Identification of good practice examples to organise and implement population-based screening programmes for colorectal cancer, cervical cancer and breast cancer by means of surveys

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Abstract

Good practices to organise and implement population-based screening programmes for colorectal cancer (CRC), cervical cancer (CC) and breast cancer (BC) were identified by means of a survey methodology. This approach aimed to share the knowledge, published as well as non-published, gained from cancer screening programmes, research projects and pilot studies on cancer screening and preparations for cancer screening programme implementation on a population level.

Surveys 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 first survey was the one on CRC screening. The principle was to ask about examples from the specific region and whether the respondents would recommend one or more examples as good practice.

The CRC questionnaire was very detailed and it took quite some time for the respondents to fill it out, especially because of many open-ended questions. Although a part of the results, more in particular the qualitative results of the answers on the open-ended questions were very interesting and useful for the CRC workshop, the analysis of the data by means of the programme QSR Nvivo 9 was very laborious. Moreover, the response on region level was 77% (20/26) but twice as many key persons (n=43) had to contacted to reach this result.

For the second survey, on CC screening, another option was chosen. To minimize the burden for the respondents and to evolve to a more efficient instrument, the length of the CC screening survey was halved compared to the CRC screening survey. 18 Out of 28 regions responded (64%).

Again, the results of this survey were partly useful for the workshop but the researchers had the impression that the information which was immediately of use, could have been gathered in a more efficient way. Therefore, the design of the third inquiry was changed completely. In an attempt to gather information which was supported by a larger group of experts, an e-mail was sent to 125 key persons whom were asked to formulate two key questions they believed should be dealt with into the workshop on BC screening. There were 85 key questions registered from 41 experts. The key questions were regrouped into five themes, which were discussed at the workshop.

General conclusion: the identification of good practice examples to organise and implement population-based screening programmes for CRC, CC and BC showed to be possible by means of workshops based on survey results. However, there are some points of particular interest. First of all, it must be taken into account that different countries and sometimes even different regions, have their own specific health care systems, cultural norms, financial prospects and so on, which make it not always easy or even impossible to adapt good practice examples as such from one country or region to another. Secondly, it seemed possible to gather interesting and useful information by asking experts to formulate two key questions, without asking them to fill out a voluminous questionnaire. On the other hand, the surveys on CRC and CC screening yielded a wealth of information which was not directly useful for the workshops but can be used as materials to fine-tune cancer screening programmes in the future. The filling out of the surveys has in several regions also resulted in a thorough consideration of their screening programme(s), something time is otherwise often lacking for.
Acknowledgements

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A special thank you is also made to those who participated actively in the development and implementation of the three regional workshops, in particular, dr. Leo van Rossum, Dr Florian Nicula, Dr Michel Candeur, Dr Josep Espinas, and Dr Helen Lewis-Parmar.

Finally, the authors wish to thank work package co-leaders Ahti Anttila and Lawrence von Karsa, and the complete EPAAC project team at the National Institute of Public Health in Slovenia.
1. INTRODUCTION AND AIM OF THE STUDY

At the end of 2009, 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.

Under the umbrella of the European Regional and Local Health Authorities (EUREGHA) association, the regions of Flanders, North of England and Veneto co-ordinated 3 workshops aimed at facilitating expert advice for competent authorities seeking to implement or improve a population-based cancer screening programme for colorectal cancer (CRC), cervical cancer (CC) and breast cancer (BC), in line with the EU Council Recommendation of 2003.

Within this partnership the University of Antwerp, in collaboration with North West of England Cancer Networks, the Flemish Agency for Care and Health, the Veneto Oncology Institute, and the European Regional and Local Health Authorities (EUREGHA), designed a survey methodology on the ‘identification of good practices to organise and implement population based screening programmes for colorectal cancer (CRC)’ to be followed by a similar survey ‘identification of good practices to organise and implement population based screening programmes for cervical cancer (CC)’. Finally, a third process was completed by which key questions regarding the implementation and improvement of population-based breast cancer screening programmes were identified via contacting 125 experts in the field.

The aim of the study is to share knowledge, published as well as non-published, gained from the three cancer screening programmes, research projects and pilot studies on CRC, CC and BC screening and preparations for programme implementation on a population level and to use this shared knowledge in the advancement of population-based cancer screening.

Following the official kick-off meeting of the EPAAC Joint Action in March 2011, an initial questionnaire 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 workshops and disseminate information on this process. 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.

2. METHODS

2.1. FRAMEWORK, PARTNERS AND EXTERNAL EXPERTS

The survey was situated within work package 6, objective 3 within the EPAAC project. Overall actions for objective 3 were aimed at facilitating expert advice to regions seeking to implement or improve cancer screening programmes as recommended by the Council of the EU. This was assessed firstly by three workshops organized by EUREGHA composed of the North West England Health Brussels Office

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(later re-named the North of England EU Health Partnership - NEEHP), the Flemish Agency for Care and Health (Vlaams Agentschap Zorg en Gezondheid – VAZG) and the Veneto Oncology Institute. The workshops focussed on screening results; methodology; obstacles, improvement in colorectal, breast and cervical cancer screening programmes with the purpose of identifying how best to improve the implementation of existing programmes and to address setting up programmes. The workshops were hosted by one of the three regions each time. The participants were mainly the experts of national and regional population based cancer programmes. The content focussed on examples for best practices for screening, raising awareness and the obstacles of implementation. Secondly, EUREGHA had set up a working group on cancer in order to support the Joint Action but also to create synergies and exchange information on the work of the partnership. Membership of the working group is based on expressions of interest, according to call for interest drafted by EUREGHA. The working group aimed to broaden the cooperation with and amongst the members and is likely to meet at least once a year with its experts. Thirdly the progress of the workshops were described in a report. The regions, i.e. North West of England, Flanders and Veneto, were participants at each of the workshops and subsequently responsible for the drafting of reports.

The partners involved (forming the coordinating group) are Northwest England Health Office, VAZG and the Veneto Oncology Institute. The North West Health Brussels Office (NWHBO), an initiative by the North West Regional European Health Group, opened in Brussels on 1 May 2004. The purpose of the office is to increase the capacity of the regional health economy to lever health, economic, social and environmental benefits from European agencies and institutions. The NWHBO is accountable to a Steering Group consisting of local and regional health sector stakeholders from the North West of England. The work of the NWHBO is divided into two areas: Public Health issues, and NHS-affecting policy. NWHBO was represented by Dr. Rona Cruickshank, from Greater Manchester & Cheshire Cancer Network, and Paul Mackenzie, from Merseyside & Cheshire Cancer Network.

The Flemish Agency for Care and Health develops and implements the health policy of the Flemish community. It is part of the Flemish Ministry for Welfare, Public Health and Family. Flanders has full responsibility for the preventive health policy, including policy on healthy life-style and screening. Pieter Vandenbulcke and Karen Colaert represent the Flemish Agency for Care and Health.

The IRCCS Istituto Oncologico Veneto (Veneto Oncology Institute - IOV) was established by the Veneto Regional Government in December 2005, after obtaining recognition of its scientific character from the Italian Health Ministry. The Institute has a juridical personality, and it is subordinated to both Veneto Regional Authorities and the Ministry of Health. The IOV is the only Cancer Centre in the Veneto region; it participates in the Italian network of Cancer Institutes (Alliance Against Cancer), which includes 11 Italian Cancer Centres and is coordinated by the Istituto Superiore di Sanità in Rome. Moreover, the IOV is a true Comprehensive Cancer Centre, since it integrates in its mission clinical activity, research and education: the IOV offers in fact preventive, curative and palliative services to the population, and it combines this fundamental mission with a steady research activity on several different aspects of cancer, as well as with a special commitment to educational issues, in strict collaboration with the Faculty of Medicine of the Padova University. Dr. Annarosa Del Mistro and Manuela Mtanis represent IRCCS.

EUREGHA is a network of regional and local health authorities. It has more or less 110 regions included in its broad platform. The main purpose of EUREGHA is to strengthen synergies between the European regions and local authorities in their health policy making. EUREGHA therefore, works through working groups on specific themes; invites experts to exchange ideas and aims bringing both the European arena and the expertise at the regional and local level closer. EUREGHA is represented in EPAAC by Solveig Wallyn and David Ritchie.

