Workshop Report

European Partnership for Action Against Cancer (EPAAC) Joint Action, WP6 Screening and Early Detection:

Regional Workshop One

“European Action: implementing colorectal cancer screening programmes”

Workshop date: 07/03/2012 – 08/03/2012
Workshop venue: Jury’s Inn Hotel, Liverpool, UK

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1. Introduction

The first regional workshop of Work Package 6 (Early Detection and Screening) objective 3 (facilitating expert advice to regions seeking to implement or improve population-based cancer screening programmes in accordance with the Council of the EU Recommendation 2003) of the European Partnership on Action Against Cancer (EPAAC) Joint Action, was held in Liverpool, United Kingdom, on Wednesday 7 March and Thursday 8 March 2012.

The first workshop was devoted to the current status of the implementation of colorectal cancer (CRC) screening programmes in Europe in accordance with the Council of the EU Recommendation 2003 and aimed to understand the barriers preventing greater implementation of the Council Recommendation across national, regional and local levels in the EU. This workshop is the first of three such workshops: the remaining two workshops will focus on cervical and breast cancer screening programmes and shall take place in Padova, Italy (October 2012) and Flanders, Belgium (June 2013) respectively.

This report details a descriptive overview of the workshop session that took place on 7 and 8 March 2012, collating the key messages and recommendations of the workshop, and providing, in annex, some of the main documents arising from, or associated with, the workshop.

Methodology

The first workshop represents the culmination of several months work initiated by the kick-off meeting of the EPAAC project in February 2011 and is the first key milestone of WP6 objective 3. A project team was created from a small consortium of partners who came together to design and implement the programming of the three workshops. These partners are: the University of Antwerp; North West of England Cancer Networks; the North West Health Brussels Office (NWHBO); the Flemish Agency for Care and Health (VAZG); the Veneto Institute of Oncology; and the European Regional and Local Health Authorities (EUREGHA).

Under the auspices of the EUREGHA network, the NWHBO and VAZG conducted a brief questionnaire investigating the cancer screening competencies of local and regional authorities across Europe, which was distributed to representatives of all EU Member States and associated countries. The chief aim of this study was to gather a pool of relevant professionals who could later be contacted for a further, more elaborate survey designed by the University of Antwerp.
Following the dissemination of the EUREGHA questionnaire, the University of Antwerp conducted a literature review to establish those regions and Member States that would be selected to receive the University of Antwerp survey. This survey targets respondents that are either leading established colorectal cancer screening programmes; principle investigators or senior researchers of pilot programmes, feasibility studies, research projects or trials for developing a colorectal cancer screening programme. As a minimum requirement, the target respondents were to be involved in colorectal cancer screening on a weekly basis.¹

The aim of the survey is to share knowledge, published as well as non-published, gained from CRC screening programmes, research projects and pilot studies on CRC screening and preparations for CRC programme implementation on a population level and to use this shared knowledge in the advancement of CRC screening. The selection of a region was performed on the basis of successful and unsuccessful experiences. In other words, extremes were selected, since this can offer a clearer view on which criteria for good practice have to be included or excluded when organising or implementing a screening programme. Regions without any colorectal cancer screening activity were excluded, since it would demand a different type of survey.

Using the pool of respondents from both the EUREGHA and University of Antwerp surveys, potential delegates for the workshop were identified from EU and associated countries selected through the research conducted by the University of Antwerp [an open call for delegates later followed]. The objective was, as much as was feasible, to achieve a diversity of participants between those with practical day-to-day involvement in colorectal cancer screening programmes, and those at the more strategic, policy-orientated level. The rationale for this was that it would allow for a more layered discussion and offer the possibility of workshop recommendations to be implemented at differing strategic levels of influence.

The responsibility for programme design of the colorectal cancer screening workshop was taken by the workshop host: the North West Cancer Screening Networks, in particular the Merseyside and Cheshire Cancer Network. This responsibility involved identifying a keynote speaker, programming the content of the various workshop sessions, locating a suitable venue, and co-organising the logistical arrangements. The intention was for the outcomes of the University of Antwerp survey to feed into the design of the workshop.

This methodology shall also be applied in the remaining two workshops. More substantial information on the methodology behind the workshop, and the findings

¹ NB. This approximation depends upon where the competency is found in each respective Member State i.e. a decentralised competency or centralised, ‘National’, responsibility.
of the University of Antwerp survey, will be available in the final report of the process that will be published by the University of Antwerp following the final workshop in 2013.
2. Key Messages from the Workshop

The following messages are the recommendations arising from the three breakout sessions which took place during the workshop. These sessions were entitled:

A. Implementation of population-based colorectal cancer screening programmes
B. Overcoming barriers to participation in colorectal screening
C. Implementing quality using data

A. Key messages for competent bodies\(^2\) seeking to implement or improve colorectal screening programmes:

1) *In order to increase participation rate, developing a robust and pragmatic strategy for encouraging citizens’ participation in screening is the key to success.*

- The notion of “customisation” – tailoring the message to the audience – is vital to success: it is important to get the message right for the community/demographic that is being targeted.
- Consequently, it is important to understand the social context of the target groups. For example, invitation letters, promotional materials, must be in the appropriate languages of the target groups.
- In order to boost participation rates, efforts should be made to understand the expectations of the target audience: think of them as ‘clients’ as well citizens. Tactics that have shown promising results include:
  a. user friendly tests - this is essential for the singularity of colorectal cancer screening;
  b. self-assessment approach;
  c. innovative social marketing methods;
  d. where appropriate, the direct involvement of GPs.
- Greater emphasis should be given for competent bodies to better understand and appreciate the possibilities offered through promoting genuine ‘health literacy’ of the population: the better informed the population is, the better the uptake is likely to be in the screening programme. This approach can also

\(^2\) This denotes that authority whom has the responsibility to act on this topic, whether it be at local, regional or national (Member State) level, depending upon the particular context of the said body in question.
deal with negative perceptions and common misunderstands of the process, which is a particular issue for colorectal cancer screening.

2) **In order to fully inform the target population, a fully informed workforce is required. Therefore, regular training and awareness-raising for health professionals about specific tests is required.**

- Authorities must be sure to reserve appropriate resources for the Continuous Professional Development (CPD) of all relevant health professionals, and make efforts to work in multi-disciplinary teams to pool knowledge and awareness.

3) **It is very important to identify and use appropriate indicators to determine the efficacy of a population-based colorectal screening programme.**

- Possible measures for outcomes and relative success can be measured through:
  - a. number of re-screen rates;
  - b. uptake by previous “refusers” for participation;
  - c. the conversion rates from screening positive to attendance for diagnostic test (especially where the screen positive result is delivered to the client/GP for action, rather than leading to active follow up as part of the screening pathway).

- It is important to regularly question as to what level of participation screening organisers should we be satisfied with. Is, for example, 53% good enough? Is it realistic for goals to be set? Reflective questions such as this should be posed by the competent authority of the screening programme. Such bodies should also consider whether there is a point at which that you have to admit that screening coverage has reached its limit.

4) **It is important to encourage general co-operation, and the sharing of knowledge and ideas, both between and within countries. Such co-operation should focus on the relative strengths and weaknesses of different population-based colorectal screening programmes. In particular, this process will be of central importance to those bodies undertaking pilot studies.**

- Comparison, cooperation and benchmarking between regions and countries are highly important, especially when piloting new or improved population-based colorectal cancer screening programmes. However, communication
and marketing tools (in the invitation procedure, for example) need to be re-thought and re-shaped depending upon each context: testing new tools versus conventional ones in this manner is therefore very important.

- Active participation of the target groups is essential in the design and implementation of the piloting process. Thus, patient groups are a fundamental part of the co-operation process.

- Comparison of screening methods is not just important for those piloting a population-based programme, but is useful for all competent bodies as it provokes the question as to what kinds of incentives are needed when replacing or re-invigorating an existing programme.

B. Key issues to consider for overcoming barriers to participation in colorectal cancer screening programmes:

1. **As colorectal screening is highly cost effective, and the test itself is cheap, it is worth investing more in activities to maximise participation.**

   - Evidence from the Veneto Region [Italy] indicates that the longer that well organised cancer screening programmes has been running, the better the results and uptake by the population will be. The localities with the best performing breast and cervical cancer screening programmes were those who were the first to activate a colorectal cancer screening programme. The greater uptake in these localities could therefore be associated with better organisation and more adequate allocation of resources, as well as to the presence of well performing screening programmes for breast and cervical cancers.

2. **In order to overcome barriers to greater implementation of a population-based colorectal cancer screening programme, it is essential to research what contributing factors the programme/organisation itself may be responsible for.**

   - Authorities should consider whether the chosen screening modality they are using is the appropriate test for their respective context. The colorectal cancer screening guidelines offer a sound evidence base for authorities: consideration should be given to also meeting the expectations of participants when implementing the guidelines in practice. Questions to consider could include: do alternative tests need to be offered in order to meet the expectations of certain audiences?
• With certain target groups, a change of philosophy is perhaps needed: addressing ‘harder-to-reach groups’ from the perspective of a health authority or system should be replaced with addressing ‘hard-to-reach’ services from a citizen’s perspective.

• With colorectal cancer screening, logistical barriers (such as the returning of kits/samples) should be further investigated. In Merseyside & Cheshire (UK), ‘lack of time’ was identified as a chief self-reported reason for non-compliance. This issue was subsequently tested by the competent bodies, determining the length of time it takes to arrive at the clinic, collect, and subsequently return the sample. This issue had a risk ratio of 10, which is high compared to most. It is therefore, up to the health service to remove this logistical barrier by simplifying the process and service access.

• Competent bodies should be aware that when it comes to identifying how the practice of the programme itself acts as a barrier to participation, there may be may be several groups to address:
  o Those who understand what is required of them for the screening programme but don’t participate because of logistics;
  o Those who don’t understand what is required due to language/barriers;
  o Those who understand but have a cultural reason not to participate.

3. **Negative messages (within screening programme materials and in the mainstream media) and fear of cancer are key reasons for non-response.**

• There are various examples of competent bodies whom have determined methods by which they can overcome barriers created through negative media messages:
  o In Cyprus, the population is informed about colorectal cancer screening through mass-media campaigns and community programmes. The Ministry of Health, the National Cancer Committee, NGOs, and Gastroenterological and surgical societies have a sustainable cooperation with the aim of raising awareness. Additionally, the Health Minister visits rural isolated communities (every two months), accompanied by a team of doctors, trained in communication, and in cooperation with the local authorities, offers interactive sessions in order to raise awareness on the main preventable cancers. This approach showed a 40% increase in uptake, which was largely attributable to the personalised approach.
  o Merseyside and Cheshire: a follow up phone call from the GP was found to be a valuable intervention, with an increased uptake of 43%. This should be measured in terms of value for money.
  o Personal/Familial compulsion: more endeavours should be placed on encouraging participation through harnessing the familial unit. This method may offer another way of addressing this issue of non-compliance.
C. Key issues to consider for implementing quality using data:

1. Measure final outcomes! We should have data pathways from screening to treatment to final outcome: a whole system approach.

   - Treatment should be subject to the same quality assurance requirements as screening. This is particularly important as the outcome of surgery denotes the most important outcome for the patient: survival and lack of morbidity.
   - Data linkage: there is a need for personal identifiers to be held in order to link screening data with outcome data (death data for survival and secondary care data for complications). However, some countries may be constrained by legislation that prevents them from holding patient level data.

2. Whole system approach should include the role that cancer registries play.

   - Fragmented approaches to data collection and quality assurance are inferior to whole systems approaches.

3. Ensure that information on complications of screening and treatment is effectively captured.

   - Patients may present to emergency care rather than responding to screening services recall, therefore, it is important that a system is in place to account for these eventualities.
   - Greater efforts are needed to capture complications arising from colonoscopy; in this instance, patients who present to hospitals may not be captured in colorectal screening programme quality assurance data. This is an important part of encouraging whole system quality.

4. Do we know what the patient’s view of quality is, and whether there is a mismatch?

   - Advantages can be found in the publication of comparative data reflecting ‘performance’ of screening centres. This could further support elements of patient choice, but would also contribute to culture of continuous improvement rather than working to and not beyond target levels.
3. Description of Workshop Sessions

Day 1 – Wednesday 7 March 2012

Session One

Opening Address

_Councillor Roz Gladden, Deputy Leader, Liverpool City Council, Cabinet Member for Health, Wellbeing and Adult Social Care_

Councillor Roz Gladden opened the workshop by officially welcoming all delegates to the City of Liverpool.

The topic of the workshop is of particular relevance for the City in two respects: firstly, the City is currently in the second year of the ‘2020 Decade of Health and Wellbeing’. The Decade of Health and Wellbeing seeks to coalesce key organisations and stakeholder groups into working together to promote health and wellbeing as a strategic priority of the region. This initiative also encourages individuals to look at making some small, achievable lifestyle changes in their own personal lives.

Moreover, a number of actions are taking place within in the city, and across the wider region of the North West of England, in line with Colorectal Cancer Awareness month (April 1-30, 2012). Around 35,000 people in the UK are diagnosed with colorectal cancer each year, with over 1,500 of these being from the Merseyside and Cheshire area. In Liverpool alone there are around 165 new cases of bowel cancer (CRC) diagnosed in males and around 110 cases in females each year.

Purpose and Overview of the Workshop

_Sandra Radoš Krnel, EPAAC Project Lead, National Institute of Public Health, Slovenia [Chair of Day One]_

Sandra Radoš Krnel, MD, Head of the Research projects services for Institute of Public Health of the Republic of Slovenia, and EPAAC Project Lead introduced the EPAAC project, providing an overview of the project’s aims and objectives, and demonstrating where the workshop fits within this framework.
Introduction
The EPAAC (European Partnership for Action Against Cancer) is a Joint Action programme funded through the EU Public Health Programme for the period between 2011-2014.

The Partnership brings together the efforts of different stakeholders into a joint response to prevent and control cancer. The National Institute of Public Health in Slovenia has assumed the role of leader of the EPAAC Joint Action, which encompasses 36 associated partners from across Europe and over 90 collaborating partners.

Aims and objectives
The EPAAC Joint Action has a broad range of goals across different areas of cancer prevention and control: health promotion and cancer prevention, including screening, identification of best practice in cancer-related healthcare, the collection and analysis of comparable data and information and a coordinated approach to cancer research.

The Joint Action should contribute to the long-term aim of reducing cancer incidence by 15% by 2020, and to the objective that all Member States have integrated cancer plans by the end of the Partnership. Organisationally, the EPAAC Joint Action is made up of ten Work Packages, which correspond to ten different sets of actions.

Work Packages
There are ten work packages in the EPAAC. These are:
WP1 – Coordination; WP2 – Dissemination; WP3 – Evaluation; WP4 – Open Forum;
WP5 - Prevention:
• \textit{Raise awareness about cancer, target vulnerable population groups}
• \textit{Re-launch of the annual European Week Against Cancer}
• \textit{Optimise the use of tools to communicate proven prevention strategies}
WP6 – Early Detection and Screening:
• \textit{Improve implementation of the Council Recommendation on Cancer Screening}
• \textit{Initiate a network of European Schools of Screening Management}
• \textit{Identify inequalities in cancer screening programmes}
• \textit{Facilitate expert advice to regions seeking to improve cancer screening programmes}
• \textit{Develop a consensus on quality criteria for health checks}
WP7 - Healthcare

- Promote the exchange of experiences and best practices across European health services
- Develop, review and harmonize Clinical Guidelines
- Implement a training strategy to improve psychosocial and communication skills among health care providers

WP8 – Research

- Identify and prioritize areas in cancer research that will benefit from coordination
- Develop a concerted approach for coordination of one third of research from all funding sources by 2013
- Implement pilot projects of research coordination in selected areas

WP9 – Information and Data

- Map the main sources of cancer data
- Unify cancer burden indicators (incidence, mortality, survival and prevalence)
- Promote a European task force aimed to assess the need for data on cancer costs
- Initiate development of a standardised approach to the routine collection of data on survivorship
- Develop an inventory of statistical methods to analyse population-based cancer data

WP10 – National Cancer Plans (NCPs)

- Overview of the current state regarding NCPs in Member States, Norway and Iceland
- Define areas to be respected in NCPs
- Guidelines for a high level standard NCP and the respecting indicators

This workshop took place within the context of Work Package 6, delivering the specific objective of facilitating expert advice to regions seeking to implement or improve population-based cancer screening programmes.

Introduction to Work Package 6: Early Diagnosis and Screening

Solvejg Wallyn, Flanders Agency for Care and Health (VAZG)

Solvejg Wallyn from the Flanders Agency for Care and Health described the WP6 actions and deliverables across the four specific objectives of the Work Package:
1) European Schools of Screening Management – Training course (led by the Finnish Cancer Registry / International Agency for Research on Cancer - IARC)

2) Identifying inequalities in cancer screening programmes – Literature Study (led by Institute for Public Health – Valencia, Spain)

3) Define regional good practices and lessons learned for implementation of cancer screening programmes as recommended by the Council of the EU 2003 – Regional Workshops (led by EUREGHA consortium)

4) Development of pan-European consensus on quality criteria for health checks (led by NEN, the Netherlands Standards Organisation)

Within specific objective 3, this workshop will be one of three workshops planned workshops that, in line with the Recommendation of the Council of the EU 2003 will focus on the following cancer screening programmes: Colorectal, Cervical, and Breast. Each workshop will focus on screening methodologies; data collection; barriers and potential improvements for effective cancer screening programmes.

The initial findings of the three workshops will be presented at the EPAAC Open Forum in Slovenia during November 2013.

Development of the workshop

Sol Wallyn highlighted the key role that the European Regional and Local Health Authorities Network (EUREGHA) played in the development of the Workshop.

An initial survey was carried out by EUREGHA in order to establish a brief overview of regional cancer policy priorities and to collate key contacts whom could be invited to provide experts to participate in the workshop. The survey was completed by 63 respondents across 25 Members States of the EU plus representatives from associated countries such as Turkey, Switzerland and Norway.

The University of Antwerp were responsible for drafting a questionnaire that would provide an indicative picture of the current status of colorectal screening programmes in 20 pre-selected regions and Members States of the EU.

Drawing on the contacts from the earlier EUREGHA survey, this questionnaire was targeted at experts whom had either practical experience of leading a cancer screening programme or, were no screening programme yet exists, were principal investigators in designing a comprehensive programme.
Invitations to attend the workshop were then extended to the respondents of the questionnaire. This was complemented with invitations to representatives from the policy level of the respective respondents’ authorities or Member State (e.g. Ministry of Health). This was approach was taken to provide a duality between practical knowledge and strategic, overarching vision.

Finally, the programming of the workshop was determined by the workshop hosts; the North West England Cancer Networks (Merseyside and Cheshire; Greater Manchester; and Lancashire and South Cumbria).

In conclusion, the development of the workshop has highlighted how cooperation between competent authorities is useful for policy development and implementation.

Emerging findings from the University of Antwerp questionnaire on colorectal cancer screening programmes

Dr Sofie Van Roosbroeck & Prof. Guido Van Hal, University of Antwerp

Dr Van Roosbroeck presented the emerging finds of the questionnaire introduced in the previous session by Sol Wallyn.

The principle aim of the questionnaire was to: ask respondents about examples of practice from their region; and to enquire as to whether the respondents would recommend the selected examples as good practice or not. Identifying barriers and how programmes had overcome these was also a fundamental purpose of the questionnaire.

For quality assurance, the questionnaire has been pre-tested by three experts prior to dissemination.

Emerging Findings

From the 26 whom were contacted, 20 respondents, encompassing 15 Member States of the EU, completed the questionnaire. Among the key reasons identified for participation in a colorectal cancer screening programme were:

- Recommendation by GP;
- Family history;
- An automatic invitation;
- Free of charge to participate;
Other:
  - Encouragement of partner
  - Awareness that early detection of colorectal cancer can prevent personal and family suffering.

