

European Science
Advisory Network for Health

Determinants for a successful implementation of population-based cancer screening programmes



Expert committee: Ahti Anttila, Finland; Magdalena Bielska - Lasota, Poland; Thomas Davidson, Sweden; Johannes JM van Delden, the Netherlands; Lawrence von Karsa, France; Elsebeth Lynge, Denmark; Sue Moss, UK; Maja Primic Žakelj, Slovenia; Leo van Rossum, the Netherlands; Nereo Segnan, Italy; Sven Törnberg, Sweden; Chris de Wolf, Switzerland

EuSANH representatives: Susanne V Allander, Sweden; Dorine Coenen, the Netherlands; Louise Gunning, the Netherlands; Monica Hultcrantz, Sweden; Måns Rosén, Sweden

September 2011



European Science Advisory Network for Health

Determinants for a successful implementation of population-based cancer screening programmes

Expert Committee: Ahti Anttila, Finland; Magdalena Bielska - Lasota, Poland; Thomas Davidson, Sweden; Johannes JM van Delden, the Netherlands; Lawrence von Karsa, France; Elsebeth Lynge, Denmark; Sue Moss, UK; Maja Primic Žakelj, Slovenia; Leo van Rossum, the Netherlands; Nereo Segnan, Italy; Sven Törnberg, Sweden; Chris de Wolf, Switzerland

EuSANH representatives: Susanne V Allander, Sweden; Dorine Coenen, the Netherlands; Louise Gunning, the Netherlands; Monica Hultcrantz, Sweden; Måns Rosén, Sweden

September 2011



Table of contents

| | | |
|---------|---|----|
| 1 | Introduction | 4 |
| 1.1 | EuSANH and EuSANH-ISA | 4 |
| 1.2 | Objective | 4 |
| 1.3 | Background | 5 |
| 2 | Framing the questions | 6 |
| 3 | Methodology | 7 |
| 3.1 | Using the EuSANH methodological framework | 7 |
| 3.2 | Using available evidence | 8 |
| 3.3 | Expert judgement | 8 |
| 3.4 | Discussion by Expert Committee | 9 |
| 3.5 | Evaluation of the advisory process | 9 |
| 3.6 | Declaration of conflict of interest | 10 |
| 4 | Advice to the Minister | 11 |
| 4.1 | Introduction | 11 |
| 4.2 | Advice | 11 |
| 4.3 | References | 12 |
| Annexes | | |
| 1. | Expert Committee | 14 |
| 2. | List of reviewers | 16 |
| 3. | A Framework for Science Advice on Health: Principles and Guidelines | 17 |
| 4. | Evaluation of the advisory process | 19 |
| 5. | Background material for the EuSANH workshop ^a | |
| 6. | Presentations at workshop ^a | |
| 7. | Draft manuscript: Determinants of a successful implementation of population-based cancer screening programmes | 21 |

^a Annexes 5 and 6 can be found at www.eusanh.eu

1 Introduction

1.1 EuSANH and EuSANH-ISA

The European Science Advisory Network for Health (EuSANH) is a network of science advisory bodies in Europe which are active in the field of health. Currently, national science advisory bodies from more than half of the European member states are represented in the formal EuSANH organisation, and more are expected to join in the near future.

Collaboration within EuSANH received a strong impulse when it received European Funding in the 7th framework programme (2009-2011) for a three-year project entitled Improving Science Advice for Health in Europe (EuSANH-ISA, agreement number 229716). Six members conducted the studies, while the others had an advisory role. During this programme, a common methodological framework for science advice, a first European science advice and a sustainable EuSANH structure have been developed. This report describes the results of the first EuSANH science advice.

For more information and detailed reports on the EuSANH-ISA studies, please visit www.eusanh.eu or contact the EuSANH coordinating secretariat Ms Dorine Coenen, d.coenen@gr.nl or eusanh@eusanh.eu.

1.2 Objective

The objective is to produce a pilot case study for a European science advisory report, thereby illustrating the common methodology developed by the EuSANH-ISA project and the functioning of the EuSANH network.

Scientific advice for health is defined as a solicited or unsolicited analysis of a defined public health, health care, or health policy problem, based on updated scientific knowledge and taking into consideration relevant expert judgment, practical experience, and ethical, cultural, and societal values and implications, with conclusions and recommendations for health policy^a.

^a Description of work: EuSANH-ISA, 10 November 2008.

The science advisory report “Determinants of a successful implementation of population based cancer screening programmes” aims to analyse the processes and procedures needed to successfully implement population-based screening programmes for cervical, breast, and colorectal cancer.

1.3 Background

Recent reports have addressed the uptake and practice of cancer screening programmes, revealing substantial variation between European countries. In 2008, the International Agency for Research on Cancer (IARC) – part of the World Health Organization – published a report on cancer screening in the European Union, indicating that considerable effort will be required in forthcoming years to overcome existing barriers against successful programme implementation. In 2009, a special issue of the European Journal of Cancer demonstrated and discussed major differences in performance and coverage of cervical cancer screening in the European Union.