The Centre for Cancer Prevention (CCP) of the University of Antwerp (UA) was called in and financed by the VAZG for expert advice. The Centre for Cancer Prevention of the UA is embedded in the Department of Epidemiology and Social Medicine that has gained great expertise concerning the research-field of organisation of preventive health care. They were actively involved in the preparatory research projects that resulted in the ‘Multi-centre study’. This study laid the foundation for the policy decisions that have led to the official Flemish programme for breast cancer screening. After the introduction of the official Flemish programme in 2001 the UA worked closely together with the other screening centres within the Flemish Consortium of breast cancer screening to further develop and optimize the programme. At first most attention was needed to get the organisation arranged. Soon after the start of the programme research on participation of target-group women was performed.

The Centre for Cancer Prevention of the University of Antwerp has organised cervical cancer screening from 1982 until 1994 in the province of Antwerp. Research on the participation to screening was a permanent priority. At regular times new exploration was done by means of questionnaires in the target group. In January 2008 the Centre for Cancer Prevention of the University Antwerp also started the official preparatory screening project for colorectal cancer screening commissioned by the Flemish Agency for Care and Health. Prof. dr. Guido Van Hal and dr. Sofie Van Roosbroeck represent the University of Antwerp.

2.2. SURVEY

Good practices to organise and implement population-based screening programmes for colorectal, breast and cervical cancer were identified by means of three separate surveys preceding the workshops: one for each of the three cancer screening types. These surveys were sent to leading screening programme managers or principal investigators in regions and countries seeking to implement a new screening programme. Subsequently, the survey results were discussed in-depth during workshops with key persons from screening programmes in several European regions, both from the management level as from the policy level, to provide an extra dimension of interpretation.

2.2.1. METHODOLOGY SURVEYS

At the outset of this process, the intention was for three separate surveys to be developed; one for each of the three cancer screening types i.e. colorectal, cervical and breast cancer screening.

A literature search was performed to select the important items to be incorporated into the survey. In the international literature, a search for information concerning practices for cancer screening was
performed using PubMed (PM). When searching for criteria for good practices to organise and implement population-based screening programmes for colorectal cancer, the PM database was consulted using the following search terms: (“colorectal” or “colon” or “bowel”) and (“cancer”) and (“screening” or “prevent* or detect*) and (“population-based” or “community” or “program” or “strategy* or campaign or intervention*) and (“practice*” or “barrier*” or access or response* or compliance* or attend* or uptake). A similar search term was employed for the literature search on breast and cervical cancer screening. The search was restricted to English language articles that were published within the last ten years. Studies targeting patients in clinical settings were excluded. Next, titles and abstracts of studies identified via the search, were reviewed. The primary outcome of interest were topics for the survey.

In addition, hand searching of journals, reports, HiT’s (Health system reviews – Health Systems in Transition (HiT) of the European Observatory on Health Systems and Policies (www.euro.who.int/observatory)) and non-published material was conducted to identify additional studies on cancer screening.

As a result of thorough discussion over a preliminary topic list by all partners involved, the survey contained topics like: inequalities in screening, informing the target group and public awareness, public understanding of screening, informed consent, invitation strategy for a screening programme, the screening test used, how communicating on the screening test results, participation, non-participation and compliance in screening programmes, screening behaviour, data collection, interventions needed to reduce inequalities in participation to screening programmes, guideline compliance, how switching from guaiac to iFOBT in CRC screening, involvement of health professionals, impact of incentives, organization and resources, description of the respondent’s function or position, … The principle of the survey was to ask about examples from the region, and to ask whether the respondents would recommend the(se) example(s) as good practice.

Three screening experts were asked to review the survey on CRC to ensure that all relevant aspects were covered (content validity). This pre-testing was performed to be sure that the questions were clear and unambiguous. The survey was adjusted based on the comments of these experts. The three selected experts for the CRC survey were Manuel Zorzi from the Venetian Tumor Registry, Padova, Italy, Ms TJ Day, Access Manager at NHS Cancer Screening Programmes, UK, and Marjoke Van der Burg from the Centre for Cancer Prevention, Antwerp University, Belgium.

According to the experiences with this survey methodology during the first workshop on CRC screening, some adaptations were made.

The CRC questionnaire was very detailed and it took quite some time for the respondents to fill it out, especially because of the many open-ended questions. Although a part of the results, more in particular the qualitative results of the answers on the open-ended questions were very interesting and useful for the CRC workshop, the analysis of the data by means of the programme QSR Nvivo 9 was very laborious. Moreover, the response on region level was 77% (20/26) but twice as many key persons (n=43) had to be contacted to reach this result.

Therefore, another option was chosen for the survey methodology for the second workshop on CC screening. To minimize the burden for the respondents and to evolve to a more efficient instrument, the length of the CC screening survey was halved compared to the CRC screening survey. As with the
CRC survey, a pre-test was undertaken for the CC survey by Dr. Anna Iossa (Insituto di Prevenzione Oncologica, Firenze), Yvonne Brown (Project Manager NW) and Dr. Helen Lewis-Parmar (Consultant in Public Health and leads NHS Cervical Screening for HEYWOOD, MIDDLETON AND ROCHDALE PCT: now Public Health England, Cheshire Centre). In total, 18 out of 28 regions responded (64%).

Again, the results of this survey were partly useful for the workshop but the researchers had the impression that the information which was immediately of use, could have been gathered in a more efficient way. Therefore, the design of the third inquiry was changed completely. In an attempt to gather information which was supported by a larger group of experts, an e-mail was sent to 125 key persons whom were asked to formulate two key questions they believed should be dealt with into the workshop. There were 85 key questions registered from 41 experts. The key questions were regrouped into five themes, which were discussed at the workshop.

2.2.2. METHODOLOGY USED FOR SELECTING RESPONDENTS

Respondents for the CRC screening survey were leading screening programme managers, experts-in-the-field, from 20 different European regions, evenly spread throughout the EU. The main selection criterion was that the region needed to have some kind of experience with colorectal cancer screening, whether as a population-based programme, as a pilot or feasibility study for a screening programme, as a research project or trial, or as opportunistic screening. Regions without any colorectal cancer screening activity were excluded, since it would demand a different type of questionnaire.

Out of the results from the EUREGHA questionnaire, a selection of 20 European countries or regions, where respectively breast, cervical or colorectal cancer screening programmes were implemented, was made to include in the study. The Euregha questionnaire mapped the regions and local authorities competent in cancer issues and identified their priorities and areas of expertise for all types of cancer. A different selection was made for every survey, i.e. for every type of cancer screening.

The selection of a region was performed on the basis of successful and unsuccessful experiences. In other words, we selected the extremes, since these can give us a clearer view on which criteria for good practice have to be included or excluded when organising or implementing a screening programme for breast, cervical or colorectal cancer.

As examples of ‘successful’ screening programmes, we can think of programmes with a high quality assurance, systematic evaluation of the programme and a high participation rate of the target population. Some examples of countries/regions with successful cancer screening programmes are The Netherlands (breast cancer screening), UK (cervical cancer screening, breast cancer screening), Iceland (cervical cancer screening) and Scotland (colorectal cancer screening).

Some examples of countries/regions with ‘unsuccessful’ screening programmes are Wallonia (colorectal cancer and breast cancer - very low participation), Flanders (breast cancer – low participation) and Italy (colorectal cancer, in certain regions).

Next, health authorities in the selected region or country identified an expert at the level of implementation and management of a screening programme. This was performed for colorectal, cervical and breast cancer screening programmes. The survey was sent by e-mail. A reminder was sent
when there was no response after three weeks. Survey data were collected gradually. If necessary, reminders were sent more than once to non-respondents and/or respondents were contacted by e-mail or telephone to complete surveys and to minimize as much as possible missing data.

### 2.2.3. SURVEY ANALYSIS

Analysis of the CRC and CC screening surveys was performed using Nvivo 9 software to identify good practices examples to organise and implement population-based screening programmes for colorectal cancer (CRC) and cervical cancer (CC), respectively. Nvivo 9 is a software programme to analyse qualitative data; in this case the answers on open-ended questions. All these answers were transcribed to make it possible to use the software programme. Then, all the material was coded isolating essential remarks, considerations and suggestions for cancer screening programme implementation. Through an iterative process of constant comparison and reflection we obtained a frame of codes, giving insight in good and bad practice examples for implementation. Results of the analysis were presented along with relevant citations from the survey transcript in order to exemplify.

The analysis of the BC screening questionnaire was completely different from the CRC and CC screening questionnaires. Since the respondents of the BC screening questionnaire were only asked to formulate two key questions they believed should be dealt with into the workshop, this methodology cannot be compared with the one of the two other surveys. ‘Relevant quotes’ are not at stake with this way of gathering data. The key questions were regrouped into five themes, which were discussed at the workshop. The five themes were the following: recruitment of the target group, challenges for the BC screening programme, the screening test, implementation of the BC screening programme and evaluation of the BC screening programme.