Reasons for non-participation in the programme were given as:

- Lack of symptoms;
- Fear and anxiety;
- In case of gFOBT: complicated and unpleasant test, distaste at handling stool, providing three samples;
- Other:
  - Viewed as low priority issue for the citizen;
  - Lack of concern; lack of GP’s recommendation;
  - Presence of other medical problems.

Key aspects of good practice concentrated around developing robust and useful information channels, which had a multi-lingual approach and brought in multiple actors from Primary Care, alongside Community-based Health Promotion campaigns.

Areas were difficulties were found included: complexity of effectively engaging GPs in certain contexts, leading to problems obtaining GP signatures, potential cost of GP visit and follow-up colonoscopy, difficulty to convince over evidence base for certain modalities, and the cost of reminder and advanced notification letters.

Observations

Dr Van Roosbroeck concluded her presentation by providing some brief observations from the initial findings of the questionnaire.

There was a difference between those respondents who stated that using age as the sole selection criterion ensures equal access and those who didn’t. There were also opposing opinions on the role of the GP. Finally, there was some comment as to whether the format of the questionnaire was too detailed.

Questions

Paolo Giorgi Rossi from the Italian Public Health Institute commented that a key problem is the fact that population-based programmes are not effectively implemented across Europe. Competent bodies moving from pilot phase to a full programme are experiencing a difficult passage.
A proportion of this difficulty is due to contextual factors at play amongst competent authorities within and between Member States. For example, the issue of GP involvement is a complex issue, which (in the example of the Lazio Region in Italy) has delivered heterogeneous results as to GP engagement and subsequent participation rates.

Roger Prudham, Pennine Acute Trust [UK], asked that given the highlighted actions for implementing or improving colorectal screening programme, how do competent authorities prioritise these actions as it may not be possible to implement them all? In response, Prof. Guido Van Hal stated that the identified actions should be viewed as a menu that authorities will have to draw upon in respect to their own context.

Sven Tornberg from Karolinska Institute [Sweden], noted that there is a lack of evidence on how to organise and effectively boost participation rate. As such, further encouragement needs to be made to stimulate research in this field.

In conclusion, selected actions to improve or implement screening programmes need to be supported with evaluations in mind.
**Session Two**

**Breakout sessions**

Following Session One of the first day of the workshop, three breakout sessions were held over two iterations, totalling 45 minutes per session. This method allowed delegates to attend two of the three breakout sessions, before returning to Plenary for feedback on all iterations of the breakout sessions.

The breakout sessions were, as follows:

A) **Implementation of population-based colorectal cancer screening programmes**

During this session, the pilot programme undertaken in Flanders [Belgium] was presented. This session explored the key issues around implementing colorectal cancer screening programmes linked to the emerging findings of the University of Antwerp questionnaire.

B) **Overcoming barriers to participation in colorectal cancer screening programmes**

During this session, the work undertaken in Merseyside [UK], to increase the uptake for non-responders in Primary Care was showcased. This session also considered the identified and emerging barriers for participation in colorectal cancer screening programmes.

C) **Implementing quality using data**

In this session, the example from Greater Manchester [UK] on staging data for colorectal cancer screening uptake was presented. This presentation was then used to support discussions on the role of Quality Assurance within colorectal cancer screening programme.

Each iteration of the breakout sessions were instructed to deliver one key question for discussion during the final session of day 2, plus one key message for competent authorities seeking to implement or improve the implementation of population-based programme.

**Feedback of the Breakout Sessions**

Following the two iterations of the breakout sessions, one facilitator from each session presented an overview of the discussions that had taken place.

From **Session A, Solveig Wallyn** indicated that the perspective of the Flanders pilot project was a useful starting point as this tackles the immediate issues presented when starting up a screening programme. Key elements that arose included: the awareness that authorities may still not understand what the citizen requires [e.g. are there specific needs?] to encourage their participation in a screening programme.
There is perhaps need for greater use of social marketing and, in turn, more investment should be made in training to ensure practitioners are equipped to tackle this issue.

From Session B, Dan Seddon, Early Detection Lead for Merseyside and Cheshire Cancer Network, posed the question as to what level of participation rates authorities should be aiming for and what impact does this have on non-respondents? This question leads to the potential barrier of cost-effectiveness of colorectal cancer screening programmes and to what extent it is worth addressing non-respondents. To conclude, it was stated that colorectal cancer screening (as identified in the Council Recommendation) is one of the most cost-effective screening programmes. Therefore, authorities shouldn't be discouraged from investing in strategies to reach non-responders as, overall, it is a cost-effective measure.

Session C was introduced by Neil Swindlehurst, Lancashire and South Cumbria Cancer Network, who noted that it was important to define what quality is and presented a brief indication of the measures and indicators used in the UK as an illustration.

The need for a ‘whole system’ approach to data was essential if quality is to be thoroughly implemented in practice. The move to achieve this at patient level will present a problem for aggregated data. Moreover, not all data is being captured with the current approaches. For example, patients presenting at Accident & Emergency, rather than at a follow-up appointment, may not be captured effectively. This led to a discussion as to who is responsible for capturing this data: Primary or Secondary Care? The session also commented on the importance of performance monitoring and the use of statistics to improve standards of quality assurance.

Each facilitator noted how both iterations approached the topic of discussion in a different manner, which led to a richer and more complex set of messages as an outcome. More in depth outcomes resulting from the discussions of the breakout sessions can be found in the Key Messages section of this report.

Regional Perspective on Implementing Colorectal Cancer Screening Programmes: Veneto Region, Italy.

Dr Annarosa Del Mistro, Veneto Oncology Institute, Italy

Dr Annarosa Del Mistro introduced the Veneto Region in Italy and provided an overview as to how the colorectal cancer screening programme is organised in that particular region.
Within the Veneto Region, there are 21 Health Authorities that organise and administer the health services of groups of municipalities, including screening programmes. Typically, these authorities are small in dimension (ranging from a population-base of 75,000 to 480,000), and they exhibit a high degree of autonomy. The first level test has a target population of approx. 1.2 million people between the ages of 50-69.

Of particular interest for the purpose of this workshop is the Local Health Authority of Verona, which undertakes a different screening procedure. Whilst the remaining 20 Authorities of Veneto offer a FIT-based programme for 50-69 year olds, Verona offers a one-time flexible sigmoidoscopy for the population at 60 years of age.

For FIT-based programmes, invitation is provided by mail with a reminder sent by mail to non-responders. Invitations take place over a 2-year interval. The test is a one time immunochemical FOBT (iFOBT), without any dietary restriction. The positivity threshold is set at 100ng Hb/mL.

Participants are notified of negative FIT result by mail; if a positive result is found, the participant is contacted and encouraged to undergo a colonoscopy. Patients are referred to endoscopic referral centres at which endoscopies are performed. Enrolment in a follow-up programme is offered following the procedure.

**Multi-Level Governance**

The Regional level in Veneto provides evaluation and approval of the Local Health Authorities projects and screening programmes. The Regional level also sets indicators to assess the screening programmes in the evaluation performed by the Local Authorities General Managers. There is also a centralised procedure for the purchase of FIT.

The Regional Health Agency provides institutional accreditation of cancer screening Programmes and sets requisite indicators. For colorectal cancer screening programmes, this is undertaken every two years.

The Veneto Tumour Registry (at the Veneto Oncology Institute) is responsible for, amongst other things, workload estimates for Local Health Units’ planning; the training of health professionals; data monitoring - including an annual survey, ad hoc data collection [interval cancers]; retraining; and the development of regional guidelines according to EU Guidelines.

**Questions to Veneto:**
Isabel Portillo, Basque Country, asked whether all FOBT tests were immunochemical and, if so, what criteria decided this? Paolo Giorgi Rossi responded that iFOBT provided consistent results with respondents; the kit is also easier to use for patient. The one drawback with iFOBT is the degradation in high temperatures.

In the Veneto example, the EU guidelines for colorectal cancer screening and the support from the Ministry of Health were crucial for effective implementation of the screening programme. In their view, efficiency states that the Council of the EU Recommendation on Cancer Screening is correct on the tests and approaches to be adopted for colorectal screening programmes. The key issues for authorities to consider are organisational and context dependent; for example, there may be professional pressures to perform a greater number of colonoscopies.

The special case of Verona (in which flexible sigmoidoscopy is performed at 60 years of age) was the subject of several questions. These included queries as to whether there was data suggesting a difference in the number of cancers detected in Verona versus the other authorities of Veneto.

The Flexible Sigmoidoscopy programme of Verona screens on average about 2500 persons per year, with a detection rate for advanced adenomas that is four times higher than the FOBT programmes, while the detection rate for carcinoma is not valuable due to the low number of cases. Compliance to invitation is about 40%, which is relatively high given the nature of the test. In 2006, a parallel invitation to FOBT to the non-responders was introduced to increase the coverage.
DAY 2 – Thursday 8 March 2012

Session Three

Day 2 was opened by the Chair for the second day Jon Hayes, Deputy Director, Merseyside and Cheshire Clinical Networks, who provided a brief overview of the previous day and introduced the agenda for the remainder of the workshop.

Good practice presentations x 5

a) Colorectal Cancer Screening Hub: pilot to present

Dr Steve Smith, Director, Midlands & NW Bowel Cancer Screening Hub

Dr Steve Smith presented on the organisation and implementation of the CRC screening programme within the English regional Bowel Cancer Screening Hub (encompassing the regions of North West England and the Midlands area of England).

Dr Smith noted that when initially developing the programme, three pilot stages were undertaken: in 2000, the first pilot round took place in Coventry & Warwickshire. Individuals aged 50 to 69 years were offered screening based on FOBT once in a 2 year period. The second round took place in 2003 with a reduced age group (60 to 69 years), before the final pilot round which started in 2005.

In England, the national programme\(^3\) is divided into 5 areas – or Screening Hubs - of which the Midlands and North West is one. The Screening Hub is responsible for call and recall; telephone helpline; FOBT analysis; and booking appointments for those with abnormal results.

Within the Screening Hub are 13 Screening Centres which are locally orientated and offer Screening Practitioner Clinics (Nurse led) to discuss abnormal results; diagnostic tests; treatment; and undertake health promotion activities. At least one colonoscopy site is offered at each screening centre.

There is a 90% route to colonoscopy from abnormal results patients. Overall, Quality Assurance is provided in each hub by a single body. All the work is facilitated by a National IT system, which captures all the data generated.

\(^3\) Please note that this is not national in the sense of EU Member State level i.e. UK.
In England, the guaiac FOBT is used as this decision was made of the best available evidence from the randomised clinical control trials performed prior to piloting in 2000. Further details on iFOBT have only emerged since then with the study of van Rossum et al in 2008.

The algorithm for the screening programme is as follows:

![Algorithm Diagram]

This algorithm procedure reduces the need for unnecessary colonoscopies and overuse of endoscopists.

Whilst it was acknowledged that the EU guidelines point towards iFOBT as the method of choice, guaiac is still preferred in England due to several outstanding queries regarding iFOBT and the variability between kits.

In terms of uptake, a socio-economic gradient is apparent, demonstrating a significant negative difference between the uptake of the those with a lower socio-economic status to those with a higher socio-economic status. Designing approaches to address this trend is central to improving overall uptake. Tactics to improve uptake have included a personalised Birthday card, plus effectively capturing the data of non-respondents. However, these approaches pose a number of data governance issues that must be taken into consideration.

b) NHS Bowel Cancer Screening Programme Lancashire: Connecting with our communities

Shahida Hanif, Health Promotion Specialist, NHS BCSP Lancashire

In Lancashire, a sub-region of North West England, uptake for colorectal cancer screening is low. In a particular, there is a markedly low uptake within specific socio-economic and minority ethnic communities. Such communities have been
conceptualised as so-called ‘harder-to-reach’ groups. Most strategies for improving uptake in these specific communities approach the issue from this perspective. However, the experience of the Lancashire BCSP indicates that a more effective approach is to understand that it is not the communities that are difficult to reach, but conversely, it is the accessibility and approach of the service that is often the actual barrier to participation.

The specific example of the Lancashire BCSP focused on the strategies tailored towards the Black and Minority Ethnic (BME) populations and the subsequent results achieved. When developing the strategy, it was noted that BME communities in Lancashire had already been the subject of intensive and extensive research into their specific needs and health situation, to such an extent that ‘research fatigue’ was evident within the communities. Rather than approach the communities from a purely empirical or epidemiological perspective, the Lancashire strategy instead wanted to compliment such data with an appreciation for the cultural needs and barriers at stake, covering such factors as the need for information to be available in minority languages.

The main areas of work for the strategy were identifying the barriers to uptake; developing initiatives based on the identified needs, including activities such as Community Engagement; Professional engagement; Multi-lingual Marketing/Media; BCSP Community training packages; and Developing local Bowel Champions. Out of this process, the ‘connecting without communities’ programme was developed: the aim of the programme was to explore the communities’ perceptions of the BCSP and the barriers to uptake within Lancashire.

The programme began by identifying key deprived groups (in low uptake areas) within Lancashire, before recruiting male and females aged 60+ via the relevant community leads or community groups. From this pool, focus group training sessions were undertaken to capture the qualitative evidence from the participants. The key lines of enquiry taken with the focus group covered the perception of the current colorectal screening programme – both as individuals and as a community; and how to involve communities in the process through, for example, colorectal cancer champions.

Other communities that were targeted in this group covered: White Deprived Groups; BME Women/Men (Indian, Pakistani, Gujarati and Bengali communities); Learning Disability/Mental Health groups.

All the data collected has been put forward towards a 3 year Health Promotion Action plan.
c) CRC screening lessons for implementation: The Netherlands & Flanders

Pilot programmes.

*Dr. Leo van Rossum, University Medical Centre Nijmegen, Health Council of the Netherlands*

The focus of this presentation was to present a brief analysis of how the Netherlands and Flanders pilot CRC screening programmes were designed and implemented. Dr van Rossum framed the presentation around the 7 steps needed to implement a robust screening programme, as determined by Lynge *et al.*

The 7 steps are:

1. **Pre-planning** – This covers initial work to facilitate focus groups and encourage a debate in the population to determine attitudes, values and identify barriers to participation. It should be noted that some patients may not want to be screened, for example if they have heart disease. In such cases, there should be data and information provisions to bring such issues to light. This stage should also review recommendations and guidelines, engage in national and international exchange of practices and scenarios, focusing on what has worked and what didn’t work in other societal contexts. It is also important at this stage to garner political support for developing a programme.

2. **Planning** – This stage should: identify a Coordinator with specific mandate and budget; focus on determining the infrastructure and ICT needs; cover the formation of a Quality Assurance Plan; and make provision for monitoring, auditing, (re)training, accreditation.

3. **Feasibility** & 4. **Pilot** – During these stages the scientific data, legal and ethical issues should be reviewed before the testing and piloting procedure proceeds. If the pilot does not perform as expected, then it is necessary to return to the first stage and begin the process again.

When comparing the Netherlands and Flanders pilot programmes, the main outcome from both pilot programmes was the participation rate that could be achieved, which reflected the feasibility, and the population’s willingness, to use the stool test (iFOBT). The participation rates for the Dutch and the Flemish pilot programmes are comparable: 60% participation in the Netherlands and 52% in Flanders. Both programmes showed that screening for CRC by means of an iFOBT is feasible.

Positivity rates and colonoscopy compliance were further outcomes that were compared between the two pilot programmes. The positivity rates [based on a 75

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ng/ml cut off value] were somewhat different: 6.4% and 5.3%, for the Dutch and the Flemish pilot programme respectively.

Follow up compliance by means of colonoscopy was adequately in the Netherlands (86%), but rather low (73%) in Flanders. This was possibly due to the fact that direct appointments were arranged in the Dutch pilot, as opposed to a request to visit the GP for further referral with a specialist in Flanders.

Also, follow up colonoscopy was considered a part of the programme in the Netherlands, and was thus free of charge for the participant. In contrast, the cost for a follow up colonoscopy was partly charged to the participant in the Flemish pilot. To conclude, the need to keep comparing data between regions was expressed.

5. **Up scale** & 6. **Full scale** – At these stages the roll-out to full population scale should be implemented. In the Netherlands, this was achieved in 6 waves, encompassing an increasing number of different age cohorts (based on year of birth) each time. It is vital to introduce effective training to manage the up scaling and to ensure that there is also sufficient capacity.

7. **Sustainability** – At the final stage, in order to allow for a sustainable environment in which the programmes can maintain their effectiveness, it is important to ensure ‘organisational anchorage’ and take measures towards continued political endorsement and societal engagement. Moreover, there should be continuous efforts to achieve sensibilisation [awareness-raising] of the programme to ensure that programme is remaining responsive population and health system needs.

d) **Different strategies for CRC screening and screening tests invitations**

*Dr. Paolo Giorgi Rossi, Agency for Public Health, Italy*

Dr Paolo Giorgi Rossi presented on a recent project undertaken in which the objective was to synthesise the scientific evidence produced by International research on the efficacy of methods employed to increase participation in screening programmes.

Key factors to consider, prior to evaluating the existing literature, include an appreciation that low participation of the target population is the most important issue hindering the effectiveness of cancer screening programmes; high participation rates are necessary to obtain a significant impact on population health; and compliance to invitation should be achieved by encouraging “informed” participation by individuals who are aware of the benefits, limitations and disadvantages of the screening programme.

The different strategy interventions that were evaluated were classified according to the target:
1) To the target population:
   - the individual - invitations, reminders, etc.
   - the population: health education, information campaigns by the mass-media; direct contact with health care workers (doctors, others), etc.

2) Screening tests: new tests or new procedures; self-administered tests; tests offered at mobile facilities, etc.

3) Health professionals: training; stimuli for physicians, audit and feedback, etc.

4) Health service organization: removing financial or economic barriers, involving more providers, fixed or open appointments, mailing the FOBT, etc.

The project found that in interventions targeted at individuals, there is strong evidence of a positive effect of employing a recall by mail strategy. Moreover, there was also consistent evidence of a modest positive effect of the GP’s signature on the invitation letter. However, it was noted that information materials mailed with the letter have no effect on participation.

The project also noted that there was a lack of reliable or substantial number of research in certain key areas; for instance, only one study has compared Flexible Sigmoidoscopy with Colonoscopy in terms of compliance.

In conclusion, the project found that organised programmes are effective in increasing test coverage; many interventions have been implemented to increase participation to screening programmes, but only a few of them have been evaluated; effectiveness of these interventions may be context-dependent; however, there are a number of interventions showed consistent positive results in many context and can be implemented with few resources, for example with mail recall and inclusion of GP’s signature on invitation letter.

e) National Colorectal Cancer Screening Programme in Slovenia: The SVIT Programme

Dominika Novak Mlakar, MD, national Institute for Public Health for Republic of Slovenia

Dominika Novak Mlakar presented the National Cancer Colorectal Cancer Screening [SVIT] programme for Slovenia, which, on a population-based approach, has achieved 70% response rate.

The SVIT Programme (nationally organised, centrally managed, population-based colorectal screening programme) is founded upon a strong scientific evidence-base and is adapted to meet the local needs and capacities of the de-centralised
populations in Slovenia. The target population coverage is 540,000 (inclusive of both male and female) aged between 50 and 69 with basic Health Insurance. The target population is invited every two years. The test is iFOBT test with automatic readings, with a screening colonoscopy for all FOBT positive cases.

Some of the key objectives of the SVIT Programme include: the reduction of colorectal cancer mortality rates by 25 - 30%; the reduction of incidence by 20%; and to increase the proportion of colorectal cancers detected early from 14% to more than 50% within 10 years.