The European Union has published detailed guidelines for cancer screening programmes. In December 2003, the Council of the European Union presented a recommendation on cancer screening. This recommendation stated that scientific evidence is available concerning the efficacy of screening for breast, colorectal, and cervical cancer. It also stated that ethical, legal, social, medical, organisational, and economic aspects must be considered before decisions can be made to implement screening programmes. However, the existing guidelines are not always implemented. Hence, policy makers need additional evidence and recommendations addressing critical factors for successful cancer screening.

2 Framing the questions

Questions: What are the important organisational aspects when implementing cancer screening programmes? How can barriers to participation in organised screening programmes be reduced? What advice can be given to decision makers in a European country that want to initiate or improve a cancer screening programme?

It is important that the scientific advice given is relevant for any European country, regardless of the present organisation of their health care system or if an organised cancer screening programme already exists or is being planned.

This report is intended for the Minister of health in any European country. Hence, the report focuses on general aspects and success factors that can be extrapolated from one cancer screening programme and applied to another. The aim is to help an interested region or country initiate or improve the implementation of a cancer screening programme.

3 Methodology

3.1 Using the EuSANH methodological framework

The EuSANH-ISA project has developed a handbook “A framework for science advice on health: principles and guidelines”, which includes guidelines for framing the issue and drafting the advisory report. The handbook will be reported separately. Annex 3 presents the seven consecutive steps and the ten principles in producing a science advice. An evaluation of the advisory process is presented in Annex 4.

A draft of the handbook was presented at the start of the workshop and followed when producing the pilot on scientific advice for implementing cancer screening.

The time frame for producing this pilot case study appears below. In summary, the time from formulating the question to submitting the report was 12 months.

Spring 2010

- Project planning
- Background research
- Formulating the question

Fall 2010

- Potential experts contacted
- Systematic literature search
- Writing of background material
- Detailed planning of workshop

Spring 2011

- Distribution of final programme and background material, January
- Workshop, February 7-9
- Writing draft
- Review (A list of the reviewers is presented in Annex 2)

Dissemination activities

- Deliverable to the Commission in September 2011
- Publications in scientific journals
- Presentations at national and international conferences

3.2 Using available evidence

Evidence already available in the form of national science advisory reports, systematic reviews, and EU guidelines served as a basis for producing the scientific advice. The Swedish Council on Health Technology Assessment, SBU, produced a background material for the workshop, including an overview of systematic reviews on the topic of participation rates and informed decision making, and also a literature review of organisational and health-economic aspects of cancer screening (www.eusanh.eu, Annex 5). The background document also included an introduction, focusing on the policy perspective and implementation, written by Leo van Rossum and Rosella Hermens.

3.3 Expert judgement

An Expert Committee was established, including professionals from different European countries – both old and new European Union member states. The experts are presented in Annex 1. Several of the experts have many years of experience in working with these questions on a European level and have been involved previously in writing European guidelines on cancer screening.

The areas of expertise covered by the Committee included:

- Cancer epidemiology
- Health care systems
- Implementation
- Policy barriers
- Oncology
- Health economics
- Medical ethics

The Committee added their professional experience and expert judgment to the existing evidence at a workshop in Stockholm, Sweden; February 7-9, 2011. Representatives from the European Commission, the European Cancer Patient Coalition, and WHO Europe were present as observers. The assignment was to complete the literature review (produced at SBU) by adding conclusions and recommendations.

The workshop began with scientific presentations by participants; illustrating key issues regarding cancer screening implementation in Europe (www.eusanh.eu, Annex 6). These presentations were followed by a general introduction to the purpose of the workshop, including an explanation of the principles and guidelines to enhance the quality and

efficiency of the scientific advice. The Committee was officially installed after the experts had presented potential conflicts of interest.

3.4 Discussion by Expert Committee

The Committee was divided into two working groups: one tasked with the initial assignment to complete the background document on participation rates and informed decision making, and the other tasked with discussing organisational issues.

On the first day, one of the groups concluded that organised population-based screening is a prerequisite for providing recommendations on determinants. Hence, they suggested drafting a document on the general topic “Determinants of successful implementation of population-based cancer screening programmes” with important points that should be considered when implementing a cancer screening programme. This idea was presented to the entire Expert Committee and resulted in a deeper discussion about the results. The results should not duplicate the present EC guidelines, but rather serve as a guide for policy makers in decisions regarding implementation. This draft in Annex 7 has now been finalised and is published in the *European Journal of Cancer*^a.

It was also agreed that a statement should be drafted, which should go beyond the evidence base and include the expert judgement of the Committee (“Advice to the Minister”). The experts could choose which document they preferred to work on and were again divided into two groups. By the end of the meeting, the two documents had been drafted and experts had been assigned to complete and circulate them for comments.

