Second ECL Cancer Screening Workshop

1-2 December 2020

Supported by: CPO Centro di Riferimento per l'Epidemiologia e la Prevenzione Oncologica in Piemonte; Joint Research Centre JRC; International Agency for Research on Cancer; World Health Organization

Report

Co-funded by the Health Programme of the European Union

ECL has received funding under an operating grant (number: 785273) from the Third Health Programme (2014-2020).

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DAY 1: BREAST CANCER SCREENING

What needs to be communicated, to whom and how? Example of breast screening.

Evidence and latest insights from the New European Guidelines on Breast Cancer Screening and research from the Joint Research Centre

Luciana Neamtiu, Joint Research Centre (JRC), European Commission

Luciana Neamtiu (LN) provided an overview of the **European Commission Initiative on Breast Cancer (ECIBC)**. The aim of the initiative is to improve the quality of breast cancer screening, diagnosis, and care and contribute to reducing inequalities in accessing breast cancer services across Europe. As part of the initiative, the European Commission developed:

- The **European guidelines for breast cancer screening and diagnosis** - are 74 recommendations on screening, diagnosis, dissemination of screening invitations, communication of results and training for healthcare professionals involved in screening and diagnosis of breast cancer.
- The **European Quality Assurance Scheme for Breast Cancer Services** - is a collection of requirements and quality indicators based on evidence that can be followed by any breast cancer service wishing to improve the quality of care offered to women. There is a total of 86 quality requirements. The adoption of the scheme is voluntary however, if a screening service adopts it, it must adhere to all 86 requirements.

Balance of benefits and harms. The need of comparable estimates

Nereo Segnan, CPO Piemonte – WHO Collaborating Centre for early detection and screening of cancer

Nereo Segnan (NS) presented approaches to balancing benefits and harms in breast cancer screening. Screening has both an individual and a societal dimension. Hence, balancing harms and benefits requires considering personal values and priorities of screening participants as well as the cost-benefit ratio of screening programmes for health systems.

To allow for informed decision making, it is essential to consider the severity of screening-related harms and agree on standard common measure to balance benefits and harms of screening.

A useful tool to compare the impact of the care pathways in organised, opportunistic and in no screening are **composite indicators,** such as disability-adjusted life years *(DALYs),* and quality-adjusted life years *(QALYs).* These measures of disability or quality of life (QoL) are independent from the mode of detection of the disease.

Role of cancer leagues in communicating quality assurance of cancer screening - Quality assurance along entire process

Antonio Ponti, CPO Piemonte – WHO Collaborating Centre for early detection and screening of cancer

Antonio Ponti (AP) stressed that measuring 'quality' is essential to properly evaluate and improve screening programmes. When measuring quality, one needs to define **quality indicators** and the associated **standards of success**.

AP informed participants that the European Society of Breast Cancer Specialists (EUSOMA) built a Europe-wide database of breast cancer data and measures that allows to develop quality indicators. The quality indicators used by EUSOMA are published in the paper ***Quality indicators in breast cancer care: an update from EUSOMA working group* (Biganzoli et al., 2017).**

AP concluded that **Cancer leagues across Europe** should get familiar with the concept of 'quality' when it comes to screening and the continuum of care. They should lobby at both the national and European level for quality assurance in all screening programmes and clinical centres. They should also aid informed decision-making by sharing quality measures of screening programmes.

Elements of effective communication strategies for cancer screening programmes

Review of communication strategies to promote informed decision-making in cancer screening

Livia Giordano, CPO Piemonte – WHO Collaborating Centre for early detection and screening of cancer

Livia Giordano (LG) highlighted the importance of effectively communicating the benefits and harms of screening to participants. Population-based screening programmes should facilitate **personal informed choice**. Informed choice is when a person is given options to choose knowing the details, benefits, risks and expected outcome of screening options.

Decision aids are effective in supporting personal informed choice. Decision aids include pamphlets, videos, or web-based tools encouraging active patient participation in decision making about health treatment and screening options. These aids should outline the benefits and harms of specific care pathways and help patients clarify their personal values. The **ECIBC's Guidelines Development Group (GDG)**, for instance, recommends using a decision aid that explains the benefits and harms of screening over a "regular" invitation letter for informing women about the benefits and harms of breast cancer screening.

Practical example of a tool to facilitate informed decision-making in cancer screening

Patricia Villain, International Agency from Research on Cancer (IARC)

Patricia Villain (PV) presented the CANelle project, a shared decision-making tool for women developed in France. PV explained that shared decision making can only be successful if patients share and clearly communicate their own preferences and values to their healthcare professionals.