The invitation process for the SVIT Programme follows a simple process by which, during an odd-numbered year, the populations invited were born during an odd-numbered year (e.g. in year 2009 we invited people born 1941, 1943, etc.). The same process was true for even numbered years (e.g. in 2010 we invited people born 1942, 1944, etc.). Overall, the first round of screening was completed between 17.04.2009 and 31.03.2011. The second round will commenced from 04.01.2011 and shall run until 31.12.2012.

The resilience of the SVIT programme lies in its user-friendly approach. Personal invitations, reminders and information about all the procedures are provided to all participants, demonstrating the user-orientated design. Participation rates are also helped by the short waiting times that exist for all procedures, which aligns with users’ expectations. Moreover, the programme places a special emphasis on communication (such as a personal counselling call centre) and facilitating accessibility as the programme is free for all participants. The algorithm for the programme is as follows:
Keynote Speech:

Development and Implementation of the European Colorectal Cancer Screening Guidelines

Prof. Julietta Patnick CBE, Director of NHS Screening Programmes

Prof. Patrick’s keynote speech centred around the development and implementation of the European Colorectal Cancer Screening Programme. In turn, the foundation of the cancer screening guidelines lies in the 2003 Council of the EU Recommendation on cancer screening. The 2003 recommendation sets out the baseline from which the guidelines could be developed as its rationale stated that the public health benefits and cost efficiency of a screening programme are achieved if the programme is implemented systematically, covering the whole target population and following best-practice guidelines.

The evidence base behind the recommendation and subsequent guidelines were largely formulated in the 1990s. However, there are a number of aspects that still stand the test of time, in particular, and crucially, this includes the arguments for cost-effectiveness and efficacy of organised screening programme. Nevertheless, there is a strong case to argue for the updating of the recommendation to take into account recent scientific and technological innovations that have occurred since adoption in 2003.

The methodology behind the development of the guidelines was presented. The factors that were most crucial to the methodology were to be thorough and inclusive. A multi-country approach to the process was adopted, including representatives from newer member states and a strong, collaborative team-working approach. What’s more, the team ensured robust, evidence-based guidelines through the utilisation of a PICOS system for evidence review.

The PICOS system [Population, Intervention, Condition; Outcome; Study design] asserts a series of challenges to the proposition in question. For example, in regards to the question: ‘Is immunochemical FOBT superior to guaiac FOBT in its test performance characteristics (e.g. sensitivity and specificity)?’ The system would then pose the challenge based upon each of the aspects of the PICOS system.

Prof. Patnick noted that for endoscopy screening there were a number of particular difficulties with representing this method in the guidelines. Firstly, these procedures do not feature in the European Council’s recommendation, which, as stated, provides the baseline for the guidelines. Nevertheless, there are several European countries...
employing it as the screening test of choice. Consequently, the guidelines devote special chapters to flexible sigmoidoscopy and colonoscopy that contain quality indicators, minimum requirements for reporting, and, amongst other issues, general principles for a quality service. There still remains a difference across countries and regions within Europe over the use of endoscopies as primary screening test or diagnostic.

The first report on the implementation of Council Recommendation for cancer screening was published in December 2008. The report found that, as of 2007, only 12 Member States were running or establishing a population-based screening programme for colorectal cancer. Indeed, 9 member states had neither a population nor non-population based programme in place at that time. Since 2007, a number of Member States have begun piloting population based programmes in accordance with the guidelines: please see Annex 2 of this report.

Prof. Patnick concluded the keynote speech with an appraisal of where the next stage of development could take the guidelines. Prof. Patnick noted that there was a need to update the annex of the Recommendation to take into account recent randomised controlled trials for flexible sigmoidoscopy. This development highlights the need to both keep the guidelines up to date, as understanding of population flexible sigmoidoscopy screening and iFOBT grows. Finally, it is important to get colorectal screening into countries where there is no or little activity and achieve greater appreciation in the public’s consciousness of colorectal screening.

Conclusions:

Discussion about research findings and tackling barriers to screening programme implementation

Dr Dan Seddon, Merseyside and Cheshire Cancer Network

The final session began with a presentation from Ana Molina Barcelo of the Centre for Public Health Research in Valencia [Spain]. The presentation updated participants on a parallel work stream of WP6 (objective 2) of the EPAAC: the identification of inequalities in colorectal cancer screening programmes. This presentation served as an introduction and to compliment to the final session, which aimed to stimulate a debate on how to tackle barriers to screening programme implementation; of which, the existence of inequalities, must be viewed as figuring highly.

This objective has two broad pillars of actions: the first is to undertake a literature review on the factors associated with inequalities in participation and/or adherence to colorectal cancer screening programmes; the second is to design a questionnaire.
to analyse whether colorectal cancer screening programmes in Europe take into account inequalities and to understand if any action has been taken to reduce these.

The conclusions of the literature review found that more studies on inequalities were made in the U.S.A. than in Europe. Moreover, in the U.S.A. there is a greater presence of studies focusing on the vulnerable population, and analysing the ethnic-cultural group as inequality axis. Whereas in Europe, most of the studies focus upon the general population, analysing the socioeconomic/education level, and sex/gender as an inequality axis. This may be due to a different multicultural development within both continents. Furthermore, territorial/geographical inequalities are analysed rarely and few qualitative studies are performed.

As a result, the researchers suggest that, in regards to research, the social inequalities perspective should be gradually included to a greater extent. Furthermore, more studies analysing any possible territorial inequalities should be performed, and the use of qualitative studies should be increased in order to get a more comprehensive understanding of inequalities.

As regards colorectal cancer screening programmes, it would be recommended to include the social inequalities perspective in their design, implementation and evaluation. The researchers are currently designing a questionnaire to evaluate whether European colorectal cancer screening programmes take into account inequalities and whether any action has been taken to reduce these.

Following this presentation, Dr Dan Seddon facilitated a final discussion session bringing out the key points raised during the workshop, focussing in particular on the breakout sessions and the key messages that were delivered as an outcome of both iterations from each session. Further details on the final recommendations and message can be found in section 2 of this document: **Key messages from the Workshop.**
4. Key points from workshop evaluation

25 delegates from the 68 who officially registered returned the electronic evaluation form, giving a respondent rate of approximately 37%. Overall, the workshop was positively evaluated. The most successful aspects of the workshop were noted as being:

- **Duration** – the two day format worked well and was very suitable for the workshop, given the logistics involved and the scope of topics to cover;
- **Breakout sessions** – these sessions were particularly well evaluated due to their interactive nature, which is a quality that should be further developed;
- **Keynote speech** – this was well received to the workshop and is important for setting the tone and providing an overall favourable impression of the workshop;
- **Appropriate number of delegates** – whilst 68 pre-registered for the workshop, the actual number across the two days ranged between 55 and 70. This was deemed a suitable level of participation as it was large enough to guarantee diversity and yet small enough to allow for more intimate discussions and networking;
- **Range of participants** – representatives from 14 Member States (including associated countries) attended and actively participated, which was crucial to bringing the variety of experiences and insights from different contexts.

Areas were the workshop could be improved centred around the following issues:

- **Delegates Packs** - more information should have been available in the delegate pack;
- **Goals and objectives** – the quantitative feedback illustrates that more can be done to communicate the learning outcomes and goals of the workshop;
- **Background information** – more could be done to inform delegates about the relative situation of the cancer screening programmes from across Europe, especially those countries and regions whose delegates are in attendance.

The questions from the evaluation are listed below with the main outcomes in summary. The quantitative scores were rated from 1 (Poor) – 5 (Excellent):

1. **From a professional point of view, how useful was this event for you?**

All respondents answered this question. The average score was **3.48/5**. This indicates that the format of the workshop is useful and should continue in a similar vain for future workshops.
2. **Were the goals and objectives of the workshop clear to you?**

All respondents answered this question. The average score was **3.24/5**. This indicates that the key objectives were clear to most delegates. However, it suggests that more can be done in future workshops to communicate to delegates the learning outcomes expected as a result of the workshop.

3.1 **Please rate the following sessions of the workshop: Day 1 Opening session**

All respondents answered this question. The average score was **3.88/5**. This indicates that the opening session was perceived as useful and informative and should continue in a similar vain for future workshops.

3.2 **Breakout Session 1: Implementing colorectal cancer screening programmes**

16 respondents answered this question [this is due to the fact that delegates could only attend a maximum of 2 out of the 3 breakout sessions]. The average score was **4.06/5**. This indicates that this session was very informative and useful for delegates.

3.3 **Breakout Session 2: Overcoming barriers**

19 respondents answered this question. The average score was **3.74/5**. This indicates that this session was informative and useful for delegates.

3.4 **Breakout Session 3: Implementing quality using data**

17 respondents answered this question. The average score was **3.65/5**. This indicates that this session was informative and useful for delegates.

3.5 **Feedback and Final session**

24 respondents answered this question. The average score was **3.88/5**. This indicates that all three of the breakout sessions were informative, generated interesting outcomes and that the format of reporting back was found to be useful.

3.6 **Day 2: Good Practice session**
22 respondents answered this question. The average score was 4.23/5. This indicates that this session was extremely well received by those who retuned the evaluation form.

3.7 Keynote speech and final session

24 respondents answered this question. The average score was 3.92/5. This session received a large quantity of high scores illustrating the importance of the keynote speech to the workshop format.

4. Please rate the following aspects of the workshop: Workshop atmosphere

24 respondents answered this question. The average score was 4.42/5. This supports the qualitative feedback which refers to the positive atmosphere at the workshop. This atmosphere is crucial for facilitating the networking component of the workshop and should be maintained in future workshops.

4.1 Duration of workshop

24 respondents answered this question. The average score was 4.25/5. This illustrates that, largely speaking, the overall programming and scheduling of the workshop was appropriate in duration. Other feedback reveals minor changes that could be made to improve individual sessions. However, the overall duration was deemed suitable to maximise the potential of the workshop.

4.2 Delegate Packs

24 respondents answered this question. The average score was 3.37/5. Although favourably rated, it appears that more information could be provided in the delegate packs for future workshops, and that more materials could be provided in the pack for workshop delegates.

4.3 Overall quality of workshop

24 respondents answered this question. The average score was 4.25/5. This very high score illustrates the overall strength of the form and content of the workshop, and provides a very solid base on which to improve for the future workshops.
5. **What were the most positive aspects of this workshop? (Open Answer)**

Responses to this question included:

- Participants were well selected and there were an appropriate number of delegates in attendance. The scale made it easier to make contact with other participants;

- The good practice presentations were very useful for delegates learning;

- The array of regional/nation representative (encompassing 14 different EU Member States) was very positive. Having such a diversity of participants working together and comparing experiences and results in a very interactive manner, was crucial to the success of the workshop.

6. **How would you rate this workshop in meeting your expectations?**

24 respondents answered this question. The average score was **4.14/5**. This score illustrates that the workshop was met and in some cases exceeded the expectations of delegates.

7. **Do you have any additional comments, constructive criticisms or suggested improvements for the following workshop? (Open Answer)**

Responses to this question included:

- Although the good practice session was useful, there was perhaps too many during the session;

- More information should have been available in the delegate pack – such as the PowerPoint presentation, and more resources – such as Pen and Paper – should have been made available;

- The time for the breakout session was too short. This highlights the value of the session and reinforces the importance of the interactivity, as longer or further breakout sessions, will result in more interactivity and, thus, even more learning as an outcome;
• Further sessions could have been made into the issue of quality for colonoscopy, responsiveness to the second or any subsequent screening round, and communication strategy with target population in case of emergencies;

• Too much data was presented on the PowerPoint slides, which made it difficult for delegates to read;

• More background information on the relative situations of screening modalities across the various countries of Europe in attendance. Providing such background information could bring all participants to a useful baseline of awareness, which would stimulate further the first day’s sessions;

• More information and research into engendering behaviour change of the target population, and innovative approaches to this.
Annex 1. Key questions from registration

During the registration process, delegates had the opportunity to submit key questions on the topic of implementing population-based colorectal cancer screening programme. These questions were to then be considered in the proceedings of the workshop.

Existing Literature/Projects including other programmes

- The article of Lynge E et al.5, Determinants of successful implementation of population-based cancer screening programmes, can be a good basic tool for the workshops. It contains seven phases with many items per phase that determine successful implementation of screening programmes, but also has elements that can be helpful for the other two workshops.

- Share experience with delegates representing other programs on factors that can affect participation (both negative and positive)

- How can we steer and control the quality of the entire screening chain (not just the quality of the testing)

- The involvement of relevant healthcare professional and facilities; training; quality assessment of the screening test and of the performance

- The role of primary care physicians in overcoming individual barriers

Victims of abuse in CRC Screening - how to make colonoscopy easier for them

Approaches to necessary improvement of communication skills of medical professionals.

Quality of communication as a part of entire screening process.

Good Practice

It will be extremely important to exchange knowledge between regions, so that we do not make the same mistakes that have been made elsewhere. On the other hand, good practices from abroad, can be implemented in the own region, be it that the specific context has to be born in mind. For me, the exchange of ideas will be by far the most interesting aspect of the workshop. I think it is really necessary to keep on going with this initiative.

- Expectations: I would like to hear some excellent examples of good practice on how to organise a program for CRC screening (e.g. the invitation procedure), and hope that these examples can be discussed between delegates of different regions. What works in one region does not necessarily work in another region.

Question: What invitation strategies for CRC screening work best?

Best practices to implement coverage and overcome barriers. Critical evaluation of the different tests in use. Understanding diffusion and efficacy and/or difficulties of CRC screening programmes in the European Member States.

Ways to increase participation, quality control and procedures, ways to deal with inequalities in screening programmes. Promotion of screening in routine contacts by GPs and identification of non-screened patients feedback to GP systems.

It would be very interesting to explore the different attitudes to screening in populations across Europe and see what we can learn in order to improve uptake amongst minority/migrant groups. So, for example, if in County X there was a community of people from Country Y and uptake was relatively low in this community, could Country X look to Y and learn from their approach for this target group?

Key Barriers
The main barrier for implementing CRC screening programmes is the lack of endoscopic resources, or the use of endoscopic resources for opportunistic screening, familiar intermediate risk screening and follow up for low grade adenomas. Once obtained adequate resources for starting population based programme, the participation is the main barrier to effectiveness of screening.

In my opinion the key barriers to participation must include the perspective of the social inequalities in health i.e. impact of social and economic status on the participation in screening; social inequalities viewed as they key issue.

How do we overcome barriers to colorectal screening in particular to minority groups- and is their evidence of good practice in overcoming these barriers that we can take forward?

A key barrier to implementation is, now, the economic resources (not) available in our region to implement a new programme. Probably, one of our main challenges in our region is to implement the quality assurance programme to provide high quality endoscopic services. There wasn’t a big tradition on this issue in Spain, although in parallel with, or due to, the beginning of colorectal screening programmes, scientific societies are working on standards and accreditation on colonoscopy services.

Barriers, pertinent information, patient understanding, Primary Care involvement, men, areas of social deprivation and ethnicity in regard to the BME communities.

Implementation/design/optimisation issues
Some information about how to design and implement a pilot program for colorectal screening, from the point of view of financial aspects and how to obtain funds, would be a good approach.
Cyprus is in the procedure to apply an organised screening for colorectal cancer. It is very important for us to share some of the problems we are facing, regarding the management of pathological results. We would also like to share some of our difficulties, regarding the implementation and compliance. Regarding the dissemination of information we would like to share some good practices.

- How can we optimize a colorectal screening program:
  1. How can we get the highest possible acceptability?
  2. Get the best possible information about screening to the public is it possible to use Twitter, Facebook?
  3. How can we get the best possible screening quality?

- Implementation planning in relatively poor data condition: cost contra efficacy, Quality. Influencing shareholders and targeted populations behaviour effective communications

- Practical aspects regarding challenges for development and implementation for those beginning to organise a screening programme.

- Quality Assurance/Data

  How to guarantee a fail-safe programme, i.e. how to make sure that screened people within the target-population with a positive screening-result have got a follow-up (diagnoses, treatment)? This is a very important parameter for qualitative population base screening? Is a FOBT, if the target population must imply the test themselves (without intervening of a doctor/general practitioner) save enough (regarding quality of the sample, false-positive, false-negative)?

- Learn from regions with a running colorectal cancer screening programme about methods for quality assurance and maximizing participation - How we can increase uptake in non-responders?

- What key requirements for reporting are expected from existing programmes?

- Quality of data in provider services identification of demographic information about people undertaking screening.
  Quality of data in GP practices about demographic profile of people undertaking screening.

- quality indicators and follow-up lesions

- Misc.

  Addressing the differences to screening approaches across regions internally in a Member State i.e. UK across the home countries (England, Ireland, Scotland and Wales), and again maintaining clear and sensible communications.
Linkage studies, interval cancers

IT Infrastructures needed ...

Modality of Informed choice; Quality assurance Faecal Occult Blood testing

gFOBT versus iFOBT ?

How will the European guidelines affect local practice?

**Specific Question for breakout sessions**

**Theme 1: Implementation of population based screening:**

1) Pilot study (promoter, cancer registry, cancer league, group of gastroenterologists) versus Governmental implementation (authorities lobbing, reimbursement policies, stakeholders). Which of the two directions should be favoured in order to implement and begin a screening program?

2) Is there a minimal number of gastroenterologists needed x 100’000 inhabitants to conduct screening?

3) Should the screening continue after a diagnosis of cancer (post-diagnostic screening for detection of multiple primaries? Frequency? How to coordinate with “normal screening“? Literature basis? Experiences?

**Theme 2: Implementing quality and data use:**

1) Role of cancer registry data and expertise in the process of promotion, implementation and in quality control of screening?