3.5 Evaluation of the advisory process

- The Expert Committee recognised the advantage of having received the prepared background material before the meeting and appreciated the evidence-based approach.
- The chairpersons played an important role throughout the workshop process. Because of the many different expectations on the meeting, the chairs were also needed to keep the discussion focused.
- Science advice on a European level, based on work of a European Expert Committee, has advantages, including access to the best experts at a European

^a Lyng E et al., Determinants of successful implementation of population-based cancer screening programmes, *Eur J Cancer* (2011), doi:10.1016/j.ejca.2011.06.051

level ('Golden network') and collaboration when preparing the scientific base for advisory reports.

See Annex 4 for further details and discussion on the advisory process.

3.6 Declaration of conflict of interest

All participants in the workshop in Stockholm, February 7-9, 2011, provided written statements regarding potential linkages, or conflicts of interest. Such conflicts of interest may exist if a member of the group receives financial compensation from parties who may be interested in the issues the group studies. Elsebeth Lynge is undertaking a comparative study of new-generation HPV tests, involving collaboration with Roche Diagnostics A/S, Genomica S. A. U., Qiagen Gaithersburg Ltd., and GenProbe Inc., and has served as unpaid advisor for GenProbe and Norchip. Nereo Segnan participated at an advisory board meeting for Colorectal Cancer Screening in January 2011, as a paid expert, on colorectal cancer blood screening assay, organised by the Roche Diagnostics Ltd. He received the formal permission by his employer, the S. Giovanni University Hospital of Turin.

4 Advice to the minister

4.1 Introduction

The following statement summarises key results of the Workshop (Stockholm; February 7-9, 2011) and has been finalised by Lawrence von Karsa in collaboration with Maja Primic Žakelj and Ahti Anttila. The advice addresses the Minister of health of any European country and aims to facilitate the initiation or improvement of cancer screening implementation.

4.2 Advice

Any policy decision in Europe to implement a cancer screening programme should take into account EU recommendations and guidelines based on the available evidence and the experience in Europe in implementing population-based cancer screening programmes. Key references in this regard are the Recommendation on Cancer Screening of 2 December 2003 of the Council of the European Union (1), the European Guidelines on quality assurance in breast, cervical and colorectal cancer screening (2-4) and recent reports dealing with the implementation of cancer screening programmes in the EU (5-7). These references recognize that societal values in addition to professional, technical and scientific standards are of prime importance in any decision to implement cancer screening programmes. Furthermore, the population-based approach to programme implementation as recommended by the Council of the EU and the authors and editors of the European Guidelines is more equitable, more effective and more cost-effective than an opportunistic approach. The latter usually leads to overuse of health resources by a portion of the target population with lower cancer risk, and underuse by less advantaged groups with higher cancer risk.

The experience in Europe shows that successful implementation of population-based cancer screening programmes requires long-term political commitment, a comprehensive quality management programme and sustainable resources. In a fully established programme the proportion of the expenditure devoted to quality assurance should be no less than 10-20%, depending on the scale of the programme. In the initial years, this proportion may be substantially higher due to the low volume of screening examinations compared to the situation after complete rollout of a nationwide programme.

Once the political decision has been taken to establish a population-based cancer screening programme, a competent coordinator should receive the mandate to manage the entire process of programme implementation beginning with a planning phase, and followed by feasibility testing, piloting and, depending on the interim results, subsequent gradual rollout of a programme fulfilling the principles and standards recommended in the Council Recommendation (1) and the European Guidelines (2-4) and relevant national standards and guidelines. The coordinator should be provided with sufficient organisational and financial resources to effectively manage the screening programme and take further decisions as necessary. These decisions should enable the coordinator and the coordination team to establish the screening programme in the respective health services context. Regardless of the context, the professional and organisational management of the programme must be equipped with the competence and the mandate to control the quality of the entire screening process, including information and invitation of the target population, performance of the screening test, diagnosis, therapy and subsequent care. The existing expertise in Europe in implementation of population-based cancer screening programmes should be available for exchange of information and experience, such as through the European cancer screening networks and the European Guidelines development activities coordinated by the International Agency for Research on Cancer (IARC), and related initiatives such as the European Partnership for Action Against Cancer (EPAAC, www.epaac.eu).

Additional tools and registries are necessary to adequately monitor and evaluate the quality and the outcome of the screening programme, including linkage of individual data on cancer occurrence and morbidity, screening history, diagnosis, treatment and vital statistics. Furthermore, key performance and quality indicators of the screening process must be recorded and monitored and the results must be analyzed and used for quality management processes. Monitoring and evaluation reports must be published regularly to inform the public and decision makers and to permit timely modification of programme policy, if necessary. The experience of EuSANH in developing advice for health policy making, taking into account not only scientific and professional, but also societal aspects could play an important role in this regard in the future.

