projects submitted for financing to the European Commission. He is currently coordinator of the Joint Action Cancer Control (CanCon), dedicated to the development of health policy support and advice to cancer control policies at the level of the EU and of the Member States.

Dr Kathi Apostolidis. Kathi is the Vice President of ECPC-European Cancer Patient Coalition and a Public Affairs Consultant with extensive experience in regulatory affairs, marketing and communications. She represents ECPC at the EMA's Patients and Consumers Working Group, she is member of the European Commission Expert Group on Cancer Control and of the Expert Group EIBC/QASDG on the Commission Initiative on Breast Cancer, participates as ECPC representative in Work Packages of the EU Joint Action on Cancer Control. She is a member of the Cancer Patients Working Group of ESMO, of the Steering Committee of HTAi's Patients and Citizens Involvement Group. At the national level, she is the Chair of the Intergroup Committee for Cancer Patient Rights Advocacy/Greece (DEDIDIKA), she serves as a Deputy Board Member at KEFI-Association of Cancer Patients, Volunteers and Physicians/Greece, and is also member of other Greek and international cancer patient associations. As a twice breast cancer survivor, she was involved in breast cancer and cancer patient rights advocacy since 1995. She has a broad interest in cancer care policy and many aspects of front line cancer care, survivorship, cancer research and economics, health technology assessment, digital technology in cancer care. Graduate of the University of Athens, Philosophy Dept. and Political & Economic Sciences and of McGill University, Canada in Business Administration. She is a member of the editorial board of the *Journal of Compassionate Health Care*.

Prof. Bettina Borisch, Professor of Public Health, Institute of Global Health, University of Geneva. Director of the World Federation of Public Health Associations, headquartered in Geneva. Dr Borisch is an MD and a Histopathologist, MPH and Fellow of the Royal College of Pathology (UK). Her scientific research work delves into neoplastic lesions of the immune system and breast cancer. Her interests also include community-based oncology, health communication and global health. She studied medicine and history at the Universities of Kiel (Germany) and Lausanne (Switzerland). She is appointed professor and head of the Institute of Clinical Pathology, University of Geneva in 1995. She becomes the president of the Swiss Cancer League's program against breast cancer. She completes an MPH in 2005 and orientates her activities to Public Health and Global Health. She joins the Institute of Social and Preventive Medicine in 2005 (from 2015 on: Institute of Global Health). She is Editor in Chief of *Pathobiology* and the Co-Editor of *Journal of Public Health Policy*. In addition to her academic work she acts as the Director and Head of the World Federation of Public Health Associations and holds positions at several Committees of Public Health oriented institutions. She was president of Europa Donna – The European Breast Cancer Forum and Founding President of the Swiss Forum of Europa Donna. She teaches at the University of Geneva, the Swiss School of Public Health and she also teaches patient support groups. She is (co)author of over 120 scientific papers.

Dr Mireille Broeders is a cancer screening epidemiologist with an academic degree in bio-medical health sciences. She is an Associate Professor at the Dept. for Health Evidence, Radboud University Medical Centre, in Nijmegen, the Netherlands. Her research focuses on establishing the impact of cancer screening programmes, in particular screening for breast cancer, and the potential value of moving to risk-based screening regimens. She has a special interest in observational research designs that can be used in this field of research. As a long-standing member of the National Evaluation Team for Breast Cancer Screening, she is also involved with the evaluation of the long-term benefit and harms of the Dutch nation-wide breast screening programme. She further works as scientific supervisor at the Dutch Reference Centre for Screening in Nijmegen. This has broadened her research interests to include *e.g.* the implementation and evaluation of technological developments in the breast screening programme, pain experience during breast compression and test sets for radiologists. All research projects at the Centre aim at the safeguard and constant improvement of the quality of the breast cancer screening programme. At a European level, she contributed, as editor and author, to the European Guidelines for Quality Assurance for Breast Screening and Diagnosis. She has been co-leading the EUROSCREEN working group, a European research effort to summarise breast cancer screening service screening outcomes, published as supplement to the *Journal of Medical Screening* (2012). She has co-authored over 100 papers in peer-reviewed journals.

Dr. Miriam Dalmas I am a medical professional specialising in Public Health Medicine. Since 2009, I have been engaged as a medical consultant in Public Health Medicine. My main role is in the coordination of policy development and in providing general support to the Chief Medical Officer (CMO). I occupied the post of Director for Policy Development, EU and International Affairs for the Ministry for Health from 2007-2011. For the past six years my work has focussed on the national cancer policy and I was the main author of the National Cancer Plan 2011-2015. I have also led the creation of the National Health Systems Strategy 2014-2020 that was launched in 2014. Presently, I am representing Malta as an associate partner in the Joint Action on Comprehensive Cancer Control (JA CANCON) and on the Board of Member States on the European Reference Networks. Recently, I have been tasked with the coordination of a new National Cancer Plan 2016-2020. In 2005, I graduated as a Master in Business Administration from the University of Malta. Since 2010, I am a doctoral candidate with the Faculty of Economics, Management and Accounting at the University of Malta in the field of Management and specifically on the subject of Organisational Learning.