Despite this analytical method, a potential weakness of this approach is the personal perceptions of those who summarise the analysis. However, this is rather inevitable with such an extent of questions, in addition to the great diversity between different programmes in Europe.

### 2.2.4. METHODOLOGY USED FOR WORKSHOPS

The workshops were planned in March 2012, October 2012, and June 2013 on colorectal, cervical and breast cancer screening, respectively. Northwest England hosted the first workshop on CRC screening, Veneto hosted the second workshop on cervical cancer, and VAZG hosted the third and final workshop on breast cancer.

Every workshop included key speakers and poster sessions on several main topics of the survey. The results of the survey were brought up to raise discussion with field experts and policy makers to obtain a profound interpretation of the survey results. By involving the field experts, especially in these workshops, this part of the project proposal became also attractive for them. The advantage for them is that they can learn from each other and that they can improve the screening programmes in their country or region.
Using the pool of respondents from both the EUREGHA questionnaire and University of Antwerp survey, 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.

During each workshop, breakout sessions were organized. Each breakout session was repeated twice, so that everyone could attend the breakout session of his or her choice, allowed the participants to discuss in more detail and in small groups, some specific themes. Each theme was introduced by a short presentation of an expert with concrete experience in the theme which was discussed.

During the Open Forum in November 2013 hosted by Slovenia the final results and impressions of the process were presented in the Open Forum Plenary.

### 3. RESULTS

#### 3.1. SURVEY COLORECTAL CANCER SCREENING

##### 3.1.1. SELECTED COUNTRIES OR REGIONS FOR CRC SURVEY

Twenty-seven selections were made. The selected regions are presented below, along with a concise description of the selection criteria at the time of the survey:

- **Finland**: Population-based screening programme since September 2004 with FOBT (guaiac by Hemoccult) and follow up colonoscopy. Gradual invitation expansion. Target group is men and women aged 60-69 years old. Personal invitation letter incl. test-kit, three samples, return prepaid envelope. All results were mailed; if positive, also contact details for follow up and direct mail to centre that arranges colonoscopy. 71% participation, 90% colonoscopy compliance (1-3). Greatly de-centralised health care system leading to variety of local contexts (4).

- **UK – England**: Screening programme since July 2006. FOBT, men and women 60-69 years. Invitation letter only, if participation then one week later a test kit will be sent. Results within two weeks, follow up colonoscopy. Reminder within 28 days. Participation after first round was 59%, after second round 52% (5, 6). In the UK - England, there was also a RCT with gFOBT (7, 8).

- **UK – Scotland**: Screening programme since June 2007. FOBT, men and women 50-74 years, home FOBT kits, direct referral for test positives. Manual available. Janice Birrell, Programme Manager, and Tracey Curtis, Assistant Programme Manager (9-12). Attendance in the first, second and third round were 55%, 53% and 55% respectively (13).

- **France**: National programme with biennial gFOBT and follow-up colonoscopy for positive screens, mailed invitations, two recalls for non-responders, in 50 to 74 year-olds (7, 14, and
Since the end of 2009, all French territories, except one overseas department, is covered. Persons need to consult their general practitioner, who in turn will provide the FOBT (16). In 2006, 23 districts were included and they reached a participation rate of 42% and 86% colonoscopy attendance in the positive screens (16). The pilot for the national programme was set up in 2002 (11, 16, 17). A trial study compared gFOBT and iFOBT in 50 to 74 year-olds in Normandy (18).

- Czech Republic: Very high incidence in renal and colorectal carcinoma (10, 19). Non population-based national CRC programme since 2001 in persons aged 50 years and older, gFOBT (Hemoccult) kits provided by GPs every two years, gFOBT analysis performed by GP (9, 11, 14, 20, 21). Attendance rate of about 20%, waiting times for colonoscopy for positive screens did not exceed three weeks, and 10 to 20% refused follow-up colonoscopy (21).

- Italy – Turin: Pilot project in 1999 and research project in 2003 with flexible sigmoidoscopy, FOBT and total colonoscopy in 55-64 year-olds (9, 11, and 20). Attendance in the FOBT group was higher (27%) than in the colonoscopy group (10%) (22). A sigmoidoscopy was found to be an acceptable and safe screening strategy for colorectal cancer (23). A trial study comparing different invitation strategies for CRC screening showed that the involvement of the general practitioner was a strong predictor for participation (24).

- Italy – Veneto: Regional programme since 2002 with FOBT, 50-69, funded by local government (25, 26), with an attendance rate of 64% and 63% in 2007 and 2008, respectively. One local programme (Verona), funded by local government, use a flexible sigmoidoscopy once in a lifetime (age 60), followed by FOBT for non-respondents (11, 25, 26).

- Italy – Tuscany: Programme since 2000 with FOBT, 50-70, funded by local government (11). Several Italian regions were selected, since attendance rates show large differences among regions, with 10% of programmes reporting rates lower than 10%. Overall attendance rate in all Italian regions was 46.3% in 2007 and 48% in 2008. Majority of the programmes use FOBT, some use a flexible sigmoidoscopy once in a lifetime, and others use a combination of both (25, 26).  

- Poland: CRC screening since 2006 (7, 10). Financed by central government. Colonoscopy in persons visiting the GP (11).

- Germany: No national population-based programme, but an opportunistic screening programme. From 55 years old, free colonoscopy (9, 10, 20). Germany was the first country to offer colonoscopy nationwide as primary screening tool for CRC (27). All inhabitants with statutory health insurance, are offered a first colonoscopy from age 55 on, and a second colonoscopy after ten years or more (27).

- Belgium - Wallonia: gFOBT, regional programme. Head of the CRC screening programme is Prof. Anne Vandenbroucke (Centre for Cancer Screening in Wallonia, Centre Communautaire de Référence pour le dépistage des cancers)

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3 The statement refers to a separate Italian National Survey but is included here to provide additional information and contextualisation in response to the EPAAC CRC survey.
- Bulgaria: Award for ‘Stop and go for a check-up’ incl. CRC screening (10).

- Hungary: Very high incidence and mortality rates for CRC (19). A comprehensive strategy for early CRC prevention is present (10). Pilot study using FOBT with 2% of the population of Hungary within the age category of 50 to 74 years (9, 14, 20). Two pilot studies have been conducted in Hungary; in 1997-1998 in Budapest, and in 2003-2004 in Ajka using gFOBT and iFOBT, originally in 45 to 65-year olds, but later modified to 50 to 70-year olds (15, 28). Individuals were invited by post and positive screens were referred to colonoscopy (28). Attendance was 30-45%, and about one-third of the positive screens refused follow-up colonoscopy (29). In contrast, in 2009 Peter et al. advised colonoscopy as a tool for a national CRC screening programme in Hungary (30).

- The Netherlands: There is currently no population-based CRC screening programme (10, 31). However, there have been three population-based pilot studies assessed (32-36). The first pilot compared gFOBT and iFOBT and compliance in two regions, Amsterdam and Nijmegen (34) Attendance was 47% with gFOBT and 60% with iFOBT (34). The second pilot compared gFOBT, iFOBT and flexible sigmoidoscopy (33, 35). The third pilot tested the effect of a notification letter on the attendance rate of a CRC screening (36). Attendance was higher (64%) with notification letter than without (61%) (36). Within the second pilot, different cut-off levels for gFOBT and iFOBT and a comparison of one and two iFOBT samples were evaluated (37-39). The Netherlands are currently in the decision process for implementing a CRC screening programme (20). In contrast, a regular CRC screening for high-risk persons is present (40).

- Slovak Republic: Currently, there is a non-population-based programme using FOBT and endoscopic screening (9, 14, 20, and 41). The Slovak Republic is planning a national programme (42). High incidence and mortality rates for CRC (19).

- Cyprus: Cyprus has currently no CRC screening programme, but plans a once in a lifetime invitation to FOBT screening (9, 14, 42).

- Denmark: No population based programme available, however a RCT with gFOBT in 45 to 75-year-olds was assessed in 1985 (8, 11, 15, 43). Estimates for effectiveness of FOBT screening were 18% (7, 43). Denmark is currently in the decision process for implementing a CRC screening programme (20).