References:

1. Council of the European Union (2003), Council Recommendation of 2 December 2003 on cancer screening (2003/878/EC), *Off J Eur Union* no. L 327:34-38.
<http://eurlex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2003:327:0034:0038:EN:PDF>
2. Segnan N, Patnick J & von Karsa L, (eds.) (2010). European Guidelines for Quality Assurance in Colorectal Cancer Screening and Diagnosis - First Edition. European Commission, Publications Office of the European Union, Luxembourg.
http://bookshop.europa.eu/is-bin/INTERSHOP.enfinity/WFS/EU-Bookshop-Site/en_GB/-/EUR/ViewPublication-Start?PublicationKey=ND3210390
3. Arbyn M, Anttila A, Jordan J, Schenck U, Ronco G, Segnan N, Wiener H, Herbert A, Daniel J & von Karsa L (eds) (2008). European Guidelines for Quality Assurance in Cervical Cancer Screening - Second edition. European Commission, Office for Official Publications of the European Communities, Luxembourg.
http://bookshop.europa.eu/is-bin/INTERSHOP.enfinity/WFS/EU-Bookshop-Site/en_GB/-/EUR/ViewPublication-Start?PublicationKey=ND7007117
4. Perry N, Broeders M, de Wolf C, Törnberg S, Holland R, von Karsa L & Puthaar E (eds) (2006). European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis – Fourth edition. European Commission, Luxembourg:Office for Official Publications of the European Communities.
http://bookshop.europa.eu/is-bin/INTERSHOP.enfinity/WFS/EU-Bookshop-Site/en_GB/-/EUR/ViewPublication-Start?PublicationKey=ND7306954
5. Anttila A, Ronco G, Working Group on the Registration and Monitoring of Cervical Cancer Screening Programmes in the European Union; within the European Network for Information on Cancer (EUNICE) (2009) Description of the national situation of cervical cancer screening in the member states of the European Union. *EJC*, 45: 2685-2708.
[http://www.ejcancer.info/article/S0959-8049\(09\)00576-0/abstract](http://www.ejcancer.info/article/S0959-8049(09)00576-0/abstract)
6. von Karsa L, Anttila A, Ronco G, Ponti A, Malila N, Arbyn M, Segnan N, Castillo-Beltran M, Boniol M, Ferlay J, Hery C, Sauvaget C, Voti L & Autier P (2008). Cancer screening in the European Union, Report on the implementation of the Council Recommendation on cancer screening - First Report. European Communities (publ.), Luxembourg.
http://ec.europa.eu/health/ph_determinants/genetics/documents/cancer_screening.pdf
7. Commission of the European Communities (2008), Report from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions - Implementation of the Council Recommendation of 2 December 2003 on cancer screening (2003/878/EC) Brussels, Report no.COM(2008) 882 final.
<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2008:0882:FIN:EN:PDF>

Annex 1: Expert Committee

Experts

| Name | Title | Country | Area of expertise | Current position |
|--------------------------|------------|-----------------|---|---|
| Ahti Anttila | PhD | Finland | Cancer epidemiology, cancer screening, reproductive health | Research Director, Mass Screening Registry of the Finnish Cancer Registry, Helsinki |
| Magdalena Bielska-Lasota | Dr | Poland | Cancer epidemiology | Professor in National Institute of Public Health – National Institute of Hygiene, Warsaw |
| Thomas Davidson | PhD | Sweden | Health Economics | Health Economist at SBU |
| Johannes JM van Delden | MD PhD | The Netherlands | Research Ethics, End-of-life ethics, ethics on population screening | Professor of Medical Ethics Julius Center for Health Sciences and Primary Care University Medical Center Utrecht |
| Lawrence von Karsa | Dr | France | Quality assurance in screening and programme implementation | Head of the Quality Assurance Group, Section of Early Detection and Prevention, International Agency for Research on Cancer, Lyon, France |
| Elsebeth Lynge | Prof | Denmark | Cancer screening | Professor of Epidemiology, University of Copenhagen |
| Sue Moss | PhD | UK | Evaluation of cancer screening programmes, epidemiology | Associate Director, Cancer Screening Evaluation Unit, Institute of Cancer Research |
| Maja Primic Žakelj | Prof | Slovenia | Cancer epidemiology, registration and screening | Head of Epidemiology and Cancer Registry, Institute of Oncology Ljubljana |
| Leo van Rossum | Dr | The Netherlands | Cancer epidemiology, Public health, screening | Assistant professor Radboud University Nijmegen Medical Centre; Scientific Staff Member, Health Council of the Netherlands |
| Nereo Segnan | MD, MS Epi | Italy | Cancer epidemiology and cancer screening | Head of the Department of Cancer Screening and Unit of Cancer Epidemiology. CPO Piemonte and S.Giovanni Battista University Hospital – Torino |
| Sven Törnberg | Director | Sweden | Screening coordination | Stockholm regional screening programme |
| Chris de Wolf | Dr | Switzerland | Public Health, cancer screening | Medical Director Centre fribourgeois de dépistage du cancer du sein Route du Beaumont 2 1709 Fribourg |