Marina Davoli. Scientific Director, Italian National Outcome Program Department of Epidemiology Lazio Region, Roma, Italy. Medical Degree in 1985 at the University of Rome 'La Sapienza'. Master of Science (MSc) in Epidemiology – London School of Hygiene and Tropical Medicine in 1991. Head of the Department of Epidemiology, Regional Health Service, Lazio Region, Operational Centre of the National Outcome Program. Member of the Regional Drug Formulary of the Lazio Region. Member of the Scientific Committee of the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) in Lisbon. Coordinating Editor of the Cochrane Drugs and Alcohol Group. Member of the GRADE (Grading of Recommendations Assessment, Development and Evaluation) Working Group. Main activities: systematic reviews of the scientific literature on the effectiveness of health care interventions; epidemiological studies on the health status of the population; comparative effectiveness research on drugs and other health care interventions; comparative analysis of health care outcomes across hospitals and geographical areas for the National Outcome Evaluation Programme and the Lazio Regional Outcome Evaluation Programme; coordination of the work package of the EU Project DECIDE on strategies for the dissemination of evidence to policy makers. Author of more than 100 scientific publications on peer reviewed journals, H index 21.

Henricus J de Koning. Born in the Netherlands, Professor Henricus (Harry) J de Koning worked as a Researcher and an Assistant Professor in the Department of Public Health of the Erasmus University in Rotterdam from 1987 to 1999. He became an Associate professor in 1999 and in 2008 he was appointed Professor of Public Health & Screening Evaluation in the same department in Rotterdam. He was also Senior Associate Department of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health from 2011 to 2012. Since 2011 he has been a Member of the Medical Advisory Board of the Royal Netherlands Academy of Arts and Sciences (KNAW). His major scientific contributions are in the areas of: designing, running and evaluating large-scale multidisciplinary population-based randomized controlled screening trials to establish the efficacy of screening; evaluating active international screening programs and tests to establish effectiveness; guiding public health policies using predictions of favourable and unfavourable effects and the cost of screening, based on micro-simulation modelling of the natural history of disease, and cost-effectiveness and cost-utility analyses.

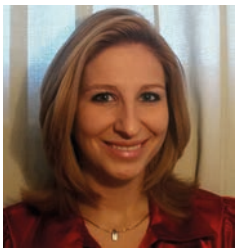
Dr Chris de Wolf. I am a medical expert specialised in breast cancer screening. I studied medicine in the Netherlands (VU Amsterdam) and afterwards I was engaged by the policy development department of the Dutch Ministry of Health (1989-1990). On request of the European Commission, I worked on European cancer screening strategies within the Europe against Cancer program for eight years, where I was charged with the development of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis. In 1999 I took a position as Head Screening and Early Detection at the International Union against Cancer (UICC, Geneva). Between 2004-2014, I had many positions all related to breast cancer screening in Switzerland. Currently, I am quality assurance specialist for Swiss cancer screening, medical director of the breast screening program in canton Wallis and consultant to the breast screening programs in Thurgau and Basel. All these activities I execute through my company ADSAN Sarl (Agence pour le développement et évaluation des politiques de santé).

Silvia Deandrea obtained her degree of Medical Doctor and specialisation in Public Health and Preventive Medicine at University of Pavia, and obtained her Biostatistics PhD at University of Milano in 2011. Before joining the Joint Research Centre in 2012, she worked in healthcare quality consultancy for the Joint Commission International, in cancer epidemiology research at Mario Negri Institute of Pharmacological Research (Milano, Italy) and in population-based cancer screening programmes organisation and evaluation at Cancer Prevention Unit of Milano Local Health Authority. For the breast and colorectal cancer programmes she covered the role of quality manager and she coordinated local activities in the context of multicentre research projects. Her current research interests include quality assessment and standardisation in breast and colorectal cancer screening, cancer pain epidemiology and Bayesian methods for evidence synthesis. She is author of more than 20 articles published in peer-reviewed international journals.

Chris Graham. Chris is the Director of Research and Policy at the Picker Institute, a charity with a vision of the highest quality health and social care for all, always. Chris has over a decade of experience in working on and promoting person centred care and the measurement and use of patient experience information. He is currently involved in a number of research projects investigating the measurement and improvement of patient experience. These include a major study investigating the value of 'near real-time' feedback for improving compassion in care, as well as collaborating with other charities and academic institutions to develop new approaches to measuring integrated care and user experiences along pathways. Chris is the chief investigator for the NHS Patient and Staff Survey Co-ordination Centres, run on behalf of Care Quality Commission (CQC) and NHS England respectively, which are sent to over 500 000 people each year. He is an NIHR fellow and an associate member of the Health Services Research Unit at University of Oxford. Prior to joining the Picker Institute, Chris worked at the CQC and Healthcare Commission, where he was responsible for managing national research programmes.