2) What type of data should produce a cancer registry? frequency?
### Annex 2. Delegate List

<table>
<thead>
<tr>
<th>Name</th>
<th>Job Title</th>
<th>Organisation</th>
<th>Role in Workshop</th>
<th>Breakout Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ana Molina (Valencia)</td>
<td>Researcher</td>
<td>Centre for Public Health Research - Valencia</td>
<td>Speaker Day 2</td>
<td>2 and 3</td>
</tr>
<tr>
<td>Andrea Bordoni (Switzerland)</td>
<td>Medical Doctor, MPH</td>
<td>Ticino Cancer Registry - Ticino (Southern Switzerland)</td>
<td>Delegate</td>
<td>1 and 3</td>
</tr>
<tr>
<td>Audrey Howarth</td>
<td>Lead of GM BCSP health improvement team</td>
<td>GM BCSP</td>
<td>Delegate</td>
<td></td>
</tr>
<tr>
<td>Barbara Elliot</td>
<td>SSP</td>
<td>University Hospital Aintree - BCSP</td>
<td>Delegate</td>
<td>2 and 3</td>
</tr>
<tr>
<td>Billie Moores</td>
<td>NW Screening Lead</td>
<td>GMCCN</td>
<td>Speaker - Breakout 3</td>
<td>3</td>
</tr>
<tr>
<td>Brenda Morton</td>
<td>SSP</td>
<td>University Hospital Aintree - BCSP</td>
<td>Delegate</td>
<td>2 and 3</td>
</tr>
<tr>
<td>Chris White</td>
<td>Senior EU Health Specialist</td>
<td>NWHBO</td>
<td>Organiser</td>
<td>1 and 2</td>
</tr>
<tr>
<td>Cllr Roz Gladden</td>
<td>Deputy Leader of the Council and Cabinet Member for Health and Adult Social Care</td>
<td>Liverpool City Council</td>
<td>Opening Address</td>
<td></td>
</tr>
<tr>
<td>Cyril Ducros (Switzerland)</td>
<td>Director of screening program</td>
<td>Foundation for breast cancer screening - Lausanne, I represent the regional area of Canton of Vaud in Switzerland. I'm also member of the Swiss cancer screening Federation (member of the steering committee).</td>
<td>Delegate</td>
<td>1 and 3</td>
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<tr>
<td>David Makin</td>
<td>CHAIR PUP.</td>
<td>GMCCN</td>
<td>Delegate</td>
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<td>David Ritchie</td>
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<td>NWHBO</td>
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<tr>
<td>Deborah Blackburn</td>
<td>PH Consultant</td>
<td>Lancashire Public Health Network</td>
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<tr>
<td>Dr. Aldis Kaufmanis (Ile-de-France)</td>
<td>Physician - Coordinator</td>
<td>ARS Ile-de-France</td>
<td>Delegate</td>
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<tr>
<td>Dr. Dan Seddon</td>
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<td>MCCN</td>
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<tr>
<td>Dr. Eileen Fairhurst</td>
<td>Chair</td>
<td>NHS CM Cluster</td>
<td>Delegate</td>
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<tr>
<td>Dr. Leo Van Rossum (Netherlands)</td>
<td>Scientific Staff Member, epidemiologist</td>
<td>Health Council NL</td>
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<tr>
<td>Dr. Manuel Zorzi (Veneto Region)</td>
<td>Epidemiologist</td>
<td>Institute of Oncology Veneto, Italy</td>
<td>Speaker Day 1</td>
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<tr>
<td>Dr. Nicula (Romania)</td>
<td>Chief of the Department of Prevention and Cancer Control, Romania</td>
<td>Department of Prevention and Cancer Control, Romania</td>
<td>Delegate</td>
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<tr>
<td>Dr. Paolo Giorgi Rossi (Italy)</td>
<td>Director of the Health Technology Assessment Unit</td>
<td>Laziosanità - Agency for Public Health</td>
<td>Speaker Days 1&amp;2</td>
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<tr>
<td>Dr. Philip Bliss</td>
<td>Clinical Director Merseyside and North Cheshire Screening Centre</td>
<td>University Hospital Aintree</td>
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<tr>
<td>Dr. Praveen Gupta</td>
<td>Network primary care lead</td>
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<tr>
<td>Dr. Sofie Van Roosbroeck (Flanders)</td>
<td>Post-doc researcher</td>
<td>University of Antwerp</td>
<td>Speaker Day 1</td>
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<tr>
<td>Dr. Stepan Suchanek (Czech Republic)</td>
<td>MD</td>
<td>Central Military Hospital Prague</td>
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<tr>
<td>Dr. Annarosa Del Mistro (Veneto Region)</td>
<td>MD</td>
<td>Institute of Oncology Veneto, Italy</td>
<td>Delegate</td>
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<tr>
<td>Dr. Attila Kovács (Hungary)</td>
<td>Deputy Chief Medical Officer</td>
<td>Office of the Chief Medical Officer - Hungary</td>
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<td>Dr. Dominika Novak Miškar (Slovenia)</td>
<td>Public Health Specialist, Head of Program Svit Department</td>
<td>National Institute of Public Health, Slovenia</td>
<td>Speaker - Day 2</td>
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<td>Dr. Erzsébet Podmaniczky</td>
<td>Head of Department</td>
<td>National Institute of Oncology, Budapest, Hungary</td>
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<tr>
<td>Elaine Whitby</td>
<td>Associate Director GM Screening Programme</td>
<td>GM Screening Programmes</td>
<td>Speaker Day 1 (breakout)</td>
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<td>Evelyn Desai</td>
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<td>NHS Oldham</td>
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<tr>
<td>Isabel Portillo (Basque Country)</td>
<td>Director, Basque Country Screening Programmes</td>
<td>Basque Country Health Service</td>
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<tr>
<td>Jane McCallum</td>
<td>Programme Manager Cancer</td>
<td>NHS Wirral</td>
<td>Delegate</td>
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<tr>
<td>Jeanette Smalley</td>
<td>Network patient facilitator</td>
<td>Lancashire and South Cumbria Cancer Network</td>
<td>Delegate</td>
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<tr>
<td>Joe V Psaila (Malta)</td>
<td>Consultant - Malta National Health Screening Programmes</td>
<td>National Screening Programme (MALTA)</td>
<td>Delegate</td>
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<tr>
<td>Jon Hayes</td>
<td>Deputy director clinical networks</td>
<td>MCCN</td>
<td>Chair day 2</td>
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<tr>
<td>Josep Alfons Espinas Pinol</td>
<td>Coordinator cancer screening programmes</td>
<td>Catalan Cancer Strategy</td>
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<tr>
<td>Karen Colaert (Flanders)</td>
<td>theme manager 'population based screening'</td>
<td>VAZG</td>
<td>Delegate</td>
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<td>Liesbeth Van Hoof (Flanders)</td>
<td>Theme manager population based colorectal cancer screening</td>
<td>VAZG</td>
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<td>Luciana Neamtiu (Romania)</td>
<td>Researcher</td>
<td>The Oncology Institute „Prof. Dr. Ion Chiricuță” - North-Western Region of Romania</td>
<td>Delegate</td>
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<tr>
<td>Lynn Donkin</td>
<td>Screening Lead Public Health Specialist</td>
<td>NHS Blackpool</td>
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<tr>
<td>Manuela Mtanis (Veneto Region)</td>
<td>International Relations and European Grants Responsible</td>
<td>Institute of Oncology Veneto, Italy</td>
<td>Delegate</td>
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<td>Marjeta Svetel (Slovenia)</td>
<td>communications officer</td>
<td>Slovenian National Institute of Public Health</td>
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<tr>
<td>Maureen Sayers</td>
<td>Health Promotion Specialist</td>
<td>Liverpool Community Health</td>
<td>Speaker Day 1 (breakout)</td>
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<tr>
<td>Michel Candeur (Wallonie)</td>
<td>CCR - coordinator</td>
<td>CCR French Community, Belgium</td>
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<tr>
<td>Morten Ramussen (Denmark)</td>
<td>Consultant surgeon Ph-D.</td>
<td>Bispebjerg University Hospital department of surgery colorectal section</td>
<td>Delegate</td>
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<td><strong>Mytro Azira</strong></td>
<td>Medical Officer 1st class</td>
<td>Ministry of Health Cyprus</td>
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<tr>
<td><strong>Nadine Delicata</strong> (Malta)</td>
<td>Head - Malta National Health Screening Programmes</td>
<td>National Screening Programme (MALTA)</td>
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<tr>
<td><strong>Neil Swindlehurst</strong></td>
<td>Network Information Lead</td>
<td>LSCCN</td>
<td>Organiser - Breakout Session 3 Facilitator</td>
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<tr>
<td><strong>Paola Armaroli</strong> (Piedmont)</td>
<td>Medical doctor, epidemiologist</td>
<td>AOU S. Giovanni Battista, CPO Piedmont, Turin</td>
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<td>2 and 3</td>
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<tr>
<td><strong>Paul Mackenzie</strong></td>
<td>Associate Director Health Inequalities</td>
<td>MCCN</td>
<td>Organiser - EPAAC Lead</td>
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<tr>
<td><strong>Prof Guido Van Hal</strong> (Flanders)</td>
<td>Professor</td>
<td>University of Antwerp</td>
<td>Speaker Day 1</td>
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<tr>
<td><strong>Prof Julietta Patnick</strong></td>
<td>Director of Screening Programmes</td>
<td>National Screening Programme</td>
<td>Keynote Speech Day 2</td>
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<tr>
<td><strong>Roger Prudham</strong></td>
<td>Clinical Director for Gastroenterology &amp; Endoscopy</td>
<td>Pennine Acute Hospitals NHS Trust</td>
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<td>Rona Cruickshank</td>
<td>PH Lead / EPAAC Lead</td>
<td>GMCCN</td>
<td>Scriber</td>
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<td>Sadiq Patel</td>
<td>Health &amp; Well Being Engagement Officer</td>
<td>Blackburn with Darwen Council for Voluntary Service</td>
<td>Delegate</td>
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<td>Sandra Rados Krnel (Slovenia)</td>
<td>Head of Department</td>
<td>National Institute of Public Health, Slovenia</td>
<td>Chair Day 1</td>
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<tr>
<td>Sara Lea</td>
<td>Hub Manager</td>
<td>National Cancer Screening Programmes - West Midlands and North West regions</td>
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<tr>
<td>Shahida Hanif</td>
<td>Health Promotion Lead</td>
<td>Lancashire BCSP/L&amp;SC Cancer Network</td>
<td>Speaker Day 2</td>
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<td>Shelagh Garnett</td>
<td>NW Screening and QA Lead</td>
<td>NHS NW</td>
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<tr>
<td>Steve Smith</td>
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<td>Midlands &amp; NW Bowel Screening Hub</td>
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<td>Susana Castán Cameo (Valencia)</td>
<td>Public Health Medical Doctor</td>
<td>Centre for Public Health Research - Valencia</td>
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<tr>
<td>Sven Tornberg (Sweden)</td>
<td>Director</td>
<td>Stockholm Cancer Screening</td>
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<td>Teresa Owen</td>
<td>Deputy Director of Public Health</td>
<td>NHS Wirral</td>
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<td>Tony Mercer</td>
<td>Health Needs Assessment manager</td>
<td>Liverpool PCT</td>
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<tr>
<td>Tracey Lambert</td>
<td>Communications &amp; Social Marketing Manager</td>
<td>CHAMPS</td>
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<td>Tracie Keats</td>
<td>MacSILD</td>
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<td>Vicky Snape</td>
<td>Public Health Development Manager</td>
<td>NHS Blackburn with Darwen</td>
<td>Delegate</td>
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</table>
Annex 3. List of Posters displayed at workshop

Shahida Hanif, BCSP/L&SC Cancer Network, UK
Showcase Bowel Cancer Screening Programme & Health Promotion work in Lancashire.

Maureen Sayer, Liverpool Community Health Trust, UK
Bowel Cancer awareness campaign improves screening uptake rates

Tracey Lambert, Cheshire and Merseyside Partnerships for Health, UK
Guidelines to reach people with a sensory impairment produced by Cheshire & Merseyside Bowel Cancer Screening Programme.

Dr Sofie Van Roosbroeck & Prof Guido Van Hal, University of Antwerp, Belgium
1) EPAAC survey - identification of good practices to organise and implement screening programmes for colorectal cancer.
2) Flanders pilot programme for colorectal cancer screening.

Ana Molina Barceló, Centre for Public Health Research, Valencia (Spain), plus other Spanish Regions.
Situation of the colorectal cancer screening programmes in Spain.

Dr. Dominika Novak Mlakar, National Institute of Public Health, Slovenia
The National Programme for Screening and Early Discovery of Precancerous Changes and Colorectal Cancer - Svit Programme.

Dr Stepan Suchanek, Central Military Hospital: Prague, Czech Republic
National Colorectal Cancer Screening in the Czech Republic.

Michel Candeur, CCR French Community: Wallonie, Belgium
Data of the first cycle of 2 years (2009-2010).
Annex 4. Colorectal Cancer Screening in the EU: indicative state of play 1/2011

PLEASE DOUBLE CLICK THE IMAGE TO ACCESS THE EMBEDDED DOCUMENT

 Courtesy of International Agency for Research on Cancer (IARC)
Updated information: a pilot testing has since been undertaken in the Netherlands and Flanders (Belgium); the regional programme in Wallonia (Belgium) is not performed with CS but with gFOBT only.78
EPAAC Workshop Event March 7th and 8th 2012

Breakout sessions

NOTE: Each delegate must register for 2 breakout sessions

Breakout 1: Implementation of population based colorectal cancer screening programmes

Facilitators:
1. Dr Sofie Van Roesbroeck – Centre for Cancer Prevention, University of Antwerp, Belgium
2. Dr Guido Van Hae - Centre for Cancer Prevention, University of Antwerp, Belgium
3. Dr Leo Van Reuseum - The Health Council of the Netherlands

Presentation: Flanders pilot programme – Dr Sofie Van Roesbroeck – 10 minutes

This breakout could explore the key issues around implementing the colorectal programme linked to the evidence from the questionnaire research survey

Outcome: 1 key question for discussion on day 2 with Dr Dan Seddon
1 message for regions implementing the population colorectal screening programme

Breakout 2: Overcoming the barriers to participation in colorectal screening

Facilitators:
1. Dr Dan Seddon – Early Detection Lead, Merseyside and Cheshire Cancer Network, UK
2. Dr. Antonio Del Mistro – Institute Oncology Veneto, Italy
3. Dr. Paolo Giorgi Rossi – Agency for Public Health, Italy.

Presentation: Increasing uptake for non-responders in Primary Care - Maureen Sayers, Health Promotion Specialist Liverpool Community Health; Tracey Lambert, Cheshire & Merseyside Public Health Network - 10 minutes

This session could explore some of the emerging barriers for participants participating in the colorectal screening programme

Outcome: 1 key question for discussion on day 2 with Dr Dan Seddon
1 message for regions implementing the population colorectal screening programme

Breakout 3: Implementing quality using data

Facilitators:
1. Billie Moores – Quality Assurance lead for colorectal screening, North West England, UK
2. Elaine Whitley – Screening Lead, Greater Manchester and Cheshire Cancer Network, UK

Presentation: Staging data colorectal screening uptake data – Billie Moores - 10 minutes

This session will explore the role of QA within the colorectal cancer screening programme and will include presentation of key data as an example.

Outcome: 1 key question for discussion on day 2 with Dr Dan Seddon
1 message for regions implementing the population colorectal screening programme

COUNCIL RECOMMENDATION
of 2 December 2003
on cancer screening
(2003/871/EC)

THE COUNCIL OF THE EUROPEAN UNION

Having regard to the Treaty establishing the European Community, and in particular Article 153(4), second subparagraph, thereof,

Having regard to the proposal from the Commission,

Having regard to the opinion of the European Parliament,

Whereas:

(1) Article 153 of the Treaty provides that Community action is to complement national policies and be directed towards improving public health, preventing human illness and disorders, and obviating sources of danger to human health. Such action shall cover, the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education. Community action in the field of public health shall fully respect the responsibilities of the Member States for the organisation and delivery of health services and medical care.

(2) Further development of cancer screening programmes should be implemented in accordance with national law and natural and regional responsibilities for the organisation and delivery of health services and medical care.

(3) Cancer is a major disease and cause of death throughout Europe, including the future Member States. An estimated number of 1,580,976 new cancer cases, excluding non-melanoma skin cancer, occurred in the European Union in 1998. Of these, 1.4% were cervical cancers, 13% breast cancers, 14% colorectal cancers and 9% prostate cancer. Cervical and breast cancer constituted 3% and 29%, respectively, of new cancers in women. Prostate cancer constituted 17% of new cancers in men.

(4) Principles for screening as a tool for the prevention of chronic non-communicable diseases were published by the World Health Organization in 1968 and by the Council of Europe in 1994. These two documents form, together with the current best practice in each of the cancer screening fields, the basis for the present recommendations.

(5) Additionally, these recommendations are based on the ‘Recommendations on cancer screening’ of the Advisory Committee on Cancer Prevention together with the experience gathered under the different actions sustained under the Europe against Cancer programme where European cooperation has helped, for example, high quality cancer screening programmes to provide efficient, European guidelines of best practice and to protect the population from poor quality screening.

(6) Important factors which have to be assessed before a population-wide implementation is decided upon include, inter alia, the frequency and interval of the application of the screening test as well as other national or regional epidemiological specifics.

(7) Screening allows detection of cancers at an early stage of development or possibly even before they become invasive. Some lesions can then be treated more effectively and the patients can expect to be cured. The most indicator for the effectiveness of screening is a decrease in disease-specific mortality. As in the case of cervical cancer, cancer precursors are detected, a reduction in cervical cancer incidence can be considered a very helpful indicator.

(8) Evidence exists concerning the efficacy of screening for breast cancer and colorectal cancer, derived from randomized trials, and for cervical cancer, derived from observational studies.

(9) Screening is, however, the testing for diseases of people for which no symptoms have been detected. In addition to its beneficial effect on the disease-specific mortality, screening can also have negative side effects for the screened population. Healthcare providers should be aware of all the potential benefits and risks of screening for a given cancer site before embarking on new population-based cancer screening programmes. Furthermore, for the informed public of today, these benefits and risks need to be presented in a way that allows individual citizens to decide on participation in the screening programmes for themselves.

(10) Ethical, legal, social medical, organisational and economic aspects have to be considered before decisions can be made on the implementation of cancer screening programmes.

Annex 7. Merseyside and Cheshire Cancer Network iVAN paper

Please double click the image to access the embedded document.

NB. The Merseyside and Cheshire iVAN was present for delegates to visit during Day 2 of the Workshop.
EUROPEAN PARTNERSHIP FOR ACTION AGAINST CANCER (EPAAC)
Work Package 6 Early Diagnosis/Screening
Workshop 2: CERVICAL CANCER SCREENING

October 2012: 8-9, Padova, Italy
Venue: University of Padova - Italy, Archivio Antico, Palazzo del Bo’
“European Action”
Implementing cervical cancer screening programmes

<table>
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<tr>
<th>Time</th>
<th>Event Description</th>
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<tr>
<td>12:00-13:00</td>
<td>Registration</td>
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<tr>
<td>13:00-13:10</td>
<td>Opening Address Welcomes to Padova &amp; Veneto Region</td>
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<td>Prof. Alberto Amadori, Veneto Oncology Institute, Padova, Italy</td>
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<tr>
<td>13:10-13:30</td>
<td>Opening Address - Overview of Work Package 6 Early Diagnosis &amp; Screening – EPAAC - Purpose of Workshop</td>
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<td>Sandra Rados Krnel, Slovenian National Institute of Public Health, EPAAC Project Lead</td>
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<td>13:30-14:00</td>
<td>Cervical Cancer Screening Research: Emerging findings from the EPAAC survey of 20+ European Regions &amp; Member States</td>
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<td>Prof. Guido Van Hal &amp; Dr. Sofie Van Roosbroeck, Centre for Cancer Prevention, University of Antwerp</td>
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<td>14:00-16:00</td>
<td>Breakout session 1 3 sessions: 60 minutes each 1- Improving compliance and participation (organizational aspects) 2- Cervical cancer screening in Eastern Europe 3- Implementation and modification of screening protocols</td>
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<td>16:00-16:30</td>
<td>Coffee</td>
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<td>16:30-17:00</td>
<td>Feedback of breakout session 1 Facilitators for each group</td>
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<td>17:00-17:30</td>
<td>Keynote – Development and Implementation of European Cervical Cancer Screening Guidelines</td>
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<td>Dr Guglielmo Ronco, Centre for Cancer Prevention, Torino, Italy</td>
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<tr>
<td>17:30-18:00</td>
<td>Keynote – Cancer screening and health system resilience</td>
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<td></td>
<td>Dr. Ahti Anttila, Head of EPAAC WP6, Finnish Cancer Registry, Helsinki, Finland</td>
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<td>18:00</td>
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<tr>
<td>20:00</td>
<td>Networking dinner invited guests</td>
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<tr>
<td>08:45-09:00</td>
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<td>09:00-09:15</td>
<td>Welcome: Reflection on Day One Introduction to Day Two</td>
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| 09:15-11:15  | Breakout session 2  
3 sessions: 60 minutes each  
1- Strategies to increase compliance  
2- Communication and information  
3- Implementing quality – role of audits | (see Breakout Sessions document)                       |
| 11:15-11:45  | Coffee                                                                                       |                                                        |
| 11:45-12:15  | Feedback of breakout session 2 Facilitators for each group                                     |                                                        |
| 12:15-12:45  | Regional/State Perspective on implementing Cervical Cancer Screening Programmes: The Netherlands | Dr. Leo van Rossum, The Health Council of The Netherlands |
| 12:45-13:15  | Discussion about research findings and good practices for screening programme implementation    | Facilitated by Dr. Dan Seddon, Merseyside and Cheshire Cancer Network, UK |
| 13:15-13:30  | Feedback, next steps, and closing of the meeting                                               | Chair                                                  |
| 13:30        | Close                                                                                        |                                                        |
Workshop report

European Partnership for Action Against Cancer (EPAAC) Joint Action, WP6 Screening and Early Detection:

Regional Workshop Two

“European Action: implementing cervical cancer screening programmes”

Workshop date: 08/10/2012 – 09/10/2012

Workshop venue: University of Padova, Padova, Italy

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1. Introduction

The second regional workshop of Work Package 6 (Early Detection and Screening) objective 3 (facilitating expert advice to regions seeking to implement or improve population-based cancer screening programmes in accordance with the Council of the EU Recommendation 2003) of the European Partnership on Action Against Cancer (EPAAC) was held in Padova, Italy, on Monday 8 October and Tuesday 9 October 2012.