Observers

| Name | Organisation |
|---------------------|--|
| Euzebiusz Dziwinski | European Cancer Patient Coalition (ECPC) |
| Karl Freese | European Commission, DG Sanco |
| Gunta Lazdane | WHO Regional Office for Europe |

EuSANH representatives

| Name | Organisation |
|--------------------|---|
| Susanne V Allander | SBU – Swedish Council on Health Technology Assessment |
| Dorine Coenen | GR – Health Council of the Netherlands |
| Louise Gunning | GR – Health Council of the Netherlands |
| Monica Hultcrantz | SBU – Swedish Council on Health Technology Assessment |
| Måns Rosén | SBU – Swedish Council on Health Technology Assessment |

Annex 2: List of reviewers

Ascunce Nieves, Spain

Bleyen Luc, Belgium

Broeders Mireille, the Netherlands

Bujanda Luis, Spain

Castells Xavier, Spain

Marina Pollán, Spain

de Koning Harry, the Netherlands

Expósito José, Spain

Gravestein Xandra together with A. Lock, H. van Veldhuizen, N. van der Veen, R. Reij, the Netherlands

Hermens Rosella, the Netherlands

Holland Roland, the Netherlands

Meijer Chris, the Netherlands

Patnick Julietta, United Kingdom

Pla Roger, Spain

Salas Lola, Spain

Sancho-Garnier H el ene, France

Tafforeau Jean, Belgium

Volf Jaroslav, Czech Republic

Annex 3: A Framework for Science Advice on Health: Principles and Guidelines

Introduction

Scientists generate knowledge and evidence with their research results and policy makers have to take decisions. These two worlds have their own dynamics and their own language. However in many instances science can help make better policy decisions. In particular Science Advisory Bodies (SABs) can help to summarize the available evidence and give sound advice to policy makers. They are usually positioned to bridge the gap between the scientists and the policy makers and are able to find a common language in their advisory reports.

In producing a science advisory report common steps in the process can be identified and certain principles need to be addressed at each step. In this methodological framework we present these principles and provide guidelines for streamlining processes according to the principles involved. We start at the basic requirements SABs should fulfil but go on aiming for the “ideal” situation. Some SABs will be further along than others in adopting these guidelines in their daily routines, so ultimately this framework will structure a dynamic process. But we feel it is important to agree on the common principles, underlying the steps in the process of producing science advisory reports, if we want to create a common EUSANH quality seal.

Table 1. Framework for science advice on health.

| STEPS | PRINCIPLES | GUIDELINES |
|--|-----------------------|---|
| Framing the issue | Need | 1 <i>Policy makers and science advisors should regularly discuss emerging issues requiring advice</i> |
| | | 2 <i>Science advisors should do so in interaction with the health research community</i> |
| | | 3 <i>In formulating a request for advice, policy makers and science advisors should determine in close cooperation the set of questions to be addressed</i> |
| | | 4 <i>Science advisors should discuss with policy makers whether a European or international perspective is appropriate</i> |
| Planning the process | Timeliness | 5 <i>In framing the issue policy makers and science advisors should discuss the scope and duration of the task, considering the stage within the policy making process when scientific advice is needed</i> |
| | | 6 <i>The advisory body should develop operation procedures to manage the entire advisory process</i> |
| Drafting the report | Credibility | 7 <i>Select committee members on the basis of professional excellence and with an appropriate range of expertise</i> |
| | | 8 <i>Select committee members who reflect the diversity of scientific opinions</i> |
| | Independence | 9 <i>Screen for conflicts of interest in order to avoid advocacy</i> |
| | | 10 <i>Committee members should carry out their deliberations in closed meetings in order to avoid political and special interest influence</i> |
| | | 11 <i>The Committee should be responsible and accountable for the final report</i> |
| | Relevance | 12 <i>Consider adding a policy maker to the Committee as an official observer</i> |
| | | 13 <i>Consider organising stakeholder hearings</i> |
| | Transparency | 14 <i>Where appropriate, specify ethical or legal principles involved</i> |
| 15 <i>Specify data and data sources used in producing the report</i> | | |
| 16 <i>Document and explain all assumptions made and methods used in interpreting and synthesizing the data</i> | | |
| 17 <i>Identify and describe all uncertainties involved</i> | | |
| Formulating the recommendations | Feasibility | 18 <i>Indicate where and how expert judgment is applied</i> |
| | | 19 <i>Consider the potential consequences of the recommendations made to policy makers</i> |
| Reviewing the report | Quality | 20 <i>Where appropriate, identify policy options based on data and research evidence</i> |
| | | 21 <i>The final draft report should undergo an independent peer review</i> |
| | | 22 <i>Guarantee continuity in producing advisory reports on similar issues</i> |
| | | 23 <i>Check whether the final draft report is consistent with other reports of the advisory body</i> |
| Publishing the report | Openness | 24 <i>Specify the response to the comments made in the peer review</i> |
| | | 25 <i>Make the report publicly available</i> |
| | | 26 <i>Where more active dissemination is required, issue press statements, press releases or press briefings</i> |
| Assessing the impact | Accountability | 27 <i>Where more clarification is required, organise meetings with policy makers and target groups</i> |
| | | 28 <i>There should be a follow-up procedure that monitors the policy makers' actions in response to the advisory report</i> |
| | | 29 <i>The advisory body should regularly perform a (self)assessment, both of the impact of its reports and of its performance</i> |

Annex 4: Evaluation of the advisory process

By the conclusion of the workshop, the Expert Committee had discussed and evaluated the workshop and participation in the development of EuSANH scientific advice. As this information is important and valuable for planning and organising future EuSANH projects, we have summarised some of the experts' comments below.