Guenther Heller, MD PhD. 1996-2002: Institute for Medical Sociology and Social Medicine, University of Marburg. 2002-2010: Research Institute of the Local Sickness Funds (Wissenschaftliches Institut der AOK: WIdO). 2010-2015: AQUA – Institute for Applied Quality Improvement and Research in Health Care GmbH. Since October 2015: Federal Institute for Quality Assurance and Transparency in Healthcare (IQTIG). My primary research interests lie in the fields of epidemiology and healthcare research. I have performed several analyses using large population-based datasets addressing volume outcome or volume quality relations, *e.g.* in the fields of perinatology, neonatology and breast surgery.

Solveig Hofvind (1961). Head of the Norwegian Breast Cancer Screening Program, professor in radiography at Oslo and Akershus University College of Applied Sciences. Hofvind is radiographer by training and did her master at the Norwegian school of sport sciences (Physical activity and risk of breast cancer). After 13 years work at Akershus University hospital, where she was the pioneer in establishing a breast clinic and the Norwegian Breast Cancer Screening Program, she started to work at the Cancer Registry of Norway. The Cancer Registry is responsible for the administration and quality assurance of the screening program. Hofvind started working as information adviser for the breast and cervical cancer screening programs in 1998. Four years later she started working on her PhD, which she finished in 2005 (The Norwegian Breast Cancer Screening Program: Selected process indicators and their utilization in epidemiological research). Hofvind was guest professor at the University of Vermont, 2006-07, and 2010-11 and a substantial network internationally. She has about 90 peer-review publications, mainly related to epidemiological aspects of breast cancer and mammographic screening.



Kitti Horváth, MD. I was born in Budapest, Hungary in 1986. I first graduated from high school in the United States of America (2004) and then in Hungary (2006). I started my higher education in 2006 at the Faculty of Medicine, University of Szeged, where I had the chance to organize almost all my internships abroad experiencing the flow of different health care systems. On the field of research I worked at the Institute of Surgical Research of the university (new possibilities in sepsis treatment) and also at the centre of Siemens Healthcare in Germany (radiological innovations in minimal invasive surgical interventions). My interest towards health promotion began directly in the first year of university, so I joined the Hungarian Medical Students' International Relations Committee (HuMSIRC) to participate in their prevention activities. Following my accession I soon became the national public health officer of the committee and after a couple years of national and international experience I was elected to be the Director of the Standing Committee on Public Health of the International Federation of Medical Students' Associations (IFMSA) in 2012. This position allowed me to work worldwide with medical students as well as with different non-governmental organizations for a better future concerning health promotion and care. After graduating from medical university I became a resident doctor at the Internal Medicine Department of the Hungarian Defence Forces' Medical Centre. Beyond my clinical work I joined the Chief Medical Officer Office of Hungary in 2015 and started specialising mainly on breast cancer and breast screening.

Michael Hübel, European Commission, DG Health and Food Safety. Primary and secondary education in Germany and the United States. Studies of Political Science (major), Public Law and History in Bonn, Germany and Canberra, Australia. Work in different German youth and social welfare organisations. 1989-1995: German Red Cross, Headquarters, Social Welfare Division, initially in the Social Policy Unit, then European Representative of the German Red Cross. In the Commission since 1995, initially in DG V (Employment and Social Affairs). Since 2000: DG Health and Consumers, now DG Health and Food Safety, Public Health Directorate. Until 2003 in policy analysis and development, working on general health policy. From 2003 in the Health Determinants unit, with responsibility for social and environmental determinants. Since 2004 Deputy Head of Unit. 2005-2012: Head of Unit for Health Determinants, with responsibilities for nutrition and physical activity, alcohol, chronic diseases and wider determinants of health. Since January 2013: Head of Unit Programme Management and Diseases. Responsible for the EU Health Programme and chronic diseases, including cancer, and rare diseases, as well as mental health.

Cary S. Kaufman, MD. Cary Kaufman is an Associate Clinical Professor of Surgery at the University of Washington, Fellow of the American College of Surgeons and the Medical Director of the Bellingham Regional Breast Centre in Washington State. Dr. Kaufman was trained at UCLA and the University of Washington and for the last 30 years has practiced as a breast surgeon. His professional life has focused on three areas: individual patient care, functional research, and physician education. He has lectured on the diagnosis and treatment of breast cancer both nationally and internationally. His interest in quality assessment of breast care has led him to have served as the Chairman of the National Accreditation Program for Breast Centres, the President of the National Consortium of Breast Centres, a Board Member of the American Society of Breast Surgeons, a Trustee of the National Consortium of Breast Centres and Chair Emeritus of the National Quality Measures for Breast Centres. He is a current member of many societies including the Society of Surgical Oncology and the American Society of Breast Surgeons. He is or has been a journal reviewer for the *Annals of Surgical Oncology*, the *American Journal of Clinical Oncology*, *The Breast Journal*, *JAMA*, and the *Journal of Surgical Oncology*. He has published over 50 articles on multiple aspects of breast care, diagnosis and treatment, including pioneering work on cryoablation for breast tumors, assessing the quality of breast care, intraoperative use of breast ultrasound, defining the value of preoperative needle biopsy, digital specimen mammography and specimen tomography as well as other subjects.