- Spain: No population based programme available, however a feasibility study with biennial FOBT in 50 to 69 year olds was assessed in 2005-2008 in three health departments (20, 44). Attendance rate was 35.7% for the first round (44). Another feasibility study from 2000 resulted in 17% participation when individuals had to request a gFOBT after receiving an invitation letter, and 22% when the gFOBT was directly mailed (45). High risk CRC screening programme (10).

- Sweden: Regional population-based programme since 2008, starting in the county of Stockholm, using FOBT in 60 to 69 year-olds (14, 15, 42). Trial study with two thousand men and women aged 59-61 years residing in the uptake areas of the University Hospitals of
Uppsala and Lund were invited for sigmoidoscopy screening. The attendance rate was 39% (46).

- Austria: Non population-based programme(14). Target group are people over 50 years of age, using an annual screening using FOBT or screening with colonoscopy every ten years or sigmoidoscopy every five years, all methods are 100% reimbursed (47). Opportunistic screening (42).

- Belgium – Flanders: A trial programme for colorectal cancer screening was set up for all average-risk persons aged 50 to 74 years in three Flemish regions with two invitation strategies. Whether a direct invitation with a letter and iFOBT were received by surface mail (mail group), or an invitation with a letter to visit the general practitioner without an iFOBT was received by surface mail (GP group). The latter group was then later provided with the sampling set by the general practitioner. A reminder letter with cross-over invitation design was sent after six weeks (31, 48). Participation rates in the mail and GP group were 64.3% and 24.8%, respectively. The overall participation rate was 44.3% (48). Leading investigator pilot screening programme is prof. dr. Guido Van Hal, Centre for Cancer Prevention, Research Group Medical Sociology and Health Policy, Department Epidemiology and Social Medicine, Faculty of Medicine, Antwerp University.

- Portugal: Takes a great interest in CRC screening (10). Is planning a regional population-based programme using FOBT (9, 14).

- Romania: Currently, there is a non-population-based programme using FOBT in 50 to 74-year-olds (9, 14, and 20).

- Greece: CRC on an opportunistic basis (49). Pilot study with a one-time FOBT screening programme in Almopea in persons over 50. Attendance was 49% (50).

- Latvia: Currently, there is a non-population-based programme using FOBT in 50 to 74-year-olds (9, 14, and 20). The programme has a 1-year interval (14).

No contact person nor a leading screening programme manager or expert-in-the-field was found for Austria and Greece with respect to CRC screening. The 27 regions which were sent a survey, are: Basque-Spain, Bulgaria, Canary Islands-Spain, Catalonia-Spain, Cyprus, Czech Republic, Denmark, England-UK, Finland, Flanders-Belgium, France, Germany, Hungary, Latvia, Murcia-Spain, Netherlands, Poland, Portugal, Romania, Scotland-UK, Slovak Republic, Sweden, Turin-Italy, Tuscany-Italy, Valencia-Spain, Veneto-Italy and Wallonia-Belgium.

3.1.2. RESPONSE CRC SURVEY

Out of the 27 regions that were sent a survey 21 regions completed and returned a survey, which corresponds with a response rate of 78%. Responding regions were Basque-Spain, Canary Islands-Spain, Catalonia-Spain, Cyprus, Czech Republic, Denmark, England-UK, Finland, Flanders-Belgium, France, Hungary, Murcia-Spain, Netherlands, Poland, Portugal, Romania, Sweden, Turin-Italy, Valencia-Spain, Veneto-Italy and Wallonia-Belgium (figure 1).
In order to attain 21 responding experts, 46 persons needed to be contacted, which corresponds with an alternative response rate of 46%. The level of involvement in CRC screening for the 21 respondents varied: on a daily basis (n=12), on a weekly basis (n=5), less than once a week, and charged with preparations for an implementation of a (pilot) programme (n=3). The survey completed by an expert that was involved in CRC screening less than once a week was excluded from the analysis.

Reasons for non-response: lack of experience (n=1), currently opportunistic screening only (n=1) or no interest (n=4). Non-responding regions were Bulgaria, Germany, Latvia, Scotland-UK, Slovak Republic and Tuscany-Italy (figure 1).

Figure 1. Response of the CRC survey.

3.1.3. CRC SURVEY RESULTS – GOOD PRACTICE EXAMPLES

Most frequently reported reasons for participation in CRC screening were: recommendation by the GP, family history, an automatic invitation from an organizing centre, that the screening is free of charge. Other reasons for participation were the understanding that screening can detect early or pre-cancer and that it can prevent personal and family suffering (awareness of the idea of prevention), and being encouraged by your partner.

Most frequently reported reasons for non-participation in CRC screening were; lack of symptoms that might indicate CRC, fear that cancer can be found and anxiety; in case of a gFOBT a complicated and unpleasant test, distaste at handling stool, and three samples. Other reported reasons for non-participation were; low priority, lack of concern, lack of GP’s recommendation and other medical problems.
With respect to which information channels should be provided to inform the target group about CRC screening several channels were proposed in the survey and respondents were asked about their level of agreement. Almost unanimously respondents agreed that a general e-mail address, a website, a free telephone number, a regional campaign and national campaign should be channels used in order to inform about a CRC screening programme. Average belief statements with a 4-point Likert scale ranging from strongly disagree (1) to strongly agree (4) were 3.2, 3.5, 3.3, 3.5 and 3.4 for the recommendation of a general e-mail address, a website, a free telephone number, a regional campaign and national campaign, respectively.

When regions currently running national, regional or pilot CRC screening programmes were asked by means of an open-ended question how the target population is informed about CRC screening (NB. this assumes that as such programmes are implementing an organised, population-based approach, by definition invitation letters will therefore be sent to individuals as a matter of course), almost all regions mention using media such as television, radio, newspapers, posters and the internet. In addition, a free, or even paid, telephone line, e-mail, information brochures, a screening webpage, a visit to the general practitioner (GP), primary health care unit, the pharmacy or a gastroenterology department, community programmes, special information sessions were mentioned. Furthermore, information channels like Twitter and Facebook, or similar internet based media, were mentioned as important channels to be used in the future (Basque – Spain, Denmark).

“By postal invitation letters, furthermore we plan reinforced additional strategies which include Primary Care Units, Pharmaceutics and City Council. The invitation letter is the key to go into CRC screening.”

(Citation from Murcia - Spain survey)

“I think that as many possibilities as possible should be used to inform people about the CRC screening programme.”

(Citation from Flanders - Belgium survey)

“I think it is needed to involve mass media and to provide new technologies like Facebook or Twitter in order to promote the compliance.”

(Citation from Basque – Spain survey)

“People are informed through media campaigns and community programmes.”

(Citation from Cyprus survey)

“The invitation letter and leaflet has basic information. The Department of Health website has additional information. All health care professionals (doctors and nurses) are informed regarding the screening. Also, community pharmacies can provide information about the screening programme.”

(Citation from Catalonia – Spain survey)
“A free telephone is useful but a non-free telephone number is useful too. National and regional campaigns would strengthen local information and would encourage people participation.”

(Citation from Veneto – Italy survey)

Many good practice examples were reported focusing on the communication of CRC screening and the health professionals involved in informing on and inviting for CRC screening.

Whatever invitation strategy is used, with or without an active role for GPs in the invitation process, the involvement of the GP remains very important for the success of a cancer screening programme (Finland, Flanders). Most respondents mention the GP’s role in follow-up. Some mention the GP’s involvement in setting up a programme and developing information material. In other regions the screening test is provided through the GP (France) or the GP focusses on sending reminders to non-participants, which increased participation with 7% (England). In this sense, the failure of a programme can also be potentially dependent upon maintaining the active role of GPs.

One respondent notes that GPs in their area are very much against screening and therefore finds their involvement rather not relevant (Sweden). Another states that a GP is not always needed at all if the system is well in place and no problems arise concerning the health of the screened individual (Finland). Active GP involvement (incl. invitation) is found in Cyprus, Czech Republic, France, Murcia, Basque, Portugal, Wallonia and Hungary. Average GP involvement is viewed in Denmark, England, Finland, Flanders, Hungary, the Netherlands, Turin, Valencia and Veneto. No GP involvement is seen in Sweden. Regardless of how much involvement is requested from GPs in the screening programme, they, and also other health workers, should be adequately informed before the start of the programme (Denmark, Flanders – Belgium).

“Due to our experience at the feasibility study it is very important to inform the GP and other health workers before the screening starts.”

(Citation from Denmark survey)

“GPs and other health professionals have to be involved in the programme from the very beginning. Only then, they will experience the programme also as their own.”