Workshop planning and preparation

The evidence-based approach was highly appreciated, and it was an advantage that prepared background material had been distributed before the meeting. Despite thorough preparations, there was a need to change direction somewhat during the meeting. All participating experts agreed to this change.

A suggestion for future workshops is to plan two face-to-face meetings, rather than one. The initial meeting should be held early in the process to frame the questions and discuss the continued approach. Thereafter, the literature search could be performed. At the second meeting, the Committee could work on the evidence and recommendations and prepare the scientific advice. The group agreed that the work process of this current workshop had been facilitated by the fact that many of the experts had collaborated previously on a European level.

Expert Committee

The fact that some of the Committee members knew each other from previous collaboration was recognised as an advantage during the group discussions. Moreover, meeting again was important as the field of cancer screening is constantly changing. The importance of including committee members from the newer EU Member States was also noted.

The chairpersons played an important role throughout the workshop since many participants wanted to express opinions during the intense two-day meeting. Because of the many different expectations on the meeting, the chairs were needed to maintain the focus of the discussion.

Science Advice and funding

The work of a European expert group emphasized the advantages of science advice on a European level. These advantages include access to the best experts at a European level ('Golden network') and collaboration in preparing the scientific base for advisory reports. The latter helps avoid overlap and duplicate activities, thereby reducing the workloads.

A discussion focused on the different definitions used in association with scientific advice. The importance of communicating “lack of knowledge” was also stressed, as this can be of interest to funders. Since the lack of resources is a common problem in this field, increased cooperation with health technology assessment agencies and science advisory bodies is important.

Dissemination

The discussion highlighted the dissemination of results from this type of project. Some of the Committee members preferred scientific publications, as this is where experts involved in screening programmes find information. However, since many countries contact WHO for information, it is also important to present the results in scientific advice or guidelines.

Future

The Committee foresees an increasing need for expertise in the area of cancer screening in general and in the implementation of cancer screening. An expert network is required to supply this need, especially in countries having limited experience with screening programmes. Since the EC also needs advice from experts, a Standing Committee for screening was suggested.

Suggested improvements in the advisory process

- Involve experts at an early stage of the project so that they can have input on the project’s aim and the background material produced.
- Ensure that the Expert Committee includes members representing different views on the topic.
- Arrange at least two face-to-face meetings.

Annex 7: Draft manuscript: Determinants of a successful implementation of population-based cancer screening programmes

The final version was accepted for publication in the *European Journal of Cancer*^a

Determinants of a successful implementation of Population-based cancer screening programmes

Elsebeth Lynge,¹ Sven Törnberg,² Lawrence von Karsa,³

Nereo Segnan,⁴ Johannes J. M. van Delden⁵

1. Department of Public Health, University of Copenhagen, Denmark
2. Department of Cancer Screening, Karolinska University Hospital, Stockholm, Sweden
3. Lawrence von Karsa, International Agency for Research on Cancer, Lyon, France
4. Department of Cancer Screening and Unit of Cancer Epidemiology, CPO Piemonte and S. Giovanni University Hospital, Torino, Italy
5. Julius Center for Health Sciences and Primary Care, Medical Humanities, University Medical Center, Utrecht, the Netherlands

Correspondence to: Elsebeth Lynge, Department of Public Health, University of Copenhagen, Øster Farimagsgade 5, DK-1014 Copenhagen K, Denmark.

Tel: + 45 35 32 76 35, Fax: + 45 35 32 73 83, E-mail: elsebeth@pubhealth.ku.dk

Word count: 1934

^a Lynge E et al., Determinants of successful implementation of population-based cancer screening programmes, *Eur J Cancer* (2011), doi:10.1016/j.ejca.2011.06.051

ABSTRACT

To facilitate the future implementation of population-based cancer screening programmes in European countries, we summarised the experiences gained from existing programmes across Europe. We listed points that citizens, advocacy groups, politicians, health planners, and health professionals should consider when planning, implementing and running population-based cancer screening programmes. The list is generic and can be applied for breast, cervical and colorectal cancer screening. The list is based on evidence presented in the three European Union guidelines on quality assurance in cancer screening and diagnosis, supplemented with other literature and expert experience presented at a European Science Advisory Network for Health workshop. The implementation of a cancer screening programme should be divided into the following 8 phases: 1) pre-decision planning, 2) planning, 3) feasibility testing, 4) piloting or trial implementation, 5) verification of pilot performance, 6) scaling-up from pilot to service, 7) running of full-scale programme, and 8) sustainability. For each phase, a substantial number of specified conditions must be met. Successful implementation of a cancer screening programme requires societal acceptance and local ownership along with the best evidence-based practice.