Jenny King. As Associate Director of Research at the Picker Institute, an international charity working across health and social care, Jenny is responsible for the organisation's research work stream. This includes managing large scale academic related grant-funded projects and commissioned evaluations designed to create new knowledge and influence policy and practice in health and social care. Jenny has eight years of experience carrying out qualitative and quantitative research exploring patient centred care, integrated care and staff experience. A current project, commissioned by The National Institute for Health Research (NIHR), and in collaboration with the University of Oxford, aims to strengthen relational care provided in hospitals and to evaluate a real-time feedback approach for informing care delivery. The study addresses an urgent need for research that evaluates the introduction and impact of real-time feedback approaches in the NHS. Jenny joined the Picker Institute in 2008 after completing an MSc in Forensic Psychology.

Susan Knox is a two time breast cancer survivor and has been Executive Director of Europa Donna since 1999. She is responsible for all on-going European advocacy initiatives in the areas of information, education and lobbying, including Pan-European advocacy conferences, meetings and information sessions at the European Parliament and European Commission, European Breast Cancer Advocacy Training Courses, publications and websites. In 2008 she launched ED's first prevention initiative – BREAST HEALTH DAY, which takes place annually on 15 October (see website www.breasthealthday.org). In addition, Susan represents ED on numerous other projects: BIG Scientific Committee, MIN-DACT and AURORA Committees, European Commission Expert Group on Cancer Control, the ECIBC project, and European Breast Cancer Conferences (EBCC). She is a speaker on patient advocacy at various international conferences and courses and has written widely on the subject. In 2009 she was also named advocacy editor of the scientific journal *The Breast*. Prior to joining Europa Donna, Susan held various managerial positions in the corporate and non-profit sectors, working for Citibank and a non-profit long-term care facility for the aged. Susan holds a B.A. degree from Smith College and an M.A. degree from Columbia University.

Donata Lerda. Born in 1962, graduated in Chemistry in 1987. Worked in the Public Administration in Italy for more than 20 years and started working in the EC in 2007. She is expert in quality assurance, accreditation, auditing and management of networks; she also has a deep knowledge of the European Commission working rules. She coordinates the European Commission initiative on Breast Cancer.

Luciana Neamtiu. Graduated in Mathematics and Physics in 1996, she obtained a PhD in Mathematics (Numerical analysis, optimisation and computer science applied to medicine) and a Master Degree in Project Management. She worked for more than ten years in the area of cancer registries and screening databases, and collaborated in setting-up the regional population-based cervical cancer screening programme and cancer registry in Romania. She is currently working for the European Commission's Initiative on Breast Cancer.

Liisa Pylkkanen, MD, PhD graduated in Medicine in 1986 and obtained her PhD in 1992. She is a Specialist in Clinical Oncology (since 1995), Health Administration (since 2001) and Palliative Medicine (since 2010). She also holds Adjunct Professor position at the University of Turku, Finland (since 2001). She has worked for more than 25 years in clinical oncology and in different management positions both in academia and pharmaceutical industry. Since 2012 she served as Chief Medical Officer at the Cancer Society of Finland and currently working as Scientific Project Officer in the Healthcare Quality Team at the JRC (since 8/2015). Her scientific interest has focused on breast and prostate cancer, bone active compounds and patient support.

Francesco Sardanelli, born in Genoa, Italy (June 14, 1953). Medicine Graduation (1982) and Post-graduation in Radio-diagnostics (1986), staff radiologist (1987-99), and professor at the Post-graduation Course in Radio-diagnostics (1992-2000), Genoa University. Director of the Department of Radiology at the Research Hospital Policlinico San Donato, Milan, Italy (2001). Associate Professor of Radiology at Milan University (2006-2015). Associate Professor/Full Professor of Radiology, Milan University (2005/2015-). Director of the Post-graduation School in Nuclear Medicine (2008-2010) and in Radio-diagnostics (2015-), Milan University. Consultant for the Istituto Superiore di Sanità (Italian Ministry of Health) and for the national radiological coordination of three multicentre studies on MRI – including screening of women at high genetic-familial risk for breast cancer (1999-2012). Member of the Board of Directors of Breast Centres Certification according to EUSOMA guidelines. Member of Editorial/Advisory Board of *European Radiology*, *The Breast*, *La Radiologia Medica*, *American Journal of Roentgenology*, *Insight Into Imaging*, *Clinical and Translational Imaging*, and reviewer for other 48 medical journals. Current societal roles: Research Committee, European Society of Radiology; Advisory Board, European Institute for Biomedical Imaging Research; Director, European Network for Assessment of Imaging in Medicine. Past-president, European Society of Breast Imaging. President, College of Breast Radiologists by the Italian Society of Medical Radiology. Honorary membership, British Society Breast Radiology, Iranian Society of Radiology.