The CANelle project is a free programme open to any woman who receives an invitation to take part in the organised breast cancer screening programme. As part of the project, women get to (i) book an appointment with their GPs dedicated to discussing the benefits and harms of breast cancer screening and (ii) to join a private social network where they can access easy to read breast cancer screening information and discuss the pros and cons of screening with healthcare professionals.

Small working group discussions

Participants were split into 3 small working groups to discuss the following questions:

- In brief, what are some of main challenges and obstacles faced in practice for the communication about cancer screening to the public?
- Are health professionals supportive of enabling informed choice about participation in screening? Are messages from health professionals consistent with the communication from cancer leagues?
- Are additional measures required for supporting an informed choice amongst people from subgroups of society that may not participate or participate less in screening? Could pursuing informed decision-making exacerbate inequalities? If so, how can this be avoided?
- ECL has a new working group on cancer prevention and early detection: What practical steps can be taken to support cancer leagues in the communication about cancer screening programmes?

Takeaways from small group discussions **[group 1] [group 2] [group 3]**

- Participants highlighted the challenges faced by cancer leagues when using *QUALYs* and *DALYs* to compare care pathways. Leagues often do not have the necessary data on mortality, deaths and overdiagnosis to calculate these indicators.
- Participants stressed the importance of adapting screening communication to different target audiences not to increase health inequities. Communication efforts should concentrate on vulnerable groups that do not take part to organised screenings. Health professionals should also be trained in better communicating cancer screening to different target audiences.
- Participants agreed that cancer leagues should advocate for quality measures and quality assurance in cancer screening and should recommend guiding principles and best practices to reach different target groups in the population.
- Participants reflected on the fact that balanced information might highlight the harms of screening programmes. How does that resonate with citizens' understanding?
- Participants highlighted the challenge posed by the emerging anti-screening movements and encouraged cancer leagues to build on the lessons learnt from the anti-vax movement.

Summary notes from the group discussions can be found here.

DAY 2: CERVICAL AND COLORECTAL CANCER SCREENINGS

What needs to be communicated, to whom and how for cervical and colorectal cancer screening?

Cervical and colorectal cancer – review of the evidence

André Carvalho, International Agency from Research on Cancer (IARC)

André Carvalho (AC) presented recent resources used by national and international health agencies to develop evidence-based interventions and policy recommendations for reducing cancer risk in the population. These include:

- **the IARC Handbooks of Cancer Prevention** (2014) which provides comprehensive reviews and consensus evaluations of the evidence on the effectiveness of preventive interventions that may reduce cancer incidence or mortality.
- **the IARC Cervical cancer screening Handbook** (2005) which reviews what is known about the occurrence, natural history and causes, before describing the established methods and newer variants and approaches for screening that are now being introduced, tested, or investigated. A new, updated handbook on cervical cancer screening is now being developed by IARC.
- **the IARC Colorectal cancer screening handbook** (2017) provides evidence-based evaluations of the effectiveness of colorectal cancer screening in reducing colorectal cancer incidence and mortality.
- **WHO guidelines for screening and treatment of precancerous lesions for cervical cancer precenting** (2013)
- **WHO Global strategy to accelerate the elimination of cervical cancer as a public health problem** (2020)

How to communicate the evidence for Cervical Cancer Screening

Paola Armaroli, CPO Piemonte – WHO Collaborating Centre for early detection and screening of cancer

Paola Armaroli (PA) presented the **guiding principles of informed choice**, namely (i) balancing harms and benefits and (ii) providing unbiased, evidence-based information, and their application to cervical screening communication.

For most women, the main source of information about cervical cancer screening is the **written invitation** they receive to participate in the programme. It seems that current invitation letters are not sufficiently informative and tend to downplay potential risks and harms, such as overdiagnosis and overtreatment. Invitation letters should avoid taking a paternalistic approach and should not be biased in favour of participation. To allow for informed decision making, it is relevant to develop evidence-based content enabling informed participation in cervical cancer screening.

How to communicate the evidence for Colorectal Cancer Screening

Carlo Senore, CPO Piemonte – WHO Collaborating Centre for early detection and screening of cancer

Carlo Senore (CS) presented effective strategies for communicating about colorectal cancer screening to the public. **Colorectal cancer screening** is particularly challenging for healthcare professionals to communicate about, as there are **several different tests** with different acceptability, risk-benefit ratios, and costs available today.

It is essential to translate evidence of screening effectiveness into sustainable protocols to ensure **equity and quality.** Evidence include benefits, harms, and individual's value, attitudes, knowledge, and

beliefs. The provision of educational material supports efforts aimed at promoting informed participation. Leaflets may also be used to convey information tailored to address barriers experienced by specific sub-groups.