(Citation from Flanders – Belgium survey)

Next to GPs, other health workers can be involved in CRC screening. Pharmacies could be involved in providing information, delivering the screening test and collecting samples (Catalonia, Veneto). Nurses could be involved in collecting and delivering information, supporting GPs, organizing (follow-up) colonoscopy appointments (Basque – Spain, England, Cyprus, Portugal, Finland, and Murcia). Patient organisations could be used to spread information on CRC screening (Basque - Spain). Of utmost importance is to provide enough training and feedback to keep all health professionals involved well informed about the CRC screening programme and screening test results, and to organize such
trainings frequently (Wallonia, Turin, Murcia, France, England, Czech Republic, Catalonia, Cyprus). Furthermore, GPs could be invited to help developing invitation letters, information leaflets and screening procedures, etc. (Flanders). The development of this information materials should be based on studies about reasons for participation or non-participation, so that it can take the needs of the target group into account (Valencia).

“In our programme, pharmacies participate in the programme providing information or, in some areas, delivering and collecting FOBT kits. Pharmacies are identified with posters of the CRC screening programme.”

(Citation from Catalonia – Spain survey)

“The role of the nurse is also very important because the patients have sometimes a more personalised relationship to him or her and dare to ask more questions.”

(Citation from Cyprus survey)

“Yes, through patients associations like ‘ASOCIACIÓN ESPAÑOLA CONTRA EL CÁNCER’ and ‘ALIANZA CONTRA EL CÁNCER’ as an answer to the question ‘Could you provide other channels in your region that are being used to spread information on CRC screening?’

(Citation from Basque – Spain)

“To keep them informed on a regular basis regarding screening results and follow-up.”

(Citation from France Survey)

“Specific training is necessary for people involved in screening, addressing issues which are specific to this setting and emphasizing the multi-disciplinary character of this intervention.”

(Citation from Turin – Italy survey)

“Feedback is essential to increase the involvement and implication of professionals in the program. Feedback of results, especially of what each one of these specialists or health professionals contribute.”

(Citation from Valencia – Spain survey)

“GPs will accept recommendations easier when they have originated from their colleagues.”
Three more good practice examples on informing the target group about CRC screening are:

- Offering information in different languages and formats. Multilingual approaches and information in many different formats (England, Flanders).

- The inflatable colon tour that provides easy and friendly access to knowledge on CRC screening (Czech Republic, France).

- Investing in personal contact with policy makers since they are close to the inhabitants. This increases the community compliance, especially for small, rural communities (Cyprus, Flanders).

“Targeting people whose first language is not English... a video has been made of delivering the training (awareness training) to a local group of Asian men in multiple dialects. The participant responses were extremely positive...a DVD in 10 languages, British sign language and subtitles available. Some groups did not have the opportunity to access information because they could not read, could not understand the language or could not see or hear.”

(Citation from England - UK survey)

“Multilingual approaches and consistently providing several formats under legal instructions for example information must be made available in a format that enable the participant to understand the information such as DVD, easy read, leaflet... Targeting people with learning disabilities: an easy read leaflet, provided in picture and easy word format enabling people with a learning disability to understand about bowel screening easier.”

(Citation from England - UK survey)

“I think that as many possibilities as possible should be used to inform people about the CRC screening programme. In our trial programme, we had an e-mail address, a website and a free telephone number. More information can be found on the website in Dutch but with a leaflet in 13 languages and an animation on how to obtain a stool sample, also in English.”

(Citation from Flanders – Belgium survey)

“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 they offer interactive sessions in order to raise awareness on the main preventable cancers.”
More good practice examples were reported in the field of **informed consent** and **inequality** in screening:

- Participants do not need health insurance to get screening by means of colonoscopy. All citizens fulfilling the inclusion criteria are eligible (Poland).

- About 10% of the population in Portugal is not registered with a GP. Therefore a redistribution of these people among the whole of GPs was performed. This strategy enhanced adherence (Portugal).

- Cartography may help to identify local areas where more or different communication or support is needed (France).

- Some regions report that no written informed consent is required for an initial screening test like a FOBT. Obtaining and returning a sample is taken as a valid consent (Catalonia, Czech Republic, and England).

- Generally the returning of a signed informed consent form or of the obtained sample are taken as signs that the participant had understood all information, but this is no guarantee. In case of non-participants ensuring that people were being fully informed is even more difficult. Ad hoc studies to assess the comprehensibility of the information given is necessary to ensure people being fully informed (Valencia).

> “Written informed consent is obtained for colonoscopy, not for the initial screening. The return of the screening kit is taken as consent. A colonoscopy consent form is provided that patient takes home to read - they must bring it back on the day of colonoscopy appointment - Accompanied by colonoscopy investigation leaflet explaining all the associated risks of colonoscopy.”

(Citation from England - UK survey)

> “The informed consent is necessary for colonoscopy examination, not for screening itself.”

(Citation from Czech Republic survey)

In addition, we isolated **bad practice examples** for implementation and organisation of CRC screening:

- Including the GP’s signature can rise organizational complexity.
- Mass media campaigns need right timing, contents and need to be universal or should be restricted to areas where the programme is running, otherwise it might be harmful.

- The effect of mass media campaigns may drop off quickly.

- Advance notification letters and reminder letters are expensive.

- A visit to the GP to obtain the test and a follow-up colonoscopy in case of a positive test, should be free.

- Some GPs are difficult to convince about the reliability of the gFOBT.

- Using three labs for FOBT analysis created problems with ways of notification, therefore a switch to using one lab was made.

- The recommendation for CRC screening in Flanders from the Flemish Society of GPs contains messages that are not in line with the screening programme and this may cause confusion.

- A link between the screening registry, oncology registry and the health insurance database is necessary in order to optimize coverage.

- Any disagreement between national, regional or local guidelines and the procedure of the screening programme can lead to confusion.

“The signature of the invitation letter by the general practitioner, it would be desirable but rises some organizational complexity.”

(Citation from Catalonia – Spain survey)

“Whilst we mentioned that a campaign in Cheshire and Merseyside provided an increase in uptake figures this drops off quickly after the campaign finishes indicating that a more sustained approach is needed.”

(Citation from England – UK Survey)

“I do not disagree on any campaign but the timing and contents are of high importance.”

(Citation from Finland survey)

“The CRC programme is functional, the population CRC mortality is stable and the target population coverage is rising. But to decrease the mortality and to increase the coverage further, two main items need to be solved: the individual address invitation and the linkage between registries (screening registry, insurance companies’ database and oncology registry)”
"Recommendations can contain messages which are not in line with the messages of the screening programme. For instance, the recommendations of the Flemish scientific society, advised to use the gFOBT, while the screening programme used the iFOBT."

(Citation from Flanders – Belgium survey)

3.2. SURVEY CERVICAL CANCER SCREENING

3.2.1. SELECTED COUNTRIES OR REGIONS FOR CC SURVEY

For the CC survey, 28 regions were selected, encompassing 15 Member States of the EU. 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 EUREGHA questionnaire that mapped regions and their priorities and areas of expertise for cancer screening.

The Euregha questionnaire mapped regions and local authorities competent in cancer issues and identified their priorities and areas of expertise for all types of cancer. Out of the European regions that completed the Euregha questionnaire, a selection of European countries or regions was made. The main selection criterion was that the region needed to have some kind of experience with CC screening, whether as a population-based programme, as a pilot or feasibility study for a screening programme, as a research project or trail, or as an opportunistic screening. Regions without any CC screening activity were excluded, since it would demand a different type of questionnaire.

The second criterion was geographical variation, within Europe. Overall sufficient variation was included in terms of invitation methods, used screening tests, the age of the target group, years of experience in CC screening, coverage, participation rates, use of reminders, protocol for informing participants about the screening test results, the general practitioner’s role, etc. The selection was performed on the basis of successful as well as unsuccessful experiences.

Twenty eight selections were made. The selected regions are presented below, along with a concise description of the selection criteria at the time of the survey:

- Austria: Opportunistic screening (51) or regionally organised programmes (52). Regional screening started in 1970, funded by the national Health Insurance, by means of personal invitations (52). Nationwide and non-population-based screening (53).

- Belgium - Flanders: Opportunistic screening and regional organized screening with over 80% coverage together (51, 52). Flemish programme in preparation.
- Denmark: Well organized cytological screening in the Nordic countries (54). 90% coverage by organized screening, screening started in 1967, organized regionally at a county level (51, 52, 55).

- Finland: Well organized cytological screening in the Nordic countries (54). A pilot was performed in 1963 (52). One of the first national programmes was set up in Finland in the 1960s (52, 55). A randomized trial on HPV-based screening techniques was performed in Finland (56, 57).