Charles Shaw trained as a doctor (London), manager (Canadian Hospital Association), and hospital inspector (Accreditation Canada). He received a PhD from the University of Wales on healthcare standards. He worked as a manager in the UK NHS, as an academic at University of Bristol, and as a policy adviser at the King's Fund and Department of Health in London. Retired from the UK NHS since 2001, he is now visiting professor at Macquarie University in Australia, and freelance consultant to ministries of health. As former president of the International Society for Quality in Healthcare (ISQua), he led a global review of 'quality and accreditation in health care services' commissioned by WHO Geneva in 2000. He has published five European and international surveys of healthcare accreditation programmes, and guidance for new schemes for WHO (HQ, EURO and EMRO), for World Bank and for several Ministries of Health. The most recent of 150 publications in peer reviewed journals proposes a European initiative to standardise healthcare standards between accreditation, certification and regulation. Charles Shaw was leader of the EC research project on 'external peer review techniques' and a partner in designing hospital assessment tools for the EC MARQuIS and DUQuE projects, seeking to demonstrate an association between accreditation, certification and quality and safety in healthcare.

Luzia Travado, PhD, MSc, ClinPsych, is clinical health psychologist and psychotherapist by the University of Lisbon, specialized in psycho-oncology and palliative care, and has doctorate degree in Psychology/Health Psychology by the University of Coimbra. She is presently head of Psycho-Oncology at the Clinical Centre of the Champalimaud Foundation, in Lisbon, Portugal (2012-). Previously was chief of Clinical Psychology at Central Lisbon Hospital Centre-Hospital S. José, where she began her career and has pioneered psychosocial programs for chronic disease patients, namely breast cancer (1985-2012). She served as adviser for the National Coordinator for Oncological Diseases in Portugal (2007-2011). She represented Portugal at the European Partnership on Action Against Cancer (2009-2014), and led the Psychosocial Oncology Action under this partnership; she presently collaborates with the European Cancer Control Joint Action (CANCON). She has been involved in European cancer policy being a speaker at various EU meetings, summits and conferences concerning cancer control and care in Europe, and also international ones related to psycho-oncology. She currently serves as President of the International Psycho-Oncology Society, and was Chair of the IPOS World Congress of Psycho-oncology in Lisbon in 2014. She serves as Specialty-editor for *The Breast* and is founder and former president of the Viva Mulher Viva Association on breast cancer. She has several scientific papers published in Int'l peer-review journals, and book-chapters. She was cover story at *Cancer World* in the Nov-Dec 2011 issue.

Özge Tunçalp, MD, PhD, is a physician and epidemiologist currently based in Geneva as a scientist in the Department of Reproductive Health and Research at the World Health Organization. In collaboration with country, regional and international partners, she uses quantitative and qualitative methodologies as well as innovative approaches to research quality of care for maternal and new-born health, including maternal morbidity and safe abortion in low- and middle-income countries. She is a member of the GRADE-CERQual Project Group, which develops a methodology to assess confidence in the evidence from reviews of qualitative research and leads the work on WHO guidelines on antenatal care, upcoming in 2016. Özge completed her PhD at Johns Hopkins Bloomberg School of Public Health and a postdoctoral fellowship at the Department of Obstetrics and Genecology at Yale School of Medicine.

Aslı Ulutürk was born in Izmir, Turkey in 1976. She graduated from Ankara University Faculty of Medicine in 2000 and received her specialist degree in Radiology in Gazi University in 2007. She worked in the Ultrasound Department of Women's Health Hospital in Bartin and held the consultant radiologist position of the city in Cancer Early Diagnosis and Screening Program coordinated by the Ministry of Health for three years. Then she moved to Istanbul and worked in Chest Diseases and Tuberculosis Research Hospital focusing on follow-up of tuberculosis and lung cancer. Her main professional interests are breast imaging, abdominal and obstetrics ultrasound. She joined the Joint Research Centre in April, 2013. As a member of the Unit for Public Health Policy Support, she works with the Healthcare Quality Team.

Yvonne Wengström is an oncology nurse and has worked at the Department of Oncology with breast cancer practice since 1989, and holds a PhD in oncology and is Professor in Nursing. She is a senior researcher at the Karolinska Institutet in Stockholm, Sweden, and leads a research team at the Department of Nursing. Dr Wengström has developed her research career with focus on breast cancer and is now recognised as a nurse leader in projects around screening, innovative interventions using e-health in cancer care, experience based co-design and is an advocate of transferring research outcomes into practice. She is also a member of several international committees and has been the President of the European Oncology Nursing Society, has participated as invited speaker at many international conferences, and is widely published. She currently serves as specialty editor for *The Breast* journal and is one of the founding members of the global network for collaboration the International Learning Committee (ILC).