The second workshop was devoted to the implementation of cervical cancer (CC) screening programmes in Europe, and is the second of three such workshops. The remaining workshop will focus on breast cancer screening programmes and shall take place in Flanders, Belgium (June 2013).

This report details a descriptive overview of the workshop sessions that took place on 8 and 9 October, collates the key messages and recommendations of the workshop, and provides, in annex, some of the main documents arising from, or associated with, the workshop.

Methodology

The second workshop is the culmination of several months work that was initiated with the kick-off of the EPAAC project in February 2011 and represents the second key milestone of WP6 objective 3. To achieve this, a small consortium of partners (working in line with objective 3) came together to design and implement the programmes of the three workshops. These partners are: the University of Antwerp, North West of England Cancer Networks, the North West Health Brussels Office (NWHBO), the Flemish Agency for Care and Health (VAZG), the Veneto Institute of Oncology (IOV), and the European Regional and Local Health Authorities (EUREGHA).

Under the auspices of the EUREGHA network, the NWHBO and VAZG conducted a brief questionnaire on cancer screening competencies that was distributed to representatives of all EU Member States and associated countries. The chief aim of this study was to gather a pool of relevant contact points for further, elaborate surveys specific for each screening programme designed by the University of Antwerp. The specific survey for this second workshop was targeted at those respondents whom would possess significant knowledge of the status of the cervical screening programme in their region or country (NB. This approximation depends upon where the competency is found in each respective Member State i.e. a decentralised competency or centralised, ‘National’, responsibility). The aim of the study is to share knowledge, published as well as non-published, gained from CC screening programmes, research projects and pilot studies on CC screening and
preparations for CC programme implementation on a population level and to use this shared knowledge in the advancement of CC screening.

Using the pool of respondents from both the EUREGHA and University of Antwerp surveys, potential delegates from different EU countries were identified for the workshop. The objective was, as much as was feasible, to achieve a diversity of participants between those with practical day-to-day involvement in cervical cancer screening programmes, and those at the more strategic, policy level. This would allow for a more layered discussion and offer the possibility of workshop recommendations to be implemented at different strategic levels of influence.

Meanwhile, the responsibility for programme design for the cervical cancer screening workshop was taken by the workshop host: the Istituto Oncologico Veneto. This involved identifying the keynote speakers, programming the content of the various workshop sessions and locating a suitable venue.

This methodology will be applied in the remaining workshop. More substantial information on the methodology behind the workshop, and the findings of the University of Antwerp survey, will be available in the final report to be published by the University of Antwerp in 2013/14.
2. Key messages for regions seeking to implement or improve cervical screening programmes:

1) *Develop population-based organized screening programmes is cost-effective in countries with lower-middle-income as well as in richer ones.*

- Organized population-based screening is more effective and less expensive than opportunistic screening.
- It is not the number of Pap smears what makes a screening system efficient.
- Women who remain unscreened or under-screened are at highest risk of developing cervical cancer, and every effort must be made to reach all the target population.
- Concept of “customisation” is valuable: it is important to understand the geographical and social context of the target groups and find the best organizational strategy.
- Commitment of the National/Regional political class is very important to get adequate economic support and to strengthen the awareness of the population.
- National and international coordination may be helpful in finding the right solutions and avoiding the same mistakes. Comparison, cooperation and benchmarking between regions and countries are all crucial. However, communication and marketing tools need to be re-thought and re-shaped for each context; testing new tools versus conventional ones is important.

2) *Participation of all target women is a fundamental requirement.*

- Pilot programmes can be used to identify specific needs (rural vs urban areas) or barriers (i.e. language, religion) and to find appropriate solutions.
- What is likely to work: user friendly tests; self-assessment approach; social marketing; involvement of GPs? A tailored approach is key to improving participation rates.
- It is important to develop parallel strategies to raise awareness for both health professionals and the general public.
- Information to the women must be high-quality, accurate, balanced, plain language, evidence-based, up-to-date.

3) *Important to guarantee systematic quality assurance.*
• All the steps and components of the programme need to be monitored and evaluated continuously, as defined in the European QA Guidelines.

• Appropriate indicators need to be defined, and systematic collection of relevant data must be put in place.

• Periodic audits are useful to identify critical aspects, errors and drawbacks; these must then be corrected.

4) **Use of HPV testing in cervical cancer screening.**

• HPV testing is actually recommended in the triage of ASC-US and post-treatment for high-grade lesions.

• HPV testing as primary screening test is more sensitive but less specific than cytology in detecting high-grade lesions and preventing cervical cancer.

• The use of clinically validated HPV tests (targeting high-risk types only, as a pool) and appropriate protocols (no co-testing, triage of hrHPV-positives, at least 5-years intervals) within organized screening programmes are crucial needs.

5) **Health professional involvement.**

• Continuous training of all health professionals involved is a key to success in cervical cancer screening.

• This ensures active commitment, adherence to the protocols, and correct and consistent information to the women.

• This is also instrumental in moving from opportunistic to population-based organized screening.

6) **Screening and anti-HPV vaccination are complementary tools to prevent cervical cancer.**

• Population-based campaigns for anti-HPV vaccination of 12-years-old girls have been or are being implemented in many European countries.

• Actual vaccines target HPV 16 and HPV 18, responsible of about 70% of invasive cancers, therefore screening will still be necessary also for vaccinated women.

• Screening timing and protocols will be different for vaccinated and non-vaccinated women. Systematic registration of all vaccinations by the competent public health system is necessary.
3. Description of Workshop Sessions

Day 1 – Monday 8 October 2012

Session One

Opening Address

Professor Alberto Amadori, Scientific Director, Veneto Oncology Institute, Padova

Professor Alberto Amadori opened the workshop by officially welcoming all delegates to the City of Padova and the old historical University headquarters. The University of Padova is the second oldest University in Italy (official foundation date 1222).

The topic of the workshop is of particular relevance for the Veneto Oncology Institute and our Region; cancer prevention is one of the key goals of the national and regional health system and it is an integral part of our comprehensive cancer care institution, where the group designated by the Region to coordinate and monitor the three cancer screenings works. Moreover, a large feasibility project involving five organized cervical cancer screening programmes of the Region on the routine use of high-risk Human Papillomavirus (hr-HPV) DNA testing as primary screening test is being carried out.

Purpose and Overview of the Workshop

Sandra Radoš Krnel, EPAAC Project Lead, National Institute of Public Health, Slovenia [Chair of Day One]

Sandra Radoš Krnel, MD, Head of the Research projects services for Institute of Public Health of the Republic of Slovenia, and EPAAC Project Lead introduced the EPAAC project, providing an overview of the project’s aims and objectives, and demonstrating where the workshop fits within this framework.

Introduction

The EPAAC (European Partnership for Action Against Cancer) is a Joint Action programme funded through the EU Public Health Programme for the period between 2011-2014.

The Partnership brings together the efforts of different stakeholders into a joint response to prevent and control cancer. The National Institute of Public Health in Slovenia has assumed the role of leader of the EPAAC Joint Action, which
encompasses 36 associated partners from across Europe and over 90 collaborating partners.

Aims and objectives
The EPAAC Joint Action has a broad range of goals across different areas of cancer prevention and control: health promotion and cancer prevention, including screening, identification of best practice in cancer-related healthcare, the collection and analysis of comparable data and information and a coordinated approach to cancer research.

The Joint Action should contribute to the long-term aim of reducing cancer incidence by 15% by 2020, and to the objective that all Member States have integrated cancer plans by the end of the Partnership. Organisationally, the EPAAC Joint Action is made up of ten Work Packages, which correspond to ten different sets of actions.

Work Packages
There are ten work packages in the EPAAC. These are:
WP1 – Coordination; WP2 – Dissemination; WP3 – Evaluation; WP4 – Open Forum;
WP5 - Prevention:
  • Raise awareness about cancer, target vulnerable population groups
  • Re-launch of the annual European Week Against Cancer
  • Optimise the use of tools to communicate proven prevention strategies
WP6 – Early Detection and Screening:
  • Improve implementation of the Council Recommendation on Cancer Screening
  • Initiate a network of European Schools of Screening Management
  • Identify inequalities in cancer screening programmes
  • Facilitate expert advice to regions seeking to improve cancer screening programmes
  • Develop a consensus on quality criteria for health checks
WP7 - Healthcare
  • Promote the exchange of experiences and best practices across European health services
  • Develop, review and harmonize Clinical Guidelines
  • Implement a training strategy to improve psychosocial and communication skills among health care providers
WP8 – Research
• Identify and prioritize areas in cancer research that will benefit from coordination
• Develop a concerted approach for coordination of one third of research from all funding sources by 2013
• Implement pilot projects of research coordination in selected areas

WP9 – Information and Data
• Map the main sources of cancer data
• Unify cancer burden indicators (incidence, mortality, survival and prevalence)
• Promote a European task force aimed to assess the need for data on cancer costs
• Initiate development of a standardised approach to the routine collection of data on survivorship
• Develop an inventory of statistical methods to analyse population-based cancer data

WP10 – National Cancer Plans (NCPs)
• Overview of the current state regarding NCPs in Member States, Norway and Iceland
• Define areas to be respected in NCPs
• Guidelines for a high level standard NCP and the respecting indicators

This workshop took place within the context of Work Package 6, delivering the specific objective of facilitating expert advice to regions seeking to implement or improve population-based cancer screening programmes.

In particular, the WP6 actions and deliverables across the four specific objectives of the Work Package are:

1) European Schools of Screening Management – Training course (led by the Finnish Cancer Registry / International Agency for Research on Cancer)
2) Identifying inequalities in cancer screening programmes – Literature Study (led by Institute for Public Health - Valencia)
3) Define regional good practices and lessons learned for implementation of cancer screening programmes as recommended by the Council of the EU 2003 – Regional Workshops (led by EUREGHA consortium)
4) Development of pan-European consensus on quality criteria for health checks (led by NEN, Netherlands Standards Organisation)

Within specific objective 3, this workshop will be one of three that, in line with the Recommendation of the Council of the EU 2003 focus on the cancer screening
programmes for Colorectal, Cervical, and Breast cancers. Each workshop will focus on: screening methodologies; data collection; barriers and potential improvements for effective cancer screening programmes.

The initial findings of the three workshops will be presented at the EPAAC Open Forum in Slovenia during 2013.

**Development of the workshop**

The European Regional and Local Health Authorities Network (EUREGHA) played a key role in the development of the Workshop.

An initial survey was carried out by EUREGHA in order to establish a brief overview of regional cancer policy priorities and to collate key contacts whom could be invited to provide experts to participate in the workshop. The survey was completed by 63 respondents across 25 Members States of the EU plus representatives from Turkey, Switzerland and Norway.

The University of Antwerp was responsible for drafting a questionnaire that would provide an indicative picture of the current status of cervical screening programmes in 28 pre-selected regions and Members States of the EU.

Drawing on the contacts from the earlier EUREGHA survey and the previous questionnaire on colorectal screening programmes, this questionnaire was targeted at experts whom had either practical experience of leading a cancer screening programme or, where no screening programme yet exists, were principal investigators in designing a comprehensive programme.

Invitations to attend the workshop were then extended to the respondents of the questionnaire. This was complemented with invitations to representatives from the policy level of the respective respondents’ authorities or Member State (e.g. Ministry of Health), and to representatives from Agencies and European projects on cervical cancer screening. This approach was taken to provide a duality between practical knowledge and strategic, overarching vision.

Finally, the programming of the workshop was determined by the workshop hosts; the Istituto Oncologico Veneto – IRCCS, Padova (Italy). Planning and invitations were discussed among EUREGHA members.
In conclusion, the development of the workshop has highlighted how cooperation between competent authorities is useful for policy development and implementation.

**Emerging findings from the University of Antwerp questionnaire on cervical cancer screening programmes**

*Dr Sofie Van Roosbroeck & Prof. Guido Van Hal, University of Antwerp*

Prof. Van Hal presented the emerging findings of the questionnaire specifically prepared for cervical cancer screening.

The principle aim of the questionnaire was to: ask respondents about examples of practice from their region; and to enquire as to whether the respondents would recommend the selected examples as good practice or not. Identifying barriers and how programmes had overcome these was also a fundamental purpose of the questionnaire.

For quality assurance, the questionnaire has been slightly modified respect the previous questionnaire on colorectal cancer screening, to include suggestions, and pre-tested by three experts prior to dissemination.

**Emerging Findings**

18 respondents, encompassing 15 Member States and associated countries of the EU with high level of involvement in CC screening, completed the questionnaire from the 28 whom were contacted (64%).

Among the recommendations reported by respondents for an efficient cervical cancer screening programme were:

- Registration of both organized as well as opportunistic screening tests;
- Standardized approaches and protocols;
- Pilot testing prior to implementation;
- No reimbursement for pap-smears taken as a health check-up;
- Efficient fail-safe system;
- Continuous quality assurance;

Among the perceived difficulties:

- Conflict of interest of some healthcare professionals;
- A legal framework that is not optimal for quality assurance activities;
• Participation in screening;
• Over-screening.

Prof. Van Hal concluded by providing the key questions emerged from the survey, related to:
• how to compare data across different screening programmes or how EPAAC could help to implement CC screening at national level;
• whether and how to introduce hrHPV testing as primary screening test;
• how to increase participation (i.e. by introducing self-sampling to women not attending regular screening).

Session Two

Breakout sessions

Following Session One of the first day of the workshop, three breakout sessions were held over two iterations, totalling 60 minutes each time. This method allowed delegates to attend two of the three breakout sessions, before returning to Plenary for feedback on the breakout sessions.

The breakout sessions were, as follows:

A) Improving compliance and participation (organizational aspects)
   During this session, the pilot programme undertaken in the North West Region of Romania was presented. Difficulties and needs resulting from disparities observed between rural and urban areas, and for cultural and religious differences were discussed.

B) Cervical cancer screening in Eastern Europe
   During this session, the work undertaken in Latvia to re-introduce a screening program after discontinuation of the previous one was presented. Law regulations on gynaecological health, involvement of GP and national policy on screening have been discussed. The importance of international initiatives in making pressure on the political level has also been stressed.

C) Implementation and modification of screening protocols
   In this session, international recommendations and national policies on screening intervals, age and follow-up protocols were presented. Aspects related with the implementation or modification of a protocol were discussed. The importance of protocols as much as possible evidence-based,
consistent and acceptable by both health professionals and target population were highlighted.

Each iteration of the breakout sessions was instructed to deliver one key question for discussion during the final session of day 2, plus one key message for competent authorities seeking to implement or improve the implementation of population-based programme.

**Feedback of the Breakout Sessions**

Following the two iterations of the breakout sessions, one facilitator from each session presented an overview of the discussions that had taken place.

From **Session A, Paolo Giorgi Rossi, Agency for Public Health, Reggio Emilia (Italy)** underlined that the pilot project in North West Romania was a useful example for issues linked to starting up a screening programme in a large country. Key elements that arose included the awareness to specifically address the different needs of women living in rural and urban areas, or with cultural/religious disparities, and the importance of dedicated training to healthcare professionals. The need for a more comprehensive model to address complex problems and the need to implement population screening programmes in Western European countries formerly with opportunistic screening were also discussed.

From **Session B, Dan Seddon, Early Detection Lead for Merseyside and Cheshire Cancer Network**, reported on the aspects related to the implementation of a screening programme after discontinuation of a previous experience. Involvement of professional groups is mandatory to build awareness and reach all the target population.

From **Session C, Leo van Rossum, The Health Council of The Netherlands**, underlined that registration of clinical episodes in a common database is a prerequisite for organizing screening, harmonize protocols and manage changes in organization or strategy.

Each facilitator noted how both iterations approached the topic of discussion in a different manner, which led to a richer and more complex set of messages as an outcome. More in depth outcomes resulting from the discussions of the breakout sessions can be found in the **Key Messages** section of this report.

**HPV-based screening for the precursors of cervical cancer: EU Guidelines and the Italian HTA report.**

*Dr Guglielmo Ronco, Centre for Cancer Prevention, Torino, Italy*
Dr Guglielmo Ronco illustrated the Italian HTA report on HPV-based screening (published in 2012), whose purpose is to define the best conditions of application of this strategy in the Italian situation. The report contains a section on efficacy and undesired effects based on a systematic literature review (conducted in strict coordination with the preparation of a supplement to the *European Guidelines for quality assurance in cervical cancer screening*), and sections on economic costs, impact on organization of services, and social, ethical and legal impact. Dr Ronco presented also unpublished data on the pooled analyses of the major randomized clinical trials on HPV-based screening ongoing in Europe. He highlighted the crucial protocol elements determining efficacy and feasibility of this strategy:

- primary testing → no co-testing and use of validated HPV tests;
- management of HPV positive women → need of triage systems;
- screening intervals → at least 5 years after a negative HPV test;
- starting age → 30-35 years (evidence of over-diagnosis in young women).

**Cancer screening and health system resilience.**

*Dr Ahti Anttila, Finnish Cancer Registry, Helsinki, Finland; Head of EPAAC Work Package 6*

Dr Anttila recalled the specific tasks/subprojects of the EPAAC WP6, and highlighted that the purpose of population-based screening is to prevent mortality from invasive cervical cancer, to improve quality of life, and to improve quality and availability of health services for cancer and precancer. He then showed the state of the art of cervical cancer screening programmes and the age-standardized rates of incidence and mortality from cervical cancer in the European Union. Comparing screening policy and incidence rates of the different States, it emerges that prevention efficacy is not related to the number of screening episodes during a woman’s life; women remain unscreened or underscreened (even though a large proportion of the population may be screened regularly but too frequently) because of barriers of not inviting properly. Sampling or diagnostic or management errors are other causes. Systematic quality assurance by continuous monitoring and evaluation (with actions to correct errors) are essential to control for failures in screening effectiveness.

Using data from Finland Dr Anttila presented some practical examples on the magnitude of the impact and financial and quality-of-life aspects of cervical cancer screening programmes. In Finland an organized cervical cancer screening programme is active since 1963; women 30-64 yrs-old (29-69 in some regions) are screened every 5 years, for a total of seven (or nine) tests lifetime. A 98% age-specific invitational coverage and 70% attendance rate are regularly reached. Nonetheless, steps to improve efficacy and save costs will be taken in the near future in Finland; addition of HPV-vaccination to the school-based vaccination program and actions to reduce the
current opportunistic screening (that is expected to gain large savings to the health care costs).

DAY 2 – Tuesday 9 October 2012

Session Three

Day 2 was opened by the Chair for the second day Paolo Giorgi Rossi, Agency for Public Health, Reggio Emilia (Italy), who provided a brief overview of the previous day and some reflections:

- Europe is very different and we do need different solutions, but How can we avoid to make the same errors?
- The resources paradox: decision makers affirm there are non resources to implement organized population-based programmes, but if we propose a less intensive protocol they only want the full optional model!

Breakout sessions

Also on day 2 of the workshop, three breakout sessions were held over two iterations, totalling 60 minutes each time. This method allowed delegates to attend two of the three breakout sessions, before returning to Plenary for feedback on the breakout sessions.