- France: Opportunistic screening (51). Since 1990 regional programmes, by personal invitation, 22% to 69% coverage (52). Both population-based as well as non-population based screening every three years (53).

- Germany: Non-population based screening, nationwide (53). Invitation is up to the woman and reminders are sent by office staff or physicians during routine medical visits (52). Coverage by organised screening is 46% to 50% (52).

- Greece: Non-population-based, nationwide screening (53). In Ormylia, a predominantly rural area, 87% coverage, by means of personal invitation (52, 58). There are two programmes, one in Northern Greece (the Ormylia screening programme), and one in Southern Greece (the Messinia and Iliia programme), these two are the sole organised cervical cancer screening activities in Greece in the absence of a national programme (58).

- Hungary: Population-based nationwide screening from 25 to 65 years, since 2003, every three years (53, 59).

- Iceland: Well organized cytological screening in the Nordic countries (54, 55). The reduction of mortality rates were 80% since the nationwide implementation of organised screening (51).

- Ireland: In 2009, the Irish government decided to extend their pilot programme nationally (51, 52).

- Italy – Emilia-Romagna: Cytological screening is well organized in a few countries, such as the Nordic countries, the United Kingdom, the Netherlands and some parts of Italy (54). Population-based nationwide screening from 25 to 64 years, every three years. Most programmes date from 1995 (52). Currently, there are 123 local programmes in Italy (in Florence since 1980, Est. 1998, Turin 1992, Emilia-Romagna 1996) (10). Coverage by organised screening in 2009 was 80%. The ONS (National centre for screening monitoring, on behalf of the Ministry of Health) collects data for monitoring screening activity over all regional programmes (60).

- Italy – Piemonte-Turin: See criteria for Emilia-Romagna region.

- Italy – Veneto Este: See criteria for Emilia-Romagna region.
- Luxembourg: One of the first national programmes was set up in Luxembourg in the 1960s (52). National programme through GPs and gynaecologists with 38% coverage (52). Non-population-based nationwide programme (53).

- Norway: Well organized cytological screening in the Nordic countries (54, 55). In 1995 a national centralized system for cervical cancer screening was set up based on all screening activities, organized as well as opportunistic (51).

- Poland: Population-based national programme since 2007, screening interval is every three years and by means of invitation (53, 59). No pilot testing was done, and currently there’s also opportunistic screening (59).

- Portugal: Regional screening in 86 counties of the Central Region (52). Coverage by screening test is 58% (53).

- Romania: Regionally population-based pilot programme since 2002 in Cluj region, and planning of a national programme to start in 2008 (53, 59). Coverage by screening test only 10% (53).


- Spain – Basque: Regional population and non-population-based screening (53).

- Spain – Catalonia: Regional population and non-population-based screening (53).

- Spain – Castilla y León: Regional programme in Castilla y León since 1986 using personal invitation, 51% coverage by organised screening (52).

- Sweden: Well organized cytological screening in the Nordic countries (54). One of the first national programmes was set up in Sweden in the 1960s (52, 55).

- The Netherlands: Cytological screening is well organized in a few countries, such as the Nordic countries, the United Kingdom, the Netherlands and some parts of Italy (54). Population-based nationwide screening (53). A randomized trial on HPV-based screening techniques was performed in the Netherlands (57). Coverage by organised screening is 80%, including opportunistic screening, invitation occurs through personal invitation to contact the GP (52). The Dutch nationwide programme started in 1989 (51).

- UK – England: In England and Wales cervical cancer screening started in 1964 and by 1988 an 85% coverage was achieved (51). The screening is nationally organized and locally co-ordinated in eight health regions (52). Personal invitations are used. Coverage by organised screening is 84% and by opportunistic screening 4% (52).

- UK – Scotland: All the programmes are country-wide i.e., England, Wales, Scotland and NI. They will all have started the same across the UK, but there may have been some minor changes and minor differences developing between the different countries in the UK over the years as this is one of the things that has been devolved to the Scottish and Welsh Governments: a process which has been underway since 1999.

- UK – Northern Ireland: See Scotland.

3.2.2. RESPONSE FOR CC SURVEY

Overall, from the 28 regions selected to receive the survey, 18 responded (64%): Belgium, Flanders; Italy, Turin; Italy, Emilia-Romagna; Italy, Veneto (Este); France, Val de Marne; Germany, (national respondent); Hungary, (national respondent); Romania, Cluj-Napoca; Slovenia Republic, (national respondent); Spain, Catalonia; Spain, Basque region; Sweden, (national respondent); UK, England; Norway, (national respondent); UK, Northern Ireland; Greece, (national respondent); Iceland, (national respondent); Austria, Wien; Portugal, (national respondent). Respondents had to be involved in CC screening at least once a week. There were different profiles of the people responding: academics charged with preparations for an implementation of a (pilot) programme, medical staff, coordinating midwives and screening coordinators.

Figure 2: Response of the CC Survey.
3.2.3. CC SURVEY RESULTS – GOOD PRACTICE EXAMPLES

The respondents gave the following recommendations for good practice: registration of both organised as well as opportunistic screening tests, standardised approaches and protocols, pilot testing prior to implementation, no reimbursement for pap-smears taken as a health check-up, an efficient fail-safe system, continuous quality assurance, follow the EU Guidelines 2008. Examples include:

Pilot testing prior to implementation -

“It took about 10 years from starting the pilot until the programme had become national (with a full rollout throughout the country). There was a good centralised monitoring system from the onset, and the first cohort follow-up studies indicating that the programme had a big impact on cervical cancer burden became available only in mid-1970s. This indicates that implementing a successful programme even in a rather small country (Finland has approx. 5 million inhabitants) is not a rapid process.”

(Citation from Finland survey)

“Pilot experiments are necessary to improve national theoretic screening guidelines. They allow to test local feasibility of the project and detect specific women and doctors’ attitudes toward the prevention of cervical cancer.”

(Citation from France, val de marne survey)

Self-sampling -

“This could be done as a second reminder, but not as the primary invitation method. We have made several interventions on this, e.g., a randomised pilot study to improve the invitation process, provide a reminder letter for those not attended based on the primary invitation letter, and then offer self-sampling with an HPV test as a second reminder. We were able to demonstrate increase of participation rate from appr. 65% to almost 85% with those methods.”

(Citation from Finland survey)

Communication and information channels -

“A leaflet can be often useful (particularly for a new programme) even though in our country it does not really improve attendance and furthermore it is always needed that also the healthcare personnel discuss and take care that women have understood.”

(Citation from Finland survey)

Invitation and communication of results -
“A successful strategy for increasing participation was a personal reminder letter. Whereas a non-effective strategy to increase participation was via newspaper advertising.”

(Citation from Norway survey)

“We only send negative test results to participants, never positive test results. If the test result is positive the participants will receive a letter with a pre-fixed appointment time sent from the gynaecologist responsible for assessing the woman with abnormal results, and also to communicate the result to the individual woman. In the invitation letter for the appointment it is stated that “her test indicated that further assessment is needed. GPs are not involved.”

(Citation from Sweden survey)

“Regarding the use of a direct invitation; there are personal and biological reasons which might require a change of a fixed appointment. A fixed appointment system entails a huge amount of administrative effort.”

(Citation from Germany survey)

“Pre-booked appointments likely to have high non-attendance rate but need to be balanced against potential increase in coverage. Invite letters directly from GP have been shown to have high uptake. Reminders are effective in getting some women to attend.”

(Citation from England survey)

Role of health professionals -

“Good examples to educate and involve health professionals. Presentations on results from the programme in professional meetings and conferences, articles in professional magazines [importance of feedback for professionals].”

(Citation from Norway survey)

“Host an annual educational event to allow those involved to feel part of the wider programme, present local audit results etc. [importance of feedback for professionals].”

(Citation from Northern Ireland survey)

 “[In our experience] Midwifes are better in taking smears than physicians.”

(Citation from Sweden survey)
Broadening participation -

“Successful example of reaching hard to reach groups e.g. involvement of migrants. Leaflets with information translated in many different languages. Involvement of "cultural mediators" and associations.”

(Citation from Turin survey)

“In our region we actively invite to screening not only the resident women but every woman registered and assisted by public health system in our region at a certain moment. This includes temporary present women, who are often considered particularly at risk.”