Simone Wesselmann. As a trained gynecologist I have been the founding member of two certified breast cancer centres in Germany (2003 and 2004). The impact of certification on the overall care of patients was strikingly convincing. Its success encouraged me to continue my career in the area of quality assurance. Subsequently I graduated with a Master's Degree in health care management, and in 2008 I started as head of the certification department of the German Cancer Society. Within our certification system we have 278 breast cancer centres certified by the German Cancer Society and the German Society for Senology in four European Member States. These centres are part of a comprehensive oncological certification system with in total over 1100 certified centres for different tumor entities. By now the German centres treat 90% of all incident breast cancer cases in Germany. I am also a member of the Guideline Group which developed the German evidence-based Guideline for Breast Cancer. The guideline is the basis for recommendations which must be met during the certification procedure. Every year my department publishes the results of over 50 000 breast cancer patients that have been treated in certified centres. In sum, my expertise has got breadth and depth, based on many years of experience in the field of quality assurance. It is part of my daily work to develop with other experts guideline based recommendations, quality indicators, nationwide working documentation and to implement them successfully.

Annex 2: List of participants

First Name	Last Name	Organisation	Country
Tit	ALBREHT	National Institute of Public Health	Slovenia
Kathi	APOSTOLIDIS	ECPC European Cancer Patient Coalition	Belgium
Riccardo	AUDISIO	European Society of Surgical Oncology	Belgium
Mariangela	AUTELITANO	ASL di Milano	Italy
Deirdre	BEECHER	Cochrane Injuries Group	United Kingdom
Elizabeth	BENNS	Independent Cancer Patients' Voice	United Kingdom
Bettina	BORISCH	Université de Genève	Switzerland
Hilde	BOSMANS	University Hospital of the KU Leuven	Belgium
Andrew	BOTTOMLEY	EORTC	Belgium
Mireille	BROEDERS	Dutch Reference Centre for Screening	Netherlands
Karen	BUDEWIG	Federal Ministry of Health	Germany
Stefan	CANO	European Institutions and other	n/a
Xavier	CASTELLS	Hospital del Mar (Fundació IMIM)	Spain
Luigi	CATALIOTTI	Breast Centres Certification	Italy
Saskia	CLAASSEN	Catharina Hospital	Netherlands
Alberto	COSTA	ECCO (European CanCer Organisation)	Belgium
Simona	CURELEA	DAkkS (German Accreditation Body)	Germany
Miriam	DALMAS	Ministry for Health	Malta
Jan	DANEŠ	Charles University in Prague, First Faculty of Medicine	Czech Republic
Marina	DAVOLI	Department of Epidemiology, Lazio Region	Italy
Harry	DE KONING	Erasmus Medical Centre	Netherlands
Christophorus	DE WOLF	ADSAN	Switzerland
Nadia	DIMITROVA	Bulgarian National Cancer Registry	Bulgaria

First Name	Last Name	Organisation	Country
Stephen	DUFFY	Queen Mary University of London	United Kingdom
Alexandru	ENIU	European Commission (not JRC)	n/a
Josep A.	ESPINÀS	Catalan Cancer Plan	Spain
Patricia	FITZPATRICK	National Screening Service	Ireland
Markus	FOLLMANN	German Cancer Society	Germany
Franco	GATTAFONI	ACCREDIA	Italy
Delia	GEARY	European Institutions and other	United Kingdom
Sija	GEERS- VAN GEMEREN	European Federation of Radiographer Societies	Netherlands
Livia	GIORDANO	Azienda Ospedaliera Citta della Salute e della Scienza di Torino	Italy
Paolo	GIORGI ROSSI	AUSL Reggio Emilia	Italy
Ljubinka	GLIGIC	Accreditation Body of Serbia	Serbia
Chris	GRAHAM	Picker Institute Europe	United Kingdom
André	GRIVEGNÉE	Institut Jules Bordet	Belgium
Axel	GRÄWINGHOLT	self employed	Germany
Sirpa	HEINAVAARA	European Institutions and other	Finland
Günther	HELLER	Federal Institute for Quality Assurance and Transparency in Healthcare (IQTIG)	Germany
Solveig	HOFVIND	Cancer Registry of Norway	Norway
Roland	HOLLAND	EUREF – European Reference Organisaton for Quality Assured Breast Screening and Diagnostic Services	Netherlands
Kitti	HORVATH	European Institutions and other	Hungary
Michael	HUEBEL	European Commission (not JRC)	Luxembourg
Elisabetta	IANNELLI	AIMaC	Italy
Verica	JOVANOVIC	Institute of Public Health of Serbia 'Dr Milan Jovanovic Batut'	Serbia
Henrik Lykkegaard	JØRGENSEN	DANAK	Denmark