The breakout sessions were, as follows:

D) Strategies to increase compliance

During this session, after a brief presentation of the preventive strategies against cervical cancer undertaken in Catalonia (Spain) since 2006, it was illustrated the project ongoing for women 40 to 65 years-old with inadequate screening history, who are offered a test of rescue with hrHPV & Pap testing; high prevalence of lesions was found. Other actions to increase coverage included greater involvement of GP, midwives and nurses, and information and health education material to professionals and target population.

E) Communication and information

During this session, the experience done in Italy with focus groups of women on communication about HPV has been presented. Since HPV testing is increasingly being used in cervical cancer screening, and it deals with two hot issues (sex + cancer), it is of extreme importance to understand the information needs of the women, and to be aware of the differences between verbal and written communication. Focus groups are a useful method for exploring values and beliefs about health issues and for collecting in-depth information about complex topics. The HPV information becomes
understandable if: it is brief; it only addresses a few key issues; it has a logical sequence; it is given at the same time of an invitation to perform the test. The information has to be up-to-date, as well.

F) Implementing quality – role of audits

In this session, the North West England Cervical Screening Health Equity Audit 2010 was presented. Mapping of deprivation areas and under-screened areas disclosed a gap in coverage between least and most deprived areas. By ethnicity, coverage for Asian women was lower than for non-Asian. Lowest uptake was observed for the 25-34 year age-band in all areas. Cervical Equity Audit through detailed analysis of routinely collected data in relation to age, deprivation and ethnicity allows identification of target groups and areas for intervention.

Each iteration of the breakout sessions was instructed to deliver one key question for discussion during the final session of day 2, plus one key message for competent authorities seeking to implement or improve the implementation of population-based programme.

Feedback of the Breakout Sessions

Following the two iterations of the breakout sessions, one facilitator from each session presented an overview of the discussions that had taken place.

From Session A, Manuel Zorzi, Veneto Tumour Registry, Padova (Italy) highlighted the key areas of debate, which related to data availability and how one can identify females who are not covered in regions and countries where such data is not mandatorily collected; and the need for more robust information provision on the results of previous screening tests.

From Session B, Carla Cogo, Veneto Tumour Registry, Padova (Italy) posed the question as to how do competent authorities provide information that is balanced, highlighting both the pro’s and con’s. However, health professionals and public health authorities should avoid sending mixed messages to women. Quality of information is crucial; information should be accurate, balanced, up-to-date and adopt plain language.

From Session C, Annarosa Del Mistro, Veneto Oncology Institute, Padova (Italy), reported on the two questions arose during discussion: how to intervene after the audit? How to intervene in an established program? Routine data collection, GP commitment and health professional involvement are instrumental for efficacious interventions. Attention must also be paid to events forecasted by the media; for example, the recent death by cervical cancer of a celebrity increased awareness and participation to the screening programme was higher for some time.
Population screening for cervical cancer: from questions asked to answer given.

Dr. Leo van Rossum, University Medical Center Nijmegen, Health Council of The Netherlands

The focus of this presentation was to present how the Health Council of The Netherlands worked to define the strategy for the prevention of cervical cancer. Science advice, policy and program director represent the so-called “power of 3”; aim of the Health Council, a governmental and independent organism, is to give science advice to policy makers. Dr van Rossum compared characteristics and caveats of vaccination and screening, two complicated strategies that must be integrated (they are complementary). He then recalled the 7 steps needed to implement a robust screening programme, as determined by Lynge et al.[Eur J Cancer 2011]: 1. Before planning – initial work to identify barriers to participation, review recommendations and guidelines, focus on what has worked and what didn’t work in other societal contexts, gain political support; 2. Planning – identify a Coordinator with mandate and budget, focus on determining the infrastructure and ICT needs, cover the formation of a Quality Assurance Plan, and make provision for monitoring, auditing, (re)training, accreditation; 3. Feasibility & 4. Pilot – review of scientific data, legal and ethical issues before testing and piloting procedures; 5. Up scale & 6. Full scale – implementation of the roll-out stages to full population scale; 7. Sustainability – ensure ‘organisational anchorage’ and take measures towards continued political endorsement and societal engagement.

The recommendations for implementation of cervical cancer screening are:

- Switch to hrHPV testing with cytology triage: deimplementation of cytology, no genotyping, hrHPV test validation, pathology guidelines, screening at 30 – 35 – 40 – 50 – 60;
- Information about switch to hrHPV;
- Boost participation: GP, appointment, early reminders, follow-up pos, self-sampling (in case of non-response 3-6 months)
- Quality assurance: laboratory quality (reference laboratories, accreditation, controls);
- Inclusion of opportunistic screening in monitoring and evaluation;
- Link vaccination and screening registries.

Conclusions:

Discussion about research findings and good practices for screening programme implementation

Dr Dan Seddon, Merseyside and Cheshire Cancer Network
Dr Seddon presented some key messages and questions from the six Breakout Sessions, focusing in particular on the key messages that were delivered as an outcome of both iterations from each session.

**Day 1 - Session A: Improving compliance and participation**
- We are in a difficult economic situation. In some countries, any public investment is a very, very difficult step.
- Do we really need more resources in order to implement systematic population-based cervical screening programmes, or are the resources already there in unsystematic, less effective, opportunistic or over-screening scenarios?
- Can we rationally and ethically delay introducing systematic population-based programmes because of affordability?
- Cost and impact modelling
- Counting all costs
- Mobilising resources
- Mobilising political, professional and public will

**Day 1 - Session B: Cervical screening in Eastern Europe**
- Is it appropriate to introduce a population-based programme in part, because of the difficulty of resourcing and implementing a complete programme? For example, in Latvia a programme has been introduced without robust fail-safe. Is this wrong?
- Do we need different guidelines and standards for young programmes versus mature, long-established programmes?

**Day 1 - Session C: Implementation and modification of screening protocols**
- What is the appropriate upper age limit for a population-based cervical cancer screening programme in the second decade of the 21st century in Europe?
- How can the key health care worker be involved so that they follow guidelines?

**Day 2 - Session D: Strategies to increase compliance**
- In a system without a legal basis that allows central reporting of screening, attendance and non-attendance, how can those women who do not attend be encouraged to think again?
Day 2 - Session E: Communication and information

• How can we produce balanced information for women as individuals and for particular groups? That is, information that describes potential harms as well as benefits.

• Key message: information must be high quality, accurate, balanced, plain language, evidence based, up to date.
And we need to inform individual women AND health professionals, lobby groups, special interest groups, politicians as well.
And we have to monitor and evaluate different communication strategies themselves to see if they work and learn what is best for different groups and purposes.

• How can we deal with information going to women that is not a uniform message? For example, women may trust their own gynaecologists advice more than messages from government.

Day 2 - Session F: Implementing quality: role of audits

• Quality assurance processes and ongoing marketing of screening to women is important for both overall coverage, and in specific population groups with lower uptake. Do we have to wait for a crisis before we act to invest in this?

Further details on the final recommendations and message can be found in section 2 of this document: key messages for regions seeking to implement or improve cervical cancer screening programmes.
**EUROPEAN PARTNERSHIP FOR ACTION AGAINST CANCER (EPAAC)**

*Work Package 6 Early Diagnosis/Screening*

**Workshop 2: CERVICAL CANCER SCREENING**

**October 2012: 8-9, Padova, Italy**

**Venue:** University of Padova - Italy, Archivio Antico, Palazzo del Bo’

**"European Action"**

**Implementing cervical cancer screening programmes**

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</tr>
</tbody>
</table>
# EUROPEAN PARTNERSHIP FOR ACTION AGAINST CANCER (EPAAC)

**Work Package 6 Early Diagnosis/Screening**

**Workshop 2: CERVICAL CANCER SCREENING**

October 2012: 8-9, Padova, Italy

Venue: University of Padova - Italy, Archivio Antico, Palazzo del Bo’

“European Action”

Implementing cervical cancer screening programmes

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
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</table>
A European Network on cervical cancer surveillance and control in the new Member States

AURORA is developed according to the Council Recommendation on cancer screening (2003/878/EC) and according to the European guidelines for quality assurance in Cervical Cancer Screening - 2nd edition.

14 partners around Europe are cooperating in AURORA project, sharing the same concept that prevention activities can significantly reduce the incidence of cervical cancer in Europe. Based on this concept and on the European Recommendations AURORA mission is to promote the implementation of high quality population based prevention for cervical cancer in the new EU-states through exchanging know-how and expertise, training of healthcare professionals and collaboration among experts and stakeholders. Furthermore, AURORA consortium believes that advocacy is essential to stimulate governmental authorities to implement cervical cancer prevention and therefore the project mission includes the training of advocacy leaders.

AURORA project is particularly dedicated to the Hard to reach population (HTRP), considered as those sections of the community that are difficult to involve in public participation. The term can be used to refer to minority group such as ethnic group, sometimes to hidden populations such as illegal immigrants, sometimes to unserved groups (no services available for these groups) or service “resistants” (people failing to access the services that are available).

Key words: Cervical cancer prevention, Hard to reach populations, Training, Advocacy, Pilot Action.

Activities

AURORA activities are organised in 8 WPs (work packages) during 36 months.

The main results of AURORA will be:

1. Analysis of the local contexts and needs of the participating countries, useful to stakeholders to organize more effective training and prevention activities.


3. Training of 24 healthcare professionals.

4. Training of 12 advocacy leaders to broad coalition with stakeholders and to influence public policies on Cervical Cancer Screening.

5. E-learning platform to offer distance courses to all interested key actors.

6. EU Network of Pilot Healthcare Centres to offer quality services.

AURORA project update

The project started in 14 Jan 2011, as far as nowadays the following activities have been completed:

- Analysis of the local context available on the AURORA project website: http://www.aurora-project.eu/upload/deliverables/AURORA_Analysis_of_the_local_context_D3.pdf
  It has been carried out in all the project participating countries with the aim to collect information about Cervical Cancer epidemiology, Screening and vaccination programmes, and on hard to reach population groups; these groups have been identified in each context and their particular needs have been assessed as part of the analysis.

  Good practices are collected from partner countries (covering most New EU Member States) as well as “gold standard” countries.

- E-learning platform is online on the AURORA project website: http://www.aurora-project.eu/en/web/e-learning
  3 modules (scientific background, communication and advocacy) tailored for healthcare professionals and advocacy leaders.

- Training for healthcare professionals and advocacy leaders is planned for October, 24-26 2012 in Milan.

- The network of pilot centers will be completed within the end of the project.
EVALUATION OF HPV DNA TEST IN CERVICAL CANCER SCREENING IN CATALONIA (SPAIN)

R. Balleix 1, J. Autonell 1, M. Sardà 1, N. Baixeras 1, M. Crespo 2, P. Pique 2, A. Pascual 2, C. Martí 2, M. Fílba 3, C. Gutiérrez 3, B. Lloveras 3, J. Moreno-Crespi 3, E. López 4, N. Baixeras 1, V. Rodriguez-Sales 1, E. Roura 1, M. Peris 5, F. X. Bosch 1

1Unit of Infections and Cancer. Cancer Epidemiology Research Programme. Catalan Institute of Oncology. Pathology Department. Hospital Consortium of Vic. Sexual and Reproductive Health centre of Bages-Solsona. Territorial administration of central Catalonia. 2Sexual and Reproductive Health centre of Bages-Solsona. 3Pathology Department. Hospital Consortium of Vic. 4Hospital Consortium of Vic. 5Pathology Department. Bellvitge University Hospital. DIBELL. Catalan Institute of Oncology. DIBELL. Catalan Institute of Oncology. DIBELL. Catalan Institute of Oncology.

INTRODUCTION

Cervical cancer is a region in the North-East of Spain with a population of 2,802,504 women aged 25 and above in 2008. The incidence of cervical cancer (CC) is 7 per 100,000 (1). Cervical cytology is recommended as the primary screening strategy for CC. Screening is offered through an opportunistic frame free of direct charge. The coverage reached about 50-70% of the population (2-4). Around 2% of the cytology results are abnormal squamous cells of undetermined significance (ASC-US). A specific retrospective case series assessment found that 70% of CC cases have no prior history of Pap smear (5).

In 2006 a new screening protocol for CC in sexually active women 25 to 65 years of age was implemented to increase coverage and to achieve a 3-year interval between cytology. HPV DNA testing for risk types (hrHC2) was introduced along to cytology for women aged 40-64. A total of 1,832 women with inadequate screening and 611 women with diagnosis of ASC-US during 2007 and 2008 from 6 reference HPV laboratories have been included in this analysis.

OBJECTIVE

This is a population based study to evaluate cervical intraepithelial lesions grade two or worse (CIN2+) using hrHPV detection as a primary screening in women with a poor CC screening history in the context of an opportunistic screening setting and in the triage of women with a cytology and a diagnostic evaluation of ASC-US.

METHODS

Inadequate screening: women aged 40 or older with no history of cervical cytology in the previous 5 years. Women are screened with a cervical cytology and adjuvant hrHPV DNA test. If both tests are negative, the screening interval is every 3 years. If one of them is positive, follow-up is within 6-12 months by colposcopy or by repetition of hrHPV test. In ASC-US cases hrHPV DNA test is performed within 3 months following ASC-US diagnosis. If the hrHPV test is negative, follow-up is every 3 years, otherwise referred to colposcopy and closer follow-up.

A total of 1,832 women with inadequate screening and 611 women with a diagnosis of ASC-US during 2007 and 2008 from 6 reference HPV laboratories have been included in this analysis.

Using electronic record linkage data, women were followed-up for at least 3 years to cover the full period of one screening round or until CIN2+ treatment in order to evaluate the extent to which hrHPV testing predicted CIN2+. Available information included results on cytology, biopsy or hrHPV test.

RESULTS

Table 1 - General characteristics of the women with a diagnosis of ASC-US from 5 sentinel screening centres in Catalonia (Spain)

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>TOTAL</th>
<th>WOMEN WITH FOLLOW UP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age mean years</td>
<td>45.3 (SD; 11-78)</td>
<td>45.3 (SD; 11-78)</td>
</tr>
<tr>
<td>Age group yrs</td>
<td>N (%)</td>
<td>N (%)</td>
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<tr>
<td>35-39</td>
<td>120 (26.0)</td>
<td>120 (26.0)</td>
</tr>
<tr>
<td>40-44</td>
<td>186 (39.0)</td>
<td>186 (39.0)</td>
</tr>
<tr>
<td>&gt;44</td>
<td>168 (35.0)</td>
<td>168 (35.0)</td>
</tr>
<tr>
<td>Total</td>
<td>394 (100)</td>
<td>394 (100)</td>
</tr>
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</table>

Table 2 - Distribution of cervical abnormalities at the end of follow-up age and hrHPV positive by entry among 453 women with ASC-US from 5 sentinel screening centres in Catalonia (Spain)

<table>
<thead>
<tr>
<th>DIAGNOSIS AT LAST FOLLOW</th>
<th>TOTAL</th>
<th>HRHPV POSITIVE</th>
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</thead>
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<tr>
<td>Normal</td>
<td>288 (63.7)</td>
<td>218 (62.1)</td>
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<tr>
<td>CIN1</td>
<td>50 (11.0)</td>
<td>32 (9.5)</td>
</tr>
<tr>
<td>CIN2</td>
<td>55 (12.1)</td>
<td>40 (11.7)</td>
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<tr>
<td>CIN3/HSIL</td>
<td>70 (15.2)</td>
<td>54 (15.7)</td>
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<tr>
<td>Cancer</td>
<td>2 (0.4)</td>
<td>2 (0.6)</td>
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Table 3 - General characteristics of women with inadequate screening from 6 sentinel screening centres in Catalonia (Spain)

<table>
<thead>
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<th>CHARACTERISTIC</th>
<th>TOTAL SAMPLE</th>
<th>WOMEN WITH FOLLOW UP</th>
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</thead>
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<tr>
<td>Age mean months (SD; range)</td>
<td>54.10 (10.2; 40-88)</td>
<td>54.10 (10.2; 40-88)</td>
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<tr>
<td>Sex</td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Male</td>
<td>638 (83.2)</td>
<td>638 (83.2)</td>
</tr>
<tr>
<td>Female</td>
<td>132 (16.8)</td>
<td>132 (16.8)</td>
</tr>
<tr>
<td>Total</td>
<td>770 (100)</td>
<td>770 (100)</td>
</tr>
</tbody>
</table>

DISCUSSION

Among women with inadequate CC screening, sensitivity and negative predictive value were higher using hrHPV test as compared to cytology one and similar if both tests were combined for CIN2+ detection. Cytology could be recommended as a triage of HPV positive subjects in this population. Triage of ASC-US with hrHPV testing showed also a high sensitivity for the detection of CIN2+ and a high negative predictive value after 3 years of follow-up. The results of this study are in line with the current guidelines for triage of women with ASC-US in the target age range of 25-65. Further investigation is needed to improve specificity of HPV test. These data demonstrate that hrHPV screening has the potential to improve the quality of cervical cancer prevention, particularly in women over 40 years old.

REFERENCES


Inadequate screening data: Balleix et al. submitted.
Conclusions

The most important preliminary results of the feasibility project ongoing in 5 service screening programmes in Veneto Region (North-East Italy) are the significant increase in women’s compliance to screening invitation and the good compliance to the 12-mos recall for those who were hrHPV+/cytology- at baseline. Triage of hrHPV+ cases by cytology is a critical step since it determines the referral rate to colposcopy. Detection rate (DR) and positive predictive value (PPV) increased in all programmes. Overdiagnosis in young women occurred.

Background

Several randomized clinical trials have clearly demonstrated that hrHPV DNA testing in cervical cancer screening has higher sensitivity than cytology to detect high-grade lesions (CIN2+) and to prevent invasive cervical cancer. However, this strategy has a lower specificity, and needs a triage test that introduces important modifications in the operative protocol. Feasibility projects nested within service screening programmes have been promoted to test in a routine setting this new strategy.

Results

As indicated in Table 1, the feasibility projects in the 5 service screening programmes have been activated in different dates. Up to December 31st, 2011, almost 50000 women have been screened by hrHPV DNA test. The positivity rates ranged between 5.8 to 7.1% (median 6.6%). The cytology triage detected equivocal/abnormal cells (ASC-US+, according to the Bethesda 2001 classification) in 36-50% of the cases in the different programmes (see Figure 1), with a referral rate to immediate colposcopy ranging between 2.5 to 3.3% (median 2.7%), and a referral to 12-mos testing repeat in about 4%. A high-grade lesion was diagnosed in 3.1% of the screened women, with a DR for CIN2+ of 5.6 among women 25-34 yrs-old and 2.3 among 35-64 yrs-olds. In comparison to the rates observed during the previous three years when cytology testing was used, a significant higher compliance of the women (Fig. 2) and a higher DR for CIN2+ were recorded (Fig. 3).

According to the protocol, all the women with hrHPV+/cyto- baseline tests have been recalled 12 months later; attendance rate has been >80%, and a hrHPV positivity rate of about 50% has been recorded.