Small working group discussions

Participants were split into 3 working groups to discuss the same questions of day 1 with a focus on cervical cancer screening.

Takeaways from small group discussions **[group 1] [group 2] [group 3]**

- Participants discussed the challenge of collecting and/or accessing all relevant data about cervical and colorectal cancer screenings to be able to communicate evidence-based information to screening participants.
- Participants reflected on the need of understanding specific barriers to participation in screening programmes faced by specific subgroups of the population. Cancer Leagues should identify and remove these barriers and design special communication tools tailored to vulnerable groups.
- Participants reflected on the challenges posed by opportunistic HPV testing and by offering the possibility to participants to choose the type of test for colorectal cancer screening they would like.
- Participants pointed out to the need of using a gender specific approach whilst communicating about colorectal cancer screening since males have a higher risk of getting colorectal cancer.

Summary notes from the group discussions can be found here.

Consequences of the Covid-19 pandemic on cancer screening in Europe

The final session of the workshop covered the effects of the Covid-19 pandemic on cancer screening services, and considered the longer term impact that may arise due to the delays and disruption caused by this unprecedented public health crisis.

Impact on Screening implementation

Mireille Broeders, Radboud University Medical Center (Radboudumc)

Mireille Broeders (MB) presented the preliminary findings of the International Cancer Screening Network (ICSN) on the impact of the Covid-19 pandemic on cancer screening services. Response to the survey was good with complete responses covering 35 countries and 66 cancer screening settings. Results relate to the period of data collection Q2 and Q3 2020 during which screening programmes were in the re-starting phase. Fuller results will be disseminated shortly and a follow up survey is likely to be developed in early 2021.

Modelling the effects of disruption to Screening

Iris Lansdorp-Vogelaar, Erasmus MC

Iris Lansdorp-Vogelaar (ILV) presented the preliminary findings on the effects of the Covid-19 pandemic on cancer screening of the Cancer Global Modelling Consortium, a part of the Covid-19 and Cancer Task Force established in March 2020. ILV explained that the Consortium used modelling to project the impact of Covid-19 on:

- Direct and indirect cancer risk
- Delays in cancer diagnosis
- Cancer survivorship

Results were presented for colorectal, cervical and breast cancer screening independently. Results have not yet been published and are presently at different stages of analysis per programme. A key result shared regarding colorectal cancer screening was that catch-up screening after 6 months of disruption can mitigate (though not entirely remove) the risk of increased long-term CRC incidence. More information can be found at the Consortium website - https://ccgmc.org//.

Impact on the work of Cancer Registries

Luciana Neamtiu, Joint Research Centre (JRC), European Commission

LN presented the preliminary findings of JRC survey on the Impact of Covid-19 pandemic on cancer registration and cancer care. The aim of the research is to assess the effects of the Covid-19 pandemic on cancer registries on the medium and long term. A questionnaire was prepared and sent to directors of cancer registries in 34 countries from 24th June until 24th July. 40 registries from 16 EU member states responded.

The cancer registration process was disturbed due to changes in work modalities for the personnel (remote work) or allocation of staff to other activities related to the pandemic control, as well as the difficulties in accessing sources and/or receiving the notifications. A number of registries are participating in or conducting studies to measure the impact of the COVID-19 in cancer care. Cancer registries could perform studies related to the impact of the pandemic in cancer screening, diagnosis and care.

Workshop agenda

	AGENDA - DAY 1
10:00 - 10:05	**BRIEF INTRODUCTION AND WELCOME**
10:05 - 10:50	**What needs to be communicated, to whom and how? Example of breast screening** **Evidence and latest insights from the New European Guidelines On Breast Cancer Screening and research from the Joint Research Centre** *Luciana Neamtiu, Joint Research Centre* **Balance of benefits and harms. The need of comparable estimates** *Nereo Segnan, CPO Piemonte* **Role of cancer leagues in communicating quality assurance of cancer screening - Quality assurance along entire process** *Antonio Ponti, CPO Piemonte*
10:50 - 11:05	**DISCUSSION**
11:05 - 11:10	**BREAK**
11:10 - 11:45	**Elements of effective communication strategies for cancer screening programmes** **Review of communication strategies to promote informed decision-making in cancer screening** *Livia Giordano, CPO Piemonte* **Practical example of a tool to facilitate informed decision-making in cancer screening** *Patricia Villain, IARC*
11:45 - 12:00	**DISCUSSION**
12:00 - 12:05	**BREAK**
12:05 - 12:50	**Breakout rooms – discussion of experiences and problems** • Participants will be divided according to similarity of their country situation regarding breast cancer screening. • Working groups will discuss the national and local context, share examples of relevant practice from cancer leagues, address specific problems in reality and identify areas for support or in which further research is required. • Participants asked to consider subgroups of the population: vulnerable groups, low health literacy and socio-economic status, etc.
12:50 - 12:55	**BREAK**
12:55 - 13:25	**PLENARY DISCUSSION**
	END OF DAY ONE