First Name	Last Name	Organisation	Country
Anja	KAESSNER	Federal Office of Public Health	Switzerland
Cary	KAUFMAN	National Accreditation Program for Breast Centers, USA (NAPBC)	United States of America
Jenny	KING	Picker Institute Europe	United Kingdom
Susan	KNOX	Europa Donna The European Breast Cancer Coalition	Italy
Ina	KOPP	Guidelines International Network/ Association of the Scientific Medical Societies in Germany	Germany
Isabell	LADIGES	European Commission (not JRC)	Luxembourg
Annette	LEBEAU	Gemeinschaftspraxis für Pathologie	Germany
Robert	MANSEL	n/a	United Kingdom
Lorenza	MAROTTI	EUSOMA	Italy
Francesca	MARTINELLI	EORTC	Belgium
Helen	MCGARRIGLE	Cardiff and Vale Breast Centre, University Hospital Llandough	United Kingdom
Lydie	MEHEUS	The Anticancer Fund	Belgium
Katrien	MOENS	Scientific Institute of Public Health, Cancer Centre	Belgium
Ana	MOLINA	Fundación para el Fomento de la Investigación Sanitaria y Biomédica (FISABIO)	Spain
Lydia	MOUZAKA	Hellenic Senologic Society	Greece
Lennarth	NYSTRÖM	Umeå University	Sweden
Leslie	PENDRILL	SP Sveriges Tekniska Forskningsinstitut	Sweden
Elsa	PÉREZ	University Hospital Dr. Josep Trueta	Spain
Piera	POLETTI	CEREF	Italy
Carmen	PONS	Dirección General de Salud Pública, Conselleria de Sanidad Universal y Salud Pública	Spain
Antonio	PONTI	CPO Piemonte	Italy
Savelina	POPOVSKA	Medical University-Pleven	Bulgaria

First Name	Last Name	Organisation	Country
Margarita	POSSO	Iberoamerican Cochrane Centre -IIB Sant Pau	Spain
Cecily	QUINN	St. Vincent's University Hospital	Ireland
Peter	RABE	Mammography Cooperative	Germany
Alexandra	RAMSSL-SAUER	Gesundheit Österreich GmbH	Austria
David	RITCHIE	Association of European Cancer Leagues	Belgium
Vitor	RODRIGUES	Faculdade de Medicina, Universidade de Coimbra	Portugal
Elio Giovanni	ROSSI	Ambulatorio di Omeopatia, Azienda USL 2 Lucca	Italy
Anna	ROUILLARD	ECCO (European CanCer Organisation)	Belgium
Tiina	SAARTO	Helsinki University Hospital, Cancer Centre	Finland
Francesco	SARDANELLI	n/a	Italy
Stefan	SCHRECK	European Commission (not JRC)	n/a
Holger	SCHUNEMANN	McMaster University	Canada
Nereo	SEGNAN	University Hospital Città della Salute e delle Scienza di Torino	Italy
Charles	SHAW	Charles Shaw	United Kingdom
Alberto	SIMEONI	CEN-CENELEC	Belgium
Tuija	SINERVO	FINAS Finnish Accreditation Service	Finland
Giorgio	STANTA	University of Trieste	Italy
Aliki	STATHOPOULOU	Hellenic Accreditation System	Greece
Laura	STEPONAVIČIENĖ	National Cancer Institute	Republic of Lithuania
Alberto	TORRESIN	EFOMP and Niguarda Ca'Granda Hospital	Italy
Luzia	TRAVADO	Champalimaud Clinical Centre, Champalimaud Foundation	Portugal
Cornelis	VAN DE VELDE	Leiden University Medical Centre	Netherlands
Cary	VAN LANDSVELD-VERHOEVEN	LRCB | Dutch Reference Centre for Screening	Netherlands

First Name	Last Name	Organisation	Country
Chantal	VAN ONGEVAL	University Hospitals Leuven	Belgium
Leo	VAN ROSSUM	EUREGHA Network	Netherlands
Yvonne	WENGSTROM	Karolinska Institutet	Sweden
Simone	WESSELMANN	German Cancer Society	Germany
Wendy	YARED	Association of European Cancer Leagues (ECL)	Belgium
Kenneth	YOUNG	Royal Surrey County Hospital	United Kingdom
Tuncalp Mingard	ÖZGE	WHO	Switzerland

Annex 3: Agenda

Plenary of the European Commission Initiative on Breast Cancer (ECIBC):

"Improving breast cancer screening, diagnosis and care in Europe"

Baveno, Lago Maggiore District, Italy, 9-11 December 2015

AGENDA

The European Commission Initiative on Breast Cancer (ECIBC) is being built upon the principles of sustainability, continuity and the transparent inclusion of experts and stakeholders. The ECIBC is taken forward by the Commission's Joint Research Centre (JRC) based on an agreement with the Commission's Directorate-General Health and Food Safety (DG SANTE).

Its aim is to ensure and harmonise quality of breast cancer services across European countries.

DG SANTE has the policy leadership as regards the implementation of EU health policy on cancer. The Commission expert group on Cancer Control, which is a forum for Member States and stakeholders to provide input into cancer policy development at EU level, will regularly review the development of the ECIBC in order to guarantee its compatibility and coordination within the overall EU policy on cancer.

JRC has the scientific and technical responsibility for the ECIBC and coordinates its implementation, ensuring synchronisation of all ECIBC objectives and the delivery of quality outputs in a timely way. Owing to the inter-dependence of the different working groups within the ECIBC, close coordination and collaboration is essential to ensure the success of the initiative. JRC also ensures appropriate linkages with other Commission services and EU projects in areas relevant to the project (for example, with the EU Joint Action on Cancer Control–CANCON).