Table 1. Activity up to December 31st, 2011

<table>
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<th>ULSS</th>
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<th>N screened</th>
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<td>15</td>
<td>July 2010</td>
<td>24067</td>
<td>11586</td>
</tr>
<tr>
<td>16</td>
<td>June 2011</td>
<td>15388</td>
<td>4983</td>
</tr>
<tr>
<td>17</td>
<td>April 2009</td>
<td>31693</td>
<td>16144</td>
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<tr>
<td>18</td>
<td>January 2011</td>
<td>14831</td>
<td>8801</td>
</tr>
<tr>
<td>19</td>
<td>December 2010</td>
<td>7478</td>
<td>4878</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>93457</td>
<td>46392</td>
</tr>
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</table>

Table 2. Positivity rates of cytology triage

<table>
<thead>
<tr>
<th>CIN2+ DRs</th>
<th>25-34 yrs-old</th>
<th>35+ yrs-old</th>
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</thead>
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<tr>
<td>HPV</td>
<td>5.4</td>
<td>2.3</td>
</tr>
<tr>
<td>Pap 2007-09</td>
<td>3.1</td>
<td>1.7</td>
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</table>

Figure 1. Positivity rates of cytology triage

Figure 2. Women’s compliance to invitation

Figure 3. Comparison of CIN2+ DRs with the two different strategies
EPAAC survey - identification of good practices to organise and implement screening programmes for cervical cancer

Van Roosbroeck S. and Van Hal G.
Research Group Medical Sociology and Health Policy, Department of Epidemiology and Social Medicine, University of Antwerp, Antwerp, Belgium

Introduction and aim of the study
At the end of 2009, the European Commission has established a European Partnership on Action Against Cancer (EPAAC) to help EU-member states to control cancer (breast, cervical and colorectal), to avoid dispersed activities and repeated work and to reduce cancer incidence with 15% by 2020.

Methods
- Good practices to organise and implement population-based screening programmes for cervical cancer (CC) were identified by means of a survey. The survey aimed to share experience and knowledge, published as well as non-published, gained from CC screening programmes, research projects and pilot studies on CC screening and preparations for CC programme implementation on a population level.
- The survey was sent out to leading screening programme managers, experts-in-the-field, preferably from at least 20 different European regions, evenly spread throughout the EU. Selections were made based on the European Regional and Local Health Authorities (EUREGHA) questionnaire that mapped regions and their priorities and areas of expertise for cancer screening.
- The survey was pre-tested with three experts in cancer screening programmes to ensure that all relevant aspects were covered (content validity) and questions were clear and unambiguous.

Key questions from survey
- How to compare data across different screening programmes?
- How could EPAAC help to implement the best CC screening option at the national level?
- How to change an existing decentralized CC screening programme? How to convince gynaecologists, cytopathologists and participants that a three year interval is safe and avoids overdiagnosis and overtreatment?
- Is it time to introduce primary HPV screening in well organised cervical cancer screening programmes in Europe and at what age to start HPV screening?
- Is it time to introduce HPV self-sampling to women not attending regular screening?
- What is the current evidence on offering HPV self-sampling as primary screening method?
- What is the current evidence on using novel technology for triage of screen-positive women?
- How to increase participation?
- How to improve the uptake of cervical screening in young women?
- What is the best practice for the change to HPV screening as primary test?

Response
18 Out of 28 regions responded (64%). The level of involvement in CC screening is at least once a week. The profile of responders varies from academics charged with preparations for an implementation of a (pilot) programme to medical staff, and from coordinating midwives to screening coordinators.

Acknowledgements
The research was supported by the Flemish Government. The authors like to thank all respondents of the survey. Further, the authors thank North West of England Cancer Network, and the Institute of Oncology Veneto, and Sol Wallyn and, in particular, David Ritchie, from EUREGHA for their assistance with recruiting survey respondents.

Presented at
Workshop 2: Cervical Cancer Screening; October 2012, 8-9, Padova, Italy

Key words
cervical cancer - screening - implementation - good practice
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<th>Activity</th>
<th>Details</th>
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</thead>
<tbody>
<tr>
<td>12:00-13:00</td>
<td>Registration/welcome coffee</td>
<td>Poster exhibition (available over full 2 days)</td>
</tr>
<tr>
<td>13:00-13:10</td>
<td>Opening Address</td>
<td>Jo Vandeurzen, Flemish Minister of Welfare, Health and Family</td>
</tr>
<tr>
<td>13:25-14:10</td>
<td>Two Keynotes:</td>
<td>Dr Livia Giordano, Unit of Epidemiology, CPO Piemonte, Italy and member of the Euroscreen Working Group</td>
</tr>
<tr>
<td></td>
<td>1. State-of-the-art of breast cancer screening programmes in Europe</td>
<td>Professor John Dewar, consultant and honorary Professor of Clinical Oncology and member of the Independent UK Panel on Breast Cancer Screening</td>
</tr>
<tr>
<td></td>
<td>2. How to keep a balance between a good participation-rate on the one hand and providing information about risks and benefits on the other hand?</td>
<td></td>
</tr>
<tr>
<td>14:10-14:30</td>
<td>Coffee</td>
<td>Poster exhibition</td>
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<tr>
<td>14:30-16:30</td>
<td>Breakout session 1</td>
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<td>16:30-16:50</td>
<td>Coffee</td>
<td>Poster exhibition</td>
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<td>16:50-17:30</td>
<td>Feedback of breakout session 1 and Q&amp;A</td>
<td>Facilitators for each group</td>
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<td>Chair</td>
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<td>Networking dinner invited guests</td>
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<td>09:00-9:15</td>
<td>Registration/welcome coffee</td>
<td>Poster exhibition (available over full 2 days)</td>
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<td>09:15-09:30</td>
<td>Welcome: Reflection on Day One and Introduction to Day Two</td>
<td>Dr Florian Nicula, Institute of Oncology, Romania - Chair of the day</td>
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<td>9:30 -10:10</td>
<td>Two Keynotes:</td>
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<td>1. Evaluating the impact of a population based screening, in particular breast cancer screening</td>
<td>Tytti Sarkeala, Finnish Cancer Registry, Helsinki, Finland</td>
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<td>2. Cost effectiveness of population based screening in particular breast cancer screening</td>
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<td>10:10-12:10</td>
<td>Breakout session 2</td>
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<td>1. Quality assessment - implementation of quality assurance in the breast cancer screening programme</td>
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<td>2. Is tailored-recruitment a solution - added value of social marketing?</td>
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<td>3. Separate trials - pilot studies implemented in national programmes and consequences for communication when divergences rise</td>
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<td>Coffee</td>
<td>Poster exhibition</td>
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<td>12:20-12:50</td>
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<td>12:50-13:20</td>
<td>Discussion about research findings and tackling barriers to screening programme implementation</td>
<td>Facilitated by Dr Dan Seddon, Merseyside and Cheshire Cancer Network, UK</td>
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<td>13:20-13:30</td>
<td>Feedback, next steps, Workshop 4 and closing of the meeting</td>
<td>Chair</td>
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Workshop report

European Partnership for Action Against Cancer (EPAAC) Joint Action, WP6 Screening and Early Detection:

Regional Workshop Three

“European Action: implementing breast cancer screening programmes”

Workshop date: 03/06/2013 – 04/06/2013
Workshop venue: Royal Academy of Medicine, Brussels, Belgium

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Background

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1. Introduction

The third regional workshop of Work Package 6 (Early Detection and Screening) objective 3 (facilitating expert advice to regions seeking to implement or improve population-based cancer screening programmes in accordance with the Council of the EU Recommendation 2003) of the European Partnership on Action Against Cancer (EPAAC) was held in Brussels, Belgium, on Monday 3 June and Tuesday 4 June 2013.

The third workshop was devoted to the implementation and/or the improvement of breast cancer (BC) screening programmes in Europe, and is the last of three such workshops. The previous workshops focused on colorectal and on cervical cancer screening programmes and occurred respectively in Liverpool (March 2012) and in Padova (October 2012).

This report details a descriptive overview of the workshop sessions that took place on 3 and 4 June, collates the key messages and recommendations of the workshop, and provides, in annex, some of the main documents arising from, or associated with, the workshop.

Methodology

The third workshop is the culmination of several months work that was initiated with the kick-off of the EPAAC project in February 2011 and represents the third key milestone of WP6 objective 3. To achieve this, a small consortium of partners (working in line with objective 3) came together to design and implement the programmes of the three workshops. These partners are: the North West of England Cancer Networks, the North of England EU Health Partnership (NEEHP), the Flemish Agency for Care and Health (VAZG) and the University of Antwerp, the Veneto Institute of Oncology (IOV), and the European Regional and Local Health Authorities (EUREGHA).

Under the auspices of the EUREGHA network, the NEEHP and VAZG conducted a brief questionnaire on cancer screening competencies that was distributed to representatives of all EU Member States and associated countries. The chief aim of this questionnaire was to gather a pool of relevant contact points for further, elaborate surveys specific for each screening programme designed by the University of Antwerp. The specific survey for this third workshop was targeted at those respondents whom would possess significant knowledge of the status of the breast cancer screening programme in their region or country (NB. This approximation depends upon where the competency is found in each respective Member State i.e. a
decentralised competency or centralised, ‘National’, responsibility). The aim of the study was to share knowledge, published as well as non-published, gained from BC screening programmes, research projects and pilot studies on BC screening and preparations for BC programme implementation on a population level and to use this shared knowledge in the advancement of BC screening. More on the methodology and the results of the survey can be found in annex 1 ‘Key questions good practices in breast cancer screening’.

Using the pool of respondents from both the EUREGHA and University of Antwerp surveys, potential delegates from different EU countries were identified for attending the workshop. The objective was, as much as was feasible, to achieve a diversity of participants between those with practical day-to-day involvement in cervical cancer screening programmes, and those at the more strategic, policy level. This would allow for a more layered discussion and offer the possibility of workshop recommendations to be implemented at different strategic levels of influence.

Meanwhile, the responsibility for programme design for the breast cancer screening workshop was taken by the workshop host: the Flanders Agency for Care and Health with the University of Antwerp. This involved identifying the keynote speakers, programming the content of the various workshop sessions and locating a suitable venue.

More substantial information on the methodology behind the workshop, and the findings of the University of Antwerp survey, will be available in the final report to be published by the University of Antwerp in 2013/14.
2. **Key messages for regions seeking to implement or improve breast screening programmes:**

1. It is essential in breast cancer screening to fully inform the target population: Appropriate communication of the benefits and harms of screening is a crucial point; communicating the uncertainty is difficult and frequently not appreciated by the media.

   Social media may offer untapped potential for targeted communication to raise awareness but not enough research exists to demonstrate effectiveness. Moreover, individual communication must be balanced with general messages via the media in terms of benefit/harm.

2. It is important to explicitly state that opportunistic screening is less effective in comparison to organised screening, which offers the best quality. Opportunistic screening wastes government, health insurers and women’s resources. However, we should be careful in using overtly negative messages in communicating this message, stressing instead the positive elements organised approaches over the weaknesses of opportunistic screening.

3. Political commitment is fundamental to provide the means for decreasing the prevalence of opportunistic screening.

4. The number of mammograms screened is not adequate quality indicator: instead, there is a need for peer meetings including open discussion; double reading; and reference to outcomes.

5. Collecting evidence through data is necessary but difficult to do: a question remains on how to improve risk stratification within the population approach, namely, what risk factors should be included in order to reach those women who are primarily in need of screening.

6. Greater resources should be available for research on screening: as there is a need across countries for such research, collaboration could be possible and should be explored through joint programming and pooling of available resources.
3. Description of Workshop Sessions

Day 1 – Monday 3 June 2013

Session One

Opening Address

Purpose and Overview of the Workshop

Mateja Krajc, EPAAC Project Lead, National Institute of Public Health, Slovenia [Chair of Day One]

Mateja Krajc, Slovenian National Institute of Public Health and EPAAC Project Lead introduced the EPAAC project, providing an overview of the project’s aims and objectives, and demonstrating where the workshop fits within this framework.

This workshop took place within the context of Work Package 6, delivering the specific objective of facilitating expert advice to regions seeking to implement or improve population-based cancer screening programmes.

In particular, the WP6 actions and deliverables across the four specific objectives of the Work Package are:

1) European Schools of Screening Management – Training course (led by the Finnish Cancer Registry / International Agency for Research on Cancer)

2) Identifying inequalities in cancer screening programmes – Literature Study (led by Institute for Public Health - Valencia)

3) Define regional good practices and lessons learned for implementation of cancer screening programmes as recommended by the Council of the EU 2003 – Regional Workshops (led by EUREGHA consortium)

4) Development of pan-European consensus on quality criteria for health checks (led by NEN, Netherlands Standards Organisation)

Within specific objective 3, this workshop will be one of three that, in line with the Recommendation of the Council of the EU 2003 focus on the cancer screening programmes for colorectal, cervical, and breast cancers. Each workshop will focus on: screening methodologies; data collection; barriers and potential improvements for effective cancer screening programmes.

The initial findings of the three workshops will be presented at the EPAAC Open Forum in Slovenia during 2013. The final EPAAC Open Forum conference will be on 26-27 November 2013 in Ljubljana, Slovenia. The focus will be on Screening/Early Diagnosis and National Cancer Plans. The day before, the current consortium NEEP...
VAZG, UA and Veneto Oncology Institute will organise a 4th workshop prior to the Open Forum.

**Keynote on the “state-of-the-art of breast cancer screening programmes in Europe”**

*Dr Livia Giordano from the Unit of Epidemiology, CPO Piemonte, Italy and member of the Euroscreen Working Group.*

Livia Giordano provided an overview of the state-of-the-art of breast cancer screening in Europe. Data collection is a complex and long process, and an updated survey is underway. She compared data published in 2007 and in 2012, pointing to a higher coverage of target population and a higher number of countries where a population-based nationwide programme is now established. Some details on the Italian situation as well as considerations on age and screening intervals, technical aspects of mammography (double reading, one-to-two-view, digital), coverage, information, data reporting and quality assurance were presented.

**Keynote on “How to keep a balance between a good participation-rate on the one hand and providing information about risks and benefits on the other hand?”**

*Professor John Dewar, consultant and honorary Professor of Clinical Oncology and member of the Independent UK Panel on Breast Cancer Screening*

John Dewar presented the assessment performed by an independent UK panel on benefits and harms associated with breast cancer screening in UK. This panel was chaired by Sir Michael Marmot who has a vast experience in the field of tackling health inequalities and working with WHO on the social determinants.

A meta-analysis of studies on breast cancer mortality showed that mortality started to decrease earlier than screening initiation and absolute benefit of screening in UK can be estimated in 1300 breast cancer deaths prevented per year.

He then presented the problem of overdiagnosis, defined as the detection of cancers on screening that would not have been found in the woman’s lifetime were it not for the screening test; it is very difficult to assess, its estimates vary widely according to used calculations. Other harms derived by screening are false positive tests (that eventually prompt unnecessary biopsies) and psychological effects.

The panel’s main conclusions were in favour of screening, which should continue and should inform the women invited for screening on the balance of benefits and harms.
Welcome to Flanders and Brussels

Jo Vandeurzen, Flanders Minister of Wellbeing, Public Health and Family

Minister Jo Vandeurzen highlighted the importance of the cooperation within EPAAC. Flanders is taking steps to set the establishment of cancer screening programmes as a health goal. This goal will be endorsed at the end of the 2013 by a multi-stakeholder health conference. He stressed, therefore, the importance of the three workshops to set the Flanders policy development on this issue in a broader, international frame.

For the past ten years, Flanders has had in place an organised screening programme on BC. Since January 2013, a programme for cervical cancer screening has begun, with a focus on women who did not have a pap smear via the opportunistic screening process. From 1st October 2013, a phased implementation was introduced for colorectal screening.

Comparison with previous workshops: update on the working with ‘key-questions instead of a survey

Prof. Guido Van Hal, University of Antwerp

Before starting the different breaking out sessions, Guido Van Hal explained the difference in methodology to set up this workshop compared to the two previous workshops. Gradually, the size of the surveys has been decreased. Even with a smaller survey to initiate the second workshop in Padova, the response rate was rather small and not comprehensive. The consortium therefore decided to build the discussion theses of the breakout sessions from the key questions that were provided earlier this year by expert views.

The outline and results are included in the annexes. The survey will remain part of the methodology of the EPAAC and consideration is given to include the survey as a tool for the countries, regions to be used internally and present it as an outcome of the project.

Session Two

Breakout sessions

Following Session One of the first day of the workshop, three breakout sessions were held over two iterations, totalling 50 minutes each time. This method allowed delegates to attend two of the three breakout sessions, before returning to Plenary for feedback on the breakout sessions. Each breakout session was instructed to deliver one key question for discussion during the final session of day 2, plus one key
message for competent authorities seeking to implement or improve the implementation of population-based programme.

The breakout sessions were, as follows:

A. From spontaneous to organised screening
B. How to assure the quality of the mammography production and reading process chain?
C. Tailored programmes and referral strategies

A. From spontaneous to organised screening

Based on the German experience, this breakout discussed the crucial steps to set up a programme. Vanessa Kääb-Sanyal explained that Germany introduced in 2002 a nationwide programme based on the 3rd edition of the EU Guidelines. The implementation of the programme is organised with the different Länder (regions). Issues of organisation nationwide were discussed, as well as the challenges of moving from opportunistic to organised screening, such as the registration, political changes, professional resistance to overcome and how to encourage specialists to participate in the screening chain process, message to the women to counter common misunderstandings that more screening means better care, the roll-out phases or the piloting take time which makes effective communication on the benefits and higher quality difficult, no guidelines on steps to make the move, start with an efficient data management that can stand through the first implementation, laws are important to link cancer registries with data from population registers, difficulties of quality control management and the need for quality standards.

B. How to assure the quality of the mammography production and reading process chain?

Chris de Wolf illustrated the technical, radiographical and radiological aspects of mammography and how they can be used for quality assurance. Image quality is dependent on dose and detector: a high signal-to-noise ratio is necessary, and referred that in UK a list of machines fulfilling the required standards has been made available.

He then illustrated a 4-level scoring system (named PGMI) developed in Switzerland to monitor and evaluate the performance of the radiographers. In reference to the recommendations reported in the European guidelines on the minimum numbers of tests performed/read by the operators, he stressed the difficulty in fulfilling the recommendations that occurs in some programmes and showed a few examples to comment on the recommendations.
Since the quality of the mammogram is the result of sensitivity and specificity of the test and competence of the operators involved in performing and reading the mammograms, and competence is a dynamic process, he underlined the importance to feed-back the quality indicators to the operators and use them to improve their competence.

The key questions focused on quality indication and evaluation and how to make use of the quality results on a personal level: time-frame for improvement, activity done outside of the screening programme, and actions to take in cases of unacceptable performances.

C. Tailored programmes and referral strategies

Joost Weyler presented his view on timely screening versus early diagnosis and a population versus the individual based starting point: we need to reach those people in the target group who have a need for a diagnosis. Timely diagnose is essential, the early screening, therefore, should be delayed as long as possible to avoid that lesions would be identified who would never grow into a cancer. This way, will only push a person in a medical situation combined with unnecessary stress.

Better risk stratification is essential, starting from an individualised and therefore tailored risk calculation for cancer. Currently, the target groups are particularly identified on basis of gender and age. His point is that the selection and invitation should become even more tailored on the individual.

The current trend to increase the target group is not the most appropriate according to him: we should reduce the target group, based on the knowledge of risk factors, e.g. a screening interval should not be similar for everyone, according to the slow or faster growing nature of the cancer.

In conclusion, tailor-made should concern the individual, which highlights even more the issue of the invitation, to whom, how many, and the referral strategies and different models applied.

Feedback of the Breakout Sessions

Following the two iterations of the breakout sessions, one facilitator from each session presented an overview of the discussions that had taken place.

From Session A, Mateja Krajc underlined the difficulty to move from spontaneous to organised screening keeping up the momentum to motivate professionals and the population about the benefit of organised screening. A rollout programme takes time, four years in the case of Germany, and the main challenge during that time was how to communicate to the non-rolled-out population during that process since the change cannot be introduced across the whole population at once (key question).
The key message was that the European level can facilitate the process by providing guidance on the importance and the different steps that are required, learn from others is key as well.

From **Session B**, Catherina Behmer reported on the aspects related to the quality of the mammographic and reading process, such as the quality control, the mammographers and radiologists.