(Citation from Emilia Romagna survey)

Use of local assets to promote programme -

“The following human resources were very helpful in increasing participation within the chosen remote areas: general practitioners, priests, sanitary communication agents. At the end of the religious service there is the custom to make announcement and in the pilot many women were convinced to participate to the screening programme by the priests.”

(Citation from Romania survey)

Fees and financial incentives -

“Incentives are usually related to reimbursement. We managed to turn an ineffective wild screening based activity into an organised and evaluable programme that is quality controlled. The incentives have been to demand that physicians follow guidelines and that is regulated in contracts. If they don’t obey to the guidelines that is regarded as breaking the contract.”

“Do not reimburse pap-smears taken as a health check-up. That will result in cost ineffective wild screening.”

(Citations from Sweden survey)

“When NP ZORA was introduced in 2003, the Health Insurance Institute of Slovenia declared, that each gynaecological team has to screen at least 70 % of their women, who are in the appropriate age group, every 3 years. If not, 4-8 % of all expenses covered by the insurance will not be refunded to that team. This is a negative incentive that seems to work, since most of the gynaecological team reach these 70 %.”
“Supervision on the number and way of payment of excessive smears can be performed at gynaecologist’s office by the doctors employed by the Health Insurance Institute, but there are financial consequences for the gynaecologist (or his organisation) only, if excessive smears were paid from the woman’s health insurance. If the woman paid for the excessive smear by herself, there are no consequences of any kind.”

(Citations from Slovenia survey)

“During 18 months, a fee was charged for pap-smear screening (15€). Participation decreased by 17% (mean) and by 23% in the youngest age-group. Removing the fee resulted in coming back to previous attendance rate [message is to remove barriers and fee is such barrier].”

(Citation from Sweden survey)

Some difficulties were mentioned by the respondents. Some health care professionals can have a conflict of interest (because of the recommendations starting at a higher age and with a wider interval compared to the common practice), a legal framework that is not optimal for quality assurance activities. For example:

Legal Framework: more specifically the respective laws regarding privacy / data protection -

“The legal framework (regarding confidentiality and the handling of sensitive information) is not optimal for quality assurance activities of the programme.”

(Citation from Norway survey)

“Problems when launching the programme → Privacy matters. We needed a written consent from the participating women for registration. This changed later on and this increased the response rate.”

(Citation from Flanders survey)

Potential conflict of interest -

“Conflict of interest of some professionals and perceived low incidence of cervical disease. Lack of knowledge of using cost-efficacy interventions.”

(Citation from Catalonia survey)

Another difficulty is the question about specificity versus sensitivity. The following quote illustrates this:
“Health care professionals are so focused on sensitivity of test (relevant for the patient) but don’t see the importance of specificity (relevant to the healthy group). They do not understand the difference between a screening test and a test that is taken as a health check-up.”

(Citation from Sweden survey)

Another difficulty which is mentioned, is the rising number of women per gynaecologist, illustrated by the following quote:

“Gynaecologists frequently report that they are overflowed with work and women, who have received central invitations. Women frequently report violation of maximum waiting periods for screening at their gynaecologist; women without selected gynaecologists frequently report that they have difficulties in finding a gynaecologist.”

(Citation from Slovenia survey)

Other mentioned difficulties, are, for instance the transmission of laboratory results to screening centre or over-screening. An example of the latter is given in the following quote:

“The project also confirms a high over-screening and/or screening out of recommended age groups mainly in gynaecologists who are difficult to reach for discussion as they consider to be correctly informed.”

(Citation from France survey)

Also participation is sometimes a difficult topic:

“There also remains a challenge in engaging younger women in the programme particularly those aged 25-29 years where coverage is falling.”

(Citation from England survey)

Some communication channels or tools that may have worked in other regions have not been successful in other, such as with text/SMS services:

“Use of SMS Text reminders for first invite to screening; young women low participation, high users of mobile phone technology. Project unsuccessful - governance issues, privacy concerns, lack of usable telephone number list (not recorded on primary care record, frequent changes to number). May hold future potential if these issues are resolved over time.”

(Citation from England survey)
The following key questions emerged out of the CC screening survey:

- How can EPAAC help to implement the best CC screening option at a national level? (Catalonia)

- How to change an existing decentralised CC screening and convince gynaecologists, cytopathologists and participants that a three year interval is safe and avoids over-diagnosis and overtreatment? (Germany)

- How to compare data across different screening programmes? (Greece)

- 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? (Slovenia)

- Is it time to introduce HPV self-sampling to women not attending regular screening? (Slovenia)

- What is the current evidence on offering HPV self-sampling as primary screening method? (Slovenia)

- What is the current evidence on using novel technology for triage of screen-positive women? (Slovenia)

- How to increase participation? (Hungary)

- How to improve the uptake of cervical screening in young women? (England)

- What is the best practice for the change to HPV screening as primary test? (England)

### 3.3. SURVEY BREAST CANCER SCREENING

#### 3.3.1. SELECTED COUNTRIES OR REGIONS FOR BC SURVEY

An e-mail was sent to 125 experts (29 December 2012). A reminder was sent to 107 experts (15 January 2013). Experts from the following countries were e-mailed: Belgium, Bulgaria, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Norway, Portugal, Romania, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, The Netherlands, and UK.

#### 3.3.2. RESPONSE FOR BC SURVEY

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.**
Responding countries were: Belgium, Cyprus, Denmark, Finland, France, Hungary, Italy, Lithuania, Luxembourg, Norway, Slovenia, Spain, Sweden, Switzerland, The Netherlands and United Kingdom.

Figure 3: Respondents of the BC survey.

3.3.3. BC SURVEY RESULTS – KEY QUESTIONS

In order to tailor the programme for the workshop optimally, we asked the experts to formulate two key questions that they believed should be dealt with into this workshop. In this sense, this third survey was organized in another way compared to the other ones. The result of the BC survey consisted of key questions which were regrouped in five main themes. Below, the key questions are given, according to the main themes:

**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 pros and cons 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, and 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 sent 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 breast cancer screening causes 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?

3.4. WORKSHOP ON COLORECTAL CANCER SCREENING

These were the key messages of the workshop on CRC screening:

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

- 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.

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

- 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.

Key issues raised to consider for overcoming barriers to participation in colorectal cancer screening programmes, were:

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

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

Key issues raised to consider for implementing quality using data, were:

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

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

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

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

3.5. WORKSHOP ON CERVICAL CANCER SCREENING

These were the key messages of the workshop on CC screening:

Developing 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.

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.

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.

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.

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.

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.

3.6. WORKSHOP ON BREAST CANCER SCREENING

These were the key messages of the workshop on BC screening:

- 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.

- 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.

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

- 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.

- 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.
• 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.

4. DISCUSSION

4.1. OVERALL PROCESS

The intention of this work was to identify a process whereby screening managers and competent authorities are provided an opportunity to share experiences - taking note of common challenges, barriers and tested solutions – in relation to implementing or improving new and existing cancer screening programmes. To facilitate this, initial questions amongst the coordinating group of this work were concerned with the issues of: “what constitutes best practice?” and “what data and practices are transferable policy development and implementation?”

Subsequently, it was decided to adopt a survey methodology, which would allow the comparison of regional data, determine key elements of good practice and identify gaps in knowledge and practice, etc. The coordinating group initially thought that a benchmarking system to compare regions would be needed. However, this aspiration proved to be hard to reach due to the great complexity involved in comparing the heterogeneous context of screening in the regions of Europe.

The survey, undertaken by the University of Antwerp, was designed to become the evidence basis for regions and countries to informally compare their screening programmes. In reality, and as previously mentioned, the survey was changed and adapted and should be seen as a tool for better co-operation amongst the constituent actors of a given screening programme, and less for comparing and contrasting across several regions and countries.

Surveys were designed to shape a series of interactive workshops amongst invited delegates, whom would discuss key aspects arising from the survey finding and share experiences in an open setting. This objective would have been better served had there been more time between the analysis of survey results and the planning of the subsequent workshops. As it happened, the two processes ran in parallel at certain key points meaning that workshops were partially programmed before the results of the survey could be released.

The workshops that took place in this process were used as platform for further cooperation, work and research or basis to launch policy proposals. It should be emphasised that neither the process nor the methodology have been designed as a decision making tool for professionals nor was it a forum in which scientific recommendations were to be issued.

The workshops brought together different voices and perspectives to what is usually heard on the local and regional level in addition to national and EU actors. This process has reached new participants who have not previously been involved in EU level discussion on cancer screening. Nevertheless, achieving a geographically balanced representation from across the EU and associated countries could still be improved.
The combination of survey and interactive workshops between not only direct peers but also amongst different professions (e.g. policy and practice level and on specific topics) has proven to be successful and rewarding for participants.