	AGENDA - DAY 2
10:00 - 10:05	**INTRODUCTION TO DAY 2**
10:05 - 11:05	**What needs to be communicated, to whom and how for cervical and colorectal cancer screening?** **Cervical and colorectal cancer – review of the evidence** *André Carvalho, IARC* **How to communicate the evidence for Cervical Cancer Screening** *Paola Armaroli, CPO Piemonte* **How to communicate the evidence for Colorectal Cancer Screening** *Carlo Senore, CPO Piemonte*
11:05 - 11:25	**DISCUSSION**
11:25 - 11:35	**BREAK**
11:35 - 12:20	**Breakout rooms – discussion of experiences and problems** • Participants will be divided according to similarity of their country situation regarding cervical and colorectal cancer screening. • As per previous working group session, groups will discuss the national and local context, share examples of relevant practice from cancer leagues, address specific problems in reality and identify areas for support or in which further research is required. • Participants asked to consider subgroups of the population: vulnerable groups, low health literacy and socio-economic status, etc.
12:20 - 12:40	**DISCUSSION**
12:40 - 12:45	**BREAK**
12:45 - 13:15	**Consequences of the Covid-19 pandemic:** **Impact on Screening implementation** - *Mireille Broeders, Radboud UMC* **Modelling effects of disruption to Screening** - *Iris Lansdorp-Vogelaar, Erasmus MC* **Impact on work of Cancer Registries** - *Luciana Neamtiu, JRC*
13:15 - 13:30	**DISCUSSION**
	END OF WORKSHOP

List of speakers

First Name	Last Name	Organisation
Luciana	Neamtiu	Joint Research Centre
Nereo	Segnan	CPO Piemonte
Antonio	Ponti	CPO Piemonte
Livia	Giordano	CPO Piemonte
Patricia	Villain	IARC
André	Carvalho	IARC
Paola	Armaroli	CPO Piemonte
Carlo	Senore	CPO Piemonte
Mireille	Broeders	Radboud UMC
Iris	Lansdorp-Vogelaar	Erasmus MC

List of participants

First Name	Last Name	Organisation
Marie-Jolin	Koester	German Cancer Society
Satu	Lipponen	Cancer Society of Finland
Balazs	Rozvanyi	Hungarian Cancer League
Urska	Ivanus	Slovenian Association of Cancer Societies
Katja	Jarm	Slovenian Association of Cancer Societies
Maryanne	Massa	Cancer Foundation Malta
Imre	Gaál	Hungarian Cancer League
Yvonne	Grendelmeier	Swiss Cancer League
Gerry	McElwee	Cancer Focus Northern Ireland
Dana	Frost	Israel Cancer Association
Miri	Ziv	Israel Cancer Association
Marina	Kafourou-Cosma	Cyprus Association of Cancer Patients & Friends
Tytti	Sarkeala	Cancer Society of Finland
Sophia	Lowes	CRUK
Sebastian	del Busto	Spanish Association Against Cancer
Lucienne	Thommes	Cancer Fondation Luxembourg
Lore	Pil	Kom op Tegen Kanker Belgium
Mathijs	Goossens	Foundaiton against Cancer Belgium
Janne	Bigaard	Danish Cancer Society
Nicoleta	Athanasiadou	Anti-Cancer Society Cyprus
Daniela	Giangreco	Italian League Against Tumours
Barbora	Dostálová	League against Cancer Slovakia
Neda	Ferencic	Croatian Leagues Against Cancer
Alice	Le Bonniec	International Agency for Research on Cancer
Leopoldina	Amaral	Portuguese League Against Cancer
Asli	Uluturk Tekin	Joint Research Centre
Caroline	Braeken	Cancer Foundation Luxembourg
Daniela	Kállayová	Ministry of Health of the Slovak Republic
Ana	Fernández-Marcos	Spanish Association Against Cancer
Laura	Kudrna	University of Birmingham
David	Ritchie	ECL
Wendy	Yared	ECL
Ginevra	Papi	ECL
Adele	Barlassina	ECL