Word count: 178

keywords: cancer, screening, population-based programme

INTRODUCTION

Screening and early detection of asymptomatic cases constitute important elements in the control of breast cancer, cervical cancer, and colorectal cancer. In accordance with the European Union (EU) council recommendation from 2003 (1), many European countries have implemented screening programmes for some or all of these three cancer sites. Other European countries are considering the possibilities of adding such screening programmes to their cancer control measures.

In principle, a good screening test should be simple and easy to apply. Moreover, the full preventive potential of screening tests will be realised only within a good screening programme, and such a programme requires complex organisation. To facilitate the future implementation of population-based screening programmes in European countries, it is therefore valuable to summarise the experiences gained from existing programmes across Europe. With this aim in mind, an expert group convened in Stockholm on 7-9 February 2011 under the auspices of the European Science Advisory Network for Health, and this paper reports on the outcome of this work.

The report is structured as a list of points that all citizens, advocacy groups, politicians, health planners, and health professionals should consider when planning, implementing and running population-based cancer screening programmes. The list is based on evidence from the scientific literature and expert experience. A major part of the evidence is reported in the EU guidelines on quality assurance of cancer screening and diagnosis (2, 3, 4). The list follows the steps in the implementation; from the societal deliberations about new cancer control measures to the sustainability of the well-implemented screening programmes. The list is generic and can as such be applied for breast, cervical, and colorectal cancer screening.

DETERMINANTS

1. Pre-decision planning

The starting point must always be to raise professional and public awareness of the purpose, the benefits and the risks of screening. This implies that one has to organize a societal debate. The second step would be to review existing evidence-based recommendations and guidelines and tailor them to the local setting. During the whole process cross border exchange of experience is encouraged.

- Building up of a professional and public understanding of benefits and risks of screening based on:
 - o Collection of information on disease incidence, stage distribution, and survival
 - o Collection of information on availability and quality of cure offered
 - o Understanding the potential role of screening in cancer control
 - o Assessment of evidence for adding screening to existing cancer control measures
 - o Collection of experiences from other countries
- Political will, commitment, at all relevant levels (EU, member states and regional)
- Decision on political responsibility for the process
- Review of existing guidelines
- Availability of treatments and facilities (both competence and resources)
- Assessment of facilitating factors/barriers for implementation of organised screening
- Economic impact and cost-effectiveness of the programme
- Formal decision and allocation of budget
- Organisation of continuous societal debate and input

2. Comprehensive planning: feasibility of screening models, professional performance, organisation, financing, and quality assurance (QA)

After the political decision has been taken to start the process of establishing a population-based cancer screening programme, the first step is comprehensive planning. This should include the entire multidisciplinary screening process as well as the organisational aspects which need to be taken into account in order to avoid unnecessary delays and costs later on.

The feasibility of screening models should be tested before detailed planning of pilot studies can begin. Professional performance, organisational and financial aspects, as well as the scope and content of a comprehensive quality assurance programme should be covered in the planning phase. The initial plans should also define the time frame within which various issues need to be further developed.

- Creation of professional dedication (understanding)
- Planning of infrastructure
- Establishing of coordinating office with supervision mandate
- Ensuring that screening is seen as a process
- Appointing a process owner with mandate to run and manage the quality of the programme
- Organisational development (self learning, quality driven)
- A separate coordination budget
- Multidisciplinary case management
- Collaboration between screening and treatment systems
- Appropriate diagnostic assessment of patients

- An appropriate screening monitoring IT-system with access and possibility to link registers e.g., population-, patient- and cancer registers
- Comprehensive information system, serving all purposes
- Development of a quality assurance (QA) plan, including technical quality
- Adoption of approved QA-plan
- Definition of performance parameters and acceptable levels for health care providers
- Contracts with health care providers
- Consideration of accreditation system or other performance control systems
- System for auditing, training and re-training
- Having tools to exclude bad performers

3. Preparation of all components of screening process, including feasibility testing

Based on the comprehensive planning, the feasibility of the screening services and key components of programme management may be tested in small-scale studies which are designed to yield initial results with a limited amount of financial, technical, staff and time resources. The study results are taken into account in revising the initial plans, if necessary prior to initiating pilot studies on a larger scale. Before the piloting phase can begin, the outcome of the feasibility phase should be thoroughly evaluated.