The purpose of the plenary is to update Member States and stakeholders on the progress that the ECIBC is making. This includes reporting on the current status of the development process of the European Guidelines for Screening and Diagnosis in Breast Cancer and the European Quality Assurance Scheme for Breast Cancer Services, as well as reporting on related projects and research activities. Furthermore, the ECIBC Plenary sets out to provide a platform for the discussion and knowledge exchange on current priority issues in breast cancer service provision in general throughout European countries, as well as to address related (healthcare) policies.

Day 1, December 9: Current State of ECIBC-projects

Moderator: Ciarán Nicholl, JRC

09:00 - 14:30	**Meetings of the ECIBC working groups (QASDG and GDG)** (not public – separate agenda)
14:30 - 15:15	**Welcome & Opening** **Video-message** (Anneli Jäätteenmäki, vice-president European Parliament) **Video message** (Alojz Peterle, President of the MEPs Against Cancer, European Parliament) • Welcome note (Krzysztof Maruszewski, JRC) • Welcome note, EC policies on (breast) cancer (Michael Hübel, DG SANTE) • Patients' expectations on EC-(breast) cancer policies (Susan Knox, Europa Donna)
15:15 - 15:30	**Introduction** Overview of the agenda for the next days
15:30 - 16:00	**Coffee**
16:00 - 17:30	**Current state of the ECIBC project** • ECIBC overview (Donata Lerda, JRC) • Development of a voluntary *European Quality Assurance Scheme for Breast Cancer Services* (Francesco Sardanelli, QASDG vice chair) • Development of *European guidelines for breast cancer screening and diagnosis* (Chris de Wolf, GDG co-chair) • Guidelines platform and web hub (Liisa Pylkkanen, JRC; Luciana Neamtiu, JRC) • Surveys and research activities: breast cancer screening and care in Europe, implemented breast cancer quality assurance schemes, and standards used in breast cancer care (Silvia Deandrea, JRC; Asli Ulutürk. JRC)

Day 2, December 10: Current Topics in Breast Cancer Care Research

Moderator: Anke Bramesfeld, JRC

09:15 - 10:00	**Key note - "The Concept of patient centred care and measuring the quality of health services"** Chris Graham, Picker Institute, UK
10:00 - 11:00	**Practice and Challenges in Assuring the Quality of Breast Cancer Care in Europe** • Hungary, Kitti Horváth, Chief Medical Officer's Office, Hungary • Malta, Miriam Dalmas, Ministry for Energy and Health, Malta • Norway, Solveig Hofvind, Cancer Registry of Norway
11:00 - 11:30	**Coffee**
11:30 - 13:00	**Together for Improving Care for (Breast) Cancer: Other Projects on Cancer from EU and abroad** • CanCon, Tit Albrecht, National Institute of Public Health, Slovenia • EU-TOPIA, Harry de Koning, Erasmus University, Rotterdam, Netherlands • US-Breast Center Accreditation, Cary Kaufmann, Bellingham Breast Cancer Center, USA • European Network of Cancer Registries, Nadya Dimitrova, Bulgarian National Cancer Registry
13:00 - 14:00	**Lunch**
14:00 - 16:00	**Current Topics from Breast Cancer Care Research: Parallel Workshops** 1. Continuity of care for breast cancer 2. Communication in person-centred services 3. Key outcomes for studies on breast cancer screening 4. Volume-outcome relation in breast cancer care
16:00 - 16:30	**Coffee, Evaluation of Event**
16:30 - 17:30	**Guided Poster Tour**
20:00	**Gala Dinner**

Day 3, December 11: The Way Forward
Moderator: Ciarán Nicholl, JRC

10:00 - 10:45	**Key note – "Dealing with evidence from qualitative research in guideline development"** Özge Tunçalp, Department of Reproductive Health and Research, WHO
10:45 - 11:00	**Coffee**
11:00 - 12:30	**Report from the parallel workshops**
12:30 - 13:00	**Last minute presentations** • Equity of access to breast cancer screening programmes in 27 European countries, Ana Molina, FISABIO, Spain • International consensus on methodological standards for guidelines, Ina Kopp, Guidelines International Network, Institute for Medical Knowledge Management, Germany • Delivery more for less, Elizabeth Benns, Independent Cancer Patients' Voice, UK
13:00 - 13:30	**Closing words (Donata Lerda, JRC)**
13:30 - 14:30	**Closing lunch**

Additional information on the European Commission Initiative on Breast Cancer is retrievable at the dedicated webpage of JRC Science Hub https://ec.europa.eu/jrc/en/research-topic/healthcare-quality

Additional information on how breast cancer care is organised in Europe is available in the JRC report on Breast Cancer Services (http://bookshop.europa.eu/en/report-of-a-european-survey-on-the-organisation-of-breast-cancer-care-services-pbLBNA26593/)

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