Key question is if 5000 mammograms per year, or if a qualitative measure show good practice and increase the specificity and sensitivity of the reading. The session discussed that the European guidelines’ quantitative numbers are good quality indicators. However, they are unlikely to be achievable in many areas. Although countries refer to the guidelines, they cannot fully comply.

Key message is that quality is a continuous issue of improvement. Reference centres could be recommended that cover quality, research minimal criteria. Those reference centres should be encouraged by the European level.

From **Session C**, Leo Van Rossum underlined that tailored programmes should challenge population screening with a focus at the individual level, which makes the discussion all the more difficult taking into account the referral strategies, the models to be used and the cut-off point for invitations. Often, discussions need to reiterate that the goal is to prevent and reduce morbidity and mortality.

Key question is how to collect the appropriate evidence required to put this approach into practice.

Key question is also on how to communicate the message that not all women needs screening and if it’s ethically acceptable to include lifestyle aspects as a risk factor for developing cancer.

The message of the session is that there is room for improvement, for example, use breast density after a first mammogram as a factor to determine the interval for the next mammography. Collecting the evidence (extensive population screening, investigation on cost-efficacy all of this fitting in a regular screening programme) should be coordinated at European level and trials that are in place need to coordinate their outcomes.

Each facilitator noted how both iterations approached the topic of discussion in a different manner, which led to a richer and more complex set of messages as an outcome.
DAY 2 – Tuesday 4 June 2013

Session Three

Welcome: Reflection on Day One and Introduction to Day Two

Day 2 was opened by the Chair for the second day Florian Nicula, Institute of Oncology, Romania, who provided a brief overview of the previous day.

Keynote 1. Evaluating the impact of a population based screening, in particular breast cancer screening

*Tytti Sarkeala, Finnish Cancer Registry, Helsinki, Finland*

Tytti Sarkeala presented how complex evaluating the impact of population based screening, focussing, in particular on breast cancer.

Evaluation of a population-based (breast) cancer screening is complex. The effectiveness of main evaluation criterion is affected by process and validity indicators, by the risk of overdiagnosis and cancer management.

Tytti Sarkeala went over different ways of studies to evaluate the impact, such as cohort studies, trend studies and case control observational studies. Questions to consider include, why to screen, how to screen, how to evaluate the most common cancer and cause of cancer death for women worldwide, especially as mortality reduction takes many years to emerge.

If randomised trial was the best means for evaluation it was performed under optimal conditions tens of years ago. Now we require observational studies with individual data that are needed to assess routine programmes with a variation in screening policies and diagnostic and therapeutic activities.

Keynote 2. Further development of the European Guidelines on breast cancer screening and of a voluntary accreditation scheme for breast cancer services: two challenges

*Silvia Deandrea, European Commission Joint Research Centre, Ispra, Italy*

Silvia Deandrea explained that the Joint Research Centre in Ispra is currently working on the maintenance, development and harmonisation of European cancer information and is striving for a EU quality assurance scheme for accreditation.

The aim is to provide women with a high degree of confidence and assurance in processes related to all stages of cancer care, screening, diagnosis, treatment, survivorship, palliative care, recurrence.
They started updating the guidelines on screening and diagnosis. A progress survey was conducted of breast cancer services in Europe and on the use of the guidelines. What is known but cannot be followed due to practical limitations.

The methods used are bilateral meetings, expert workshop, literature review and desktop research and stakeholder meetings will follow.

**Breakout sessions**

Also on day 2 of the workshop, three breakout sessions were held over two iterations, totalling 50 minutes each time. This method allowed delegates to attend two of the three breakout sessions, before returning to Plenary for feedback on the breakout sessions.

The breakout sessions were, as follows:

- **A. Quality assessment - implementation of quality assurance in the breast cancer screening programme**
- **B. Is tailored-recruitment a solution - added value of social marketing?**
- **C. Separate trials - pilot studies implemented in national programmes and consequences for communication when divergences rise**

**Michel Candeur** illustrated the breast cancer screening programme of Wallonia (started in January 2007 and centralized in July 2008), with particular reference to quality assurance, performed at three levels: accredited mammography unit, second reading centre, breast unit. He showed that they registered low attendance rates and delays both at reading levels and for further assessment.

The discussion were on how the organization of the programme can be improved to increase quality: the invitation letter should contain a pre-defined appointment (in Wallonia the woman receives a letter but has to provide by herself for the mammogram), involvement of GPs for delivering the response and organize second level assessment appears to contribute to the delays and to the low attendance of the women to the programme.

A screening programme acquires strength and appreciation from the women (fidelity usually increases over time) by assuring the all process, with minimum requirements to invited women.

The need for feedback should be extended to the clinicians. The role of quality assurance, should be relevant for organised as well as opportunistic screening, and
should focus on bridging the gap between screening and care and treatment services for women diagnosed with breast cancer.

**B. Is tailored-recruitment a solution - added value of social marketing?**

**Bernard Van Isacker** presented tips and tricks on how to reach people through social media and Carmen Vidal presented the Catalan experience to use text messages reminders for women to attend their screening appointment. She concluded that the SMS reminders can reduce failure to attend at a reliably low cost. It could be used as an alternative approach to contact hard to reach people. Of course, this means looking into availability and technological literacy aspects especially as not all people have same level of access to social media.

Bernard Van Isacker demonstrated the added value of social media but stressed that it is important to invest in time and organisational capacity, creating a team environment that is socially minded. There is a risk of failure if an organisation has many restrictions on work computers.

A tip in relation to breast cancer screening programmes is to attract the younger people or daughters of women of age to attend. Engaging daughters and granddaughters could be a key to improving compliance through social media campaigns. There is some concern over the possible adverse effects and poor quality of the messages if the overall management and accountability process of new and social media tool is not adequate.

**C. Separate trials - pilot studies implemented in national programmes and consequences for communication when divergences rise**

**Eugenio Paci** presented data on several trials (KARMA and PROCAS) in order to show how research can impact on screening. An issue much debated in the past was density, but digital mammography is now changing it. He underlined four important topics: networking, quality harmonization, technological innovation, tailored screening.

He presented several example of trials or research studies nested within screening programmes; these included the UK age trial of screening in young women, and the current trial in the UK of the age extension to 47-73. He addressed the question of moving towards a personalised risk screening for breast cancer taking into account age, breast density, previous results and familial history, and described a study in Italy of tailored screening in premenopausal women that is also embedded in service screening. He emphasised that such studies may need only short informed consent and some extra information gathering.

Dr Paci highlighted the technological advances including automated breast density assessment and genotyping that may lead to improvements in risk prediction, and facilitate the development of personalised screening strategies. However, a major
issue currently is the appropriate communication of the benefits and harms of screening; communicating the uncertainty is difficult and frequently not appreciated by the media. Political commitment is fundamental to provide means for decreasing opportunistic screening. And in essence research should focus on how to draw people in.

Again, each breakout sessions was instructed to deliver one key question for discussion during the final session of day 2, plus one key message for competent authorities seeking to implement or improve the implementation of population-based programme.

Feedback of the Breakout Sessions

Following the two iterations of the breakout sessions, one facilitator from each session presented an overview of the discussions that had taken place.

From **Session A**, Helen Lewis Palmer reported that the audience looked into the various quality assurance measures monitored across the Belgian Walloon screening programme compared with the EU Guidelines. The definition of a high quality programme was discussed and the issue was raised of a standard minimum data set. A set of questions concerned financial mechanisms and potential role of QA ensuring that opportunistic screening services meet same standards for screening.

A question was raised on the benefit of an improved link to treatment services in opportunistic services.

The key message was that quality assurance needs to be across the whole system from invite to referral into treatment services, ensuring that quality is continuously improved by the process: this is underscored by an emphasis on things that have the greatest impact on outcomes; to set standards and measure against them as peer performance is a strong tool.

From **Session B**, Ana Molina reported that the discussion on tips and tricks for using and applying social media clearly showed that using social media means to build out a strategy that encompasses both traditional and new technological tools. In general, positive messages are more effective than negative messages.

A key question “is your team/organisation social?” was raised and discussed. This point highlights the importance of peers for spreading message, for instance, in social media the snowball effect is very important for spreading message. Therefore, be social and connect with peers.

The key message that was the importance of embedding research in screening programmes, particularly through mapping pilot trials.
From **Session C**, Sue Moss reported the discussion on the role of breast density as a risk factor, but also its impact on screening sensitivity, and on the challenges of communicating to women about their individual risk of breast cancer and the implications for screening interval.

The need to move away from opportunistic screening was discussed; it was suggested that when radiologists move from opportunistic to organised screening, it might be attractive to them if it provides the opportunity to get involved in research.

The role of both the GP and of patient organisations was seen as important in the communication process.

A key message from the session is for the need to make the infrastructure of the screening programme such that it allows research trials/studies to be embedded. At the same time, it is important to identify the appropriate research questions and not to harm the screening programme.

Two questions came across: (1) can we improve the information available about studies/trials going on in different countries? This could assist other countries in becoming involved and promote collaboration and help make the best use of available data; (2) can resources and advice be made available to help new countries that are starting screening get involved in research and perhaps promote multi-centre studies?

**Conclusions:**

An open discussion on following questions: Is the benefit/ harm equation, in breast screening, different from other accepted cancer screening programmes? How hard should we be promoting it and removing barriers to implementation?

*Dr Dan Seddon, Merseyside and Cheshire Cancer Network*

Dr Seddon presented following key messages and questions:

1. **How to communicate with those women that are not yet being offered screening?** i.e. the “why not me yet question.”

Looking into new, stronger message to say that opportunistic screening is not effective, and wastes resources, such as: Government resources, Health Insurers’ resources and Women’s resources

It’s understood that the biggest barriers to population based cancer screening implementation are: Political understanding & vision; Professional understanding and self-interest; Cultural expectations amongst women

2. **Quality of mammography reporting**
The number of mammograms screened is not adequate quality indicator: instead, there is a need for peer meetings including open discussion; double reading; and reference to outcomes.

The revision of the EU guidelines in breast cancer screening could thus pay attention to this area.

3. Tailoring

Tailoring is needed for: different densities; genetic risks; risk stratification and for different ages. The discussion has during the workshop focused on whether less but more focussed or to maintain the same level but adapt to new knowledge and approaches?

4. Screening rates and impact of high participation of opportunistic screening

The implementation of a step by step programme is likely to result in a high quality programme.

Quality assurance needs to be across the whole of the service, need to focus on the aspects that have the greatest impact. Most important is that quality assurance continually improves the quality of the service.

5. Raising awareness and communication through social media

SMS messaging: a potentially good strategy to increase participation but must be cautious with privacy issues.

A possibility could be to employ mixed-model communication strategies using social media in parallel with traditional tools, such as letters, emails etc. However, it must be borne in mind that different people use different types of communication and differing levels of proficiency, in addition to potential barriers to access must be avoided so as not to create or exacerbate inequalities.

If we want to use social media, our organisation needs to be social. However, use of social media needs time, effort and money as attempting to reach a high number of people, is resource intense.
Annex 1

Key questions good practices in breast cancer screening

European Partnership on Action Against Cancer (EPAAC): identification of good practices to organise and implement population based screening programmes for breast cancer

Background

The European Commission has established a European Partnership on Action Against Cancer (EPAAC) in order to help EU-member states to control cancer and to avoid dispersed activities and repeated work. Within this Partnership North West England (NWE), the Flemish Agency for Care and Health and the Veneto Institute of Oncology, in collaboration with the University of Antwerp, are planning a workshop in June in Brussels on the ‘identification of good practices to organise and implement population based screening programmes for breast cancer’.

The aim of the workshop is to share the knowledge gained from breast cancer screening programmes, research projects, pilot studies and preparations for breast cancer screening programme implementation on a population level, and to use this shared knowledge in the advancement of breast cancer screening. The scope of the final report will be to make recommendations on breast cancer screening for daily practice, based on experience from experts-in-the-field, and suitable for regions lacking a breast cancer screening programme as well as for regions running a programme but wanting to improve their current programme.

In order to tailor the programme for the workshop optimally, we asked experts from different countries to formulate two key questions that they believe should be dealt with into this workshop.

Response

- An e-mail was sent to 125 experts (29 December 2012)
- A reminder was sent to 107 experts (15 January 2013)
- 9 persons answered they were not actually involved in breast cancer screening. Mostly they forwarded the e-mail to the right persons.
- 16 countries out of the 26 contacted countries responded
- In total, 41 experts (or teams of experts) sent their key questions
- In total, these experts sent 85 key questions
Response: Belgium, Cyprus, Denmark, Finland, France, Hungary, Italy, Lithuania, Luxembourg, Norway, Slovenia, Spain, Sweden, Switzerland, The Netherlands, United Kingdom.

Non-response: Bulgaria, Czech Republic, Estonia, Germany, Ireland, Latvia, Malta, Portugal, Romania, Slovakia, Cyprus, Malta.

Key questions

Recruitment of the target group

- Participation rate: What are the most effective methods to increase the participation rate in general, and more specifically in hard to reach groups (for example socially disadvantaged women)?

- Tailored recruitment: Are different strategies for recruitment used for different groups in the population? Is this effective?

- New social media: How is your experience with the integration of new social media or electronic communication (like SMS and apps) in promoting the screening programme?

- Good practices to inform and communicate about the risks and benefits: Should women merely be motivated to participate and this in order to have a participation rate as high as possible, or should women be recruited based on a “decision aid” in which the pro’s and con’s are explained and guidance is provided for making a personal decision concerning participation? How do we need to help the women taking part in breast cancer screening to make an informed decision? What are the best ways (examples) in delivering clear and balanced information? Are there examples or studies on the impact of the participation in function to the information delivered?

Challenges for the breast cancer screening programme

- New technologies: Should ongoing (scientific) innovation be integrated in the population based screening programme or outside the programme in separate trials? How do we have to take into account these new technologies and how do we remain flexible?

- Opportunistic screening: What about the interference in an official breast cancer screening programme of ‘opportunistic screening’? What are (good) examples of local policies that have been introduced in order to control it?

- A tailored programme: Is it possible to develop screening programmes with tailored protocols taking into account age, breast density, previous results and familial history? Are we ready to move towards a personalised risk screening for breast cancer and if so, how do we get started?

The screening test
• Who should take the mammogram: Should the mammogram be taken by dedicated breast units, a centrally organised nationwide screening network, general hospitals, private clinics?

• Quality control of mammograms: What are good practices to assure, maintain and improve optimal radiological/radiologists performance in an organized breast cancer screening programme (sensitivity, specificity and predictive value)?

• A positive mammogram: How can we optimize the process between a positive mammogram and diagnostic verification (minimize delay without losing quality control)?

• Referral strategy: In breast cancer screening, a diagnostic characteristic (imaging of breast tissue) is transformed into a ‘screening test’. By doing this, the diagnostic potential of the characteristic is ignored and the test result is only relevant in terms of being an indicator for referral (yes/no). Would it be possible to optimize the usefulness of the programme by introducing more categories in the screening test, leading to other referral strategies (e.g. definitely breast cancer, breast cancer likely, breast cancer unlikely, no signs for breast cancer)?

**Implementation of the breast cancer screening programme**

• From spontaneous to organized screening: How to switch from individual practices (either correct or wrong) to organized collective practices?

• Efficient and effective implementation: What are indicators or criteria on efficient implementation of a breast cancer screening programme? How can the effectiveness of breast cancer screening be secured at time of implementation? What are the crucial and most important steps, a kind of Standard Operating Procedure (SOP)/guideline of sequence of “events”, that should be followed before the first invitation letter is send out in order to assure that the EU guidelines could be followed as required?

• Organizational model: Which organizational model is followed by the different European countries in the implementation of their population-based screening programmes? Is the standard model followed, with particular regard to the screening interval, target groups, screening test and the health professionals performing the test? In the Padova 2012 EPAAC cervical screening workshop we learnt that some countries with inadequate screening extension (e.g. 20%) were at the same time implementing service screening utilizing organizational models different from the standard ones (e.g. 1 year screening interval, pap smear performed by gynaecologists). Is a similar situation true for breast cancer screening?

**Evaluation of the breast cancer screening programme**
• Contribution of independent experts: Is an independent audit and quality system feasible and necessary?

• Calculation of the participation rates: Different problems arise when assessing participation rates in a breast cancer screening programme: what is the appropriate time interval to be considered between two screenings, the fact that the target population is dynamic rather than cohort, the identification of the target population (prior breast cancers to be excluded, recently examined to be excluded). How to deal with these problems in order to improve the relevance of participation rates?

• Data registration: How to ensure data registration of all aspects of the breast cancer screening programme to enable the evaluation and monitoring of the programme? How to include, besides the breast cancer screening, all other aspects of breast cancer care (diagnosis, treatment, supportive and palliative care)?

• Evaluation of the impact: To which degree does breast cancer screening reduce breast cancer mortality? And to which degree causes breast cancer screening overtreatment and over diagnosis? Is it possible to identify a balance between mortality reduction and overtreatment/over diagnosis that justifies breast cancer screening? How to include in the not only the direct impact (the mortality reduction), but also the indirect impact (quality improvement of the health assistance, the cancer treatments, the cancer research, the social perception of the disease)?

• Evaluation of the quality: How can the quality of a breast cancer screening programme be assured on a long term? What are good examples of how quality assurance (QA) activity is implemented in the breast cancer screening programme?
## Annex 2

### Delegate List

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<th>Name</th>
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<td>Els Van de Mieroop</td>
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<td>John Dewar</td>
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Helen Lewis-Parmar UK England
Sue Moss UK London
David Ritchie UK NofEngland
Wendy J Storey UK NofEngland
Annex 3

List of Posters displayed at workshop

<table>
<thead>
<tr>
<th>EXAMPLES OF GOOD PRACTICES: ABSTRACTS and Posters</th>
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<tbody>
<tr>
<td>• HELEN LEWIS-PARMAR, Quality Assurance in the NHS Breast Screening Programme (England)</td>
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<tr>
<td>• MATEJA KRAJC, Evaluation of implementation of organized mammography screening in Slovenia strictly following EU guidelines since introduction</td>
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<td>• MONTSE GARCIA, CARMEN VIDAL, NÚRIA MILÀ, LLÚCIA BENITO, GEMMABINEFA, VÍCTOR MORENO, Threats to quality assurance in a population-based screening program for breast cancer in Catalonia, Spain</td>
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<tr>
<td>• CARMEN VIDAL, MONTSE GARCIA, LLÚCIA BENITO, NÚRIA MILÀ, GEMMABINEFA, VÍCTOR MORENO, Bidirectional text short message service (SMS) reminders: are they a cost-effective strategy to improve participation in a population-based breast cancer screening programme?</td>
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<tr>
<td>• DEANDREA S; FREEMAN C; GIULIANI M; LOPEZ-ALCALDE J1; LERDA D1; NICHOLL C 1; TIDONE E; ULUTURK A Tools to assess women’s satisfaction and perception of organised breast cancer screening programmes: a systematic review (European Commission, DG Joint Research Centre (JRC))</td>
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Annex 4

List of publications

- Eugenio Paci, Summary of the evidence of breast cancer service screening outcomes in Europe and first estimate of the benefit and harm balance sheet *J Med Screen* September 2012 19: 5-13,
- Catherine Colin, MD, PhD, Florent de Vathaire, PhD, Alain Noël, PhD, Mathilde Charlot, MD, Clément Devic, BSc, Nicolas Foray, PhD, Pierre-Jean Valette, MD, PhD Updated Relevance of Mammographic Screening Modalities in Women Previously Treated with Chest Irradiation for Hodgkin Disease *Radiology*: Volume 265: Number 3—December 2012

• Catherine Colin, Anne-marie Schott, Re: Breast Tissue Composition and Susceptibility to Breast Cancer JNCI Journal of the National Cancer Institute Advance Access published November 18, 2010