### 4.2. SURVEY METHODOLOGY AND FINDINGS

During the EPAAC project the surveys needed to be fine-tuned, and adjusted to the suggestions made by respondents and partners, for instance; use less questions and develop more questions of the open-type, invites less respondents and focus more on the more experienced regions. This led to a divergence in methodologies between both the CRC and CC surveys.

In addition, the response rate for the CRC survey was rather low, taking into account that survey was sent to health professionals. The length and level of detail of the survey, however, makes the format of the CRC survey open for discussion. The CRC survey was rather detailed and labour intensive to complete. Many questions remained partly or completely unanswered. Some questions were overlapping. The great variety in programmes makes the development of one survey that fits all regions complex and particularly difficult to analyse.

Despite the complexity involved, with the opportunity of the CRC workshop in Liverpool (7\(^{th}\) and 8\(^{th}\) of March 2012), it was possible to make some key observations on the survey findings. During the workshop, respondents, project partners and workshop participants were invited to the discussion. The comments given on the survey format, further illustrations on good and bad practice examples, comments on the examples, i.e. on what works, what doesn’t work, etc., were summarized into the workshop report.\(^4\)

There were many opposite opinions on the role of the GP reported in CRC screening: varying from the GP handing out the screening test in France to absolutely no involvement of the GP in Sweden. This shows that every region has its specific characteristics, some practices work well in some regions but not in others.

For the second survey - CC screening - another option was chosen for the survey method. To minimize the burden for the respondents and to evolve to a more efficient instrument, the length of the CC screening survey was halved compared to the CRC screening survey. 18 Out of 28 regions responded (64%).

The results of this survey were partly useful for the workshop (8\(^{th}\) and 9\(^{th}\) October 2012, Padova, Italy).

The design of the third inquiry was changed completely. The researchers had the impression that the information which was immediately of use, could have been gathered in a more efficient way. In an attempt to gather information which was supported by a larger group of experts, an e-mail was sent to 125 key persons whom were asked to formulate two key questions they believed should be dealt with into the workshop. There were 85 key questions registered from 41 experts. The key questions were regrouped into five themes, which were discussed at the workshop.

During the BC screening workshop (3rd and 4th June, Brussels, Belgium), participants noted that the risk and benefit discussion for breast cancer screening is becoming an increasingly more important topic and, thus, more precise and clear information is needed.

Utilising different approaches for each survey, was not an ideal situation but was nonetheless a necessary development to respond to the complexity of the situation. Both these factors render it difficult to confidently benchmark the survey respondents, which had been an initial aspiration of the process, and ultimately precludes the issuance of recommendations.

Moreover, the diversity of personal experience and the different nature and contexts of the various screening programmes across Europe presents the risk that conclusions are too subjective or may present too many discrete responses that even statistical software may only present vague conclusions. The analysis may thus be enhanced via a specific methodology to re-group and prioritise answers.

4.3. WORKSHOP ORGANISATION

Workshops are useful tool for discussing emerging findings and arriving at a consensus decision. However, the context of the EPAAC joint action the workshops could be improved by having a greater focus. For example, workshops may be enhanced by taking an issue specific focus opposed to being programme specific.

Repeating the breakout sessions gave different discussions, gave an opportunity to express own experiences because the groups are small; it provides an opportunity to enhance the discussions afterwards. However, the success depends on facilitators and the composition of the group. A positive evolution can be identified once the participants are familiarized with the concept. Many questions have been raised and it was clear that after the third workshop participants felt more than at first the need for more exchange.

4.4. ADDED VALUE

It is important to investigate the added value of this work for relevant professionals and to evaluate the impact and use of the process. Although the process is efficient at identifying common challenges and barriers for cancer screening programme implementation, it must be noted that there is a difficulty of replicating or transferring solutions across borders both within and across EU member states and associated countries.

Nevertheless, issues perceived as good practice can still be identified and, if difficulties exist with transferral or replication of such practice, then this can act as a prompt for further work or research.

The responses to the surveys and workshop participation was very much linked to the interest for and experience in a specific cancer programme. Consequently, there is a risk that the process may end in getting the ‘usual suspects’ around the table. The umbrella of pan-European working endorsed and
supported by EU resources has proved helpful in overcoming this potential pitfall but still more work needs to be done in promoting this cooperation to a wider, yet still relevant, audience.

Although some of the participating countries and regions have long-established and solid programmes, it occurred during this process that those areas with mature or advanced programmes can also learn too from peers and perhaps gain new ideas or insights from areas that have emerging programmes. Nevertheless, special work is needed for those transitioning from a situation without a specific cancer screening programme to population-based organised programme: especially in a context of entrenched opportunistic practice.

The pan-European nature of this work add a further add-value to the process as a momentum has been created whereby peers have found the opportunity to compare and discuss their common issues (such as participation rates); found insight and arguments for their own problems and identify issues that may need more European co-ordination (for example, joint programming and pooling of research on screening).

EU added-value can been discerned from the potential to use this process, in particular conversations taking place in the workshops, to provide discussions and informal feedback on the practical implementation of the respective European guidelines for cancer screening. An indicative example raised during the workshops included the desire from regional screening managers more support or guidance on communication techniques, including the use of mobile screening van, new and innovative media, etc.

Overall, evaluating the added-value of the process demonstrates the co-operation forged and sustained over the life-course of EPAAC suggests that it is worthwhile to consider continuing this process. This observation is supported by the fact that the organisation of population-based cancer screening programmes is an on-going activity and thus requires frequent and regular update of experience and knowledge relevant to implanting and improving cancer screening programmes. In this manner topics that have not yet been fully appreciated within the process (i.e. the cost-effectiveness of the screening programmes) could be addressed at a later date.

5 CONCLUSION

Based on the experience from experts-in-the-field in CRC, CC and BC screening, the surveys yielded a list of good practice examples. These examples can be used by regions lacking a screening programme as well as by regions running a screening programme but wanting to improve their current programme. Furthermore, following the survey analysis with a series of interactive workshops was a rewarding way to discuss and evaluate the findings of the survey, whilst sharing key knowledge and experience in screening programme implementation in the process.

Despite the acknowledged difficulty for confidently analysing the data gathered via the survey, it was nevertheless possible to determine key observations, such as the importance of piloting prior to implementation and the provision of continuous quality assurance.

Piloting was felt and shown to be very useful both in countries or regions intending to start a new screening programme, as well as in those implementing an existing one (i.e. when changing screening
modality). This also highlights context-specific needs and provides means to measure workloads. In addition, whilst appropriate indicators are necessary to monitor the efficacy of screening programmes, quality assurance should be viewed as a circular process. The results of the evaluation form the basis for discussing and learning among the health operators involved in the programme.

Using the survey as an impetus to bring together actors within a screening programme is a potential useful strategy. The survey itself can be used by internal partners of a screening programme as a tool to highlight gaps and acknowledge strengths of the respective programmes. The benefits of utilising the survey developed for this work as an organisational assessment tool would be further enhanced by defining subtypes of existing screening programme (like FIT or colonoscopy based, nationwide or pilot, organized, non-organized, etc.,) after defining we could use more precise and robust questionnaires and drive to better conclusions. Or at least to analyse existing survey clustering answers by type of program.

In terms of co-operation, the trans-national collaborations forged by this initiatives highlight the importance of working across multiple layers of governance and practice within and around cancer screening programmes. The sub-national perspective is of particular importance in this process due to the fact that responsibility for cancer screening can often lie with regional and local authorities in a number of EU member states. Therefore, such levels are where hands on experience provides ideas for research and feedback for decision makers. Nevertheless, even in more centralised systems, the regional and local levels are crucial for the effective implementation of quality population-based screening programmes.

One of the main values reported by participants in this process was network-building with peers across Europe for continuous exchange of knowledge and experience. This process therefore has considerable value as a mechanism for learning from peers about innovative and successful practices; understanding the barriers to implementation or weaknesses in existing programmes; and discussing the contrasting opinions on common issues.

There is a clear need to enhance the exchange of experiences and boost for the potential for supportive cooperation in the manner undertaken as part of this process. Initial ideas in this regard have included developing further a mechanism of coaching or “twinning” practitioners amongst the competent authorities across Europe. Mentoring systems could be particularly helpful in assisting with the implementation of new programmes. In general, future iterations of this process would have to take into account improved and more representative selection of participants from across EU member states and associated countries.
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