- Scientific and ethical review of feasibility protocol
- Correct and balanced information on “benefit and risk”
- Societal input
- Creation of oversight for screening programmes
- Scientific publication of outcome

4. Piloting and modification, if necessary, of all screening systems and components, including quality assurance in routine settings

Having gained experiences from a feasibility phase, screening implementation has basically followed two different routes. In England, programme implementation started in pilot areas, and based on these experiences the programme was scaled up to national coverage. In Finland, programme implementation started in randomly selected cohorts, and was gradually extended to all targeted age groups. The Finnish approach requires a national decision on screening implementation and the availability of a national population register. The Finnish approach does, however, allow the outcome to be evaluated as a randomised controlled trial. The two routes are well illustrated from the implementation of colorectal cancer screening in England (5) and Finland (6), respectively.

If the pilot implementation model is followed, this phase starts with selection of a few pilot settings. Supervision and coaching is important in this phase in order to pick up problems

in the screening process as soon as possible. The pilot phase also services as a testing ground for the legal framework.

- Supervision and coaching of screen performers
- Working out of the legal framework
- Ability to exclude bad performers

5. Verification of adequacy of pilot performance

The outcome of the piloting should be reported in the scientific literature. Furthermore the outcome should be widely disseminated to health planners, politicians and health professionals. Based on the piloting, the financial implications of the roll-out of the programme should be determined.

- Budgeting
- Ensure financial commitment
- Scientific publication of outcome

6. Scaling-up from pilot to service screening

This is the actual implementation of the piloted intervention. All the points below need to be scaled up to the size of the programme. Special attention should be paid to building up societal confidence in the programme.

- Defining and contracting the screening team, defining responsibilities
- Setting up of infrastructure for coordination within health care settings
- Developing a plan for evaluation
- Assuring the supply of medical and other skilled manpower
- Multidisciplinary case management
- Training, reference centre
- Comprehensive information system, serving all purposes
- Collaboration between screening, treatment and IT systems
- Technical quality assurance
- Reducing of barriers to participate
- Tools to manage compliance
- Advocacy and collaboration with local civil society organisations
- Population confidence

7. Running full-scale screening programme. Intensive monitoring of programme roll-out for early detection and correction of quality problems

Maintaining high quality performance requires continuous supervision and rigorous scientific reporting.

- Supervision
- Ability to exclude bad performers
- Provision for testing new technologies
- Monitoring benefits and harms of screening
- Scientific publication of outcome

8. Sustainability

Sustainability and plans for long-term evaluation need to be developed. Continuous financial support needs to be ensured. Sustain confidence in the programme. Ensure high quality testing, reporting of screening outcomes and follow-up of screening findings.

- Building population confidence
- Ensuring financial resources

DISCUSSION

The importance of screening as a tool in cancer control has been on the EU agenda for more than 20 years. In the European Code Against Cancer from 1989, women were advised to “have a cervical smear regularly” and “if possible, [to] undergo mammography at regular intervals above the age of 50” (7). The need for organisation of screening into population-based programmes was stressed by the first quality assurance guidelines on breast (8) and cervical (9) cancer from 1993 and further developed in the preparatory work for the EU Council recommendation (10). In the 2003 Council Recommendation, the Member States unanimously agreed to recommend population-based screening for breast, cervical, and colorectal cancer (1).

The actual implementation of population-based screening programmes in EU Member States is, however, still far from complete. By 2007, close to half of European women were covered only by opportunistic screening for cervical cancer, and 30% of European women and men were not offered screening for colorectal cancer (11), Table 1. By 2009, the lifetime number of recommended screening tests for cervical cancer varied from 6 to 50+ across the EU member states (12). Various obstacles in the political priority setting and/or health care systems can impede the implementation of population-based

screening. In new Member States, lack of resources is a significant problem. In old Member States, organisation of screening may conflict with a traditional fee-for-service payment system. To decrease the use of opportunistic smears, Dutch doctors were for some period paid for not taking smears; and English doctors were paid only if they reached a high coverage in their patient population. Several countries have encountered problems with data confidentiality, despite the fact that the EU directive on data protection allows for linkages of health services data. The EU obligation to invite tenders for provision of large scale services has also in some cases impeded centralization of some services e.g. cytology.

To ensure successful implementation of a population-based cancer screening programme it is mandatory that there is a broad societal understanding of the benefits and risks, that there is effective local ownership of the programme, and that it follows updated, evidence-based guidelines. Ambitions should not be set too high. In some countries or regions, not all the points listed here may be feasible, and the points have to be seen in the perspective of the actual setting. Having considered the list carefully, a country or a region may decide how to develop a screening programme tailored to the local circumstances. It is better to implement one cancer screening programme at a time, rather than to start screening for all 3 cancer sites at once. The detailed lists provided in this paper can serve as a guide to a gradual and successful implementation.

Given the complexity of the process, it is not surprising that 10 or more years are commonly required to implement population-based cancer screening programmes (11). Effective, sustained coordination with a clear vision of the process and adequate resources to provide leadership, develop consensus, and adapt to the evolving needs of programme development is required, beginning early in the process.

CONCLUSION

It is of utmost importance that screening programmes are implemented effectively and operate in accordance with societal values and priorities. A prerequisite for a successful screening programme is the societal acceptance, local ownership, and effective coordination along with the best evidence-based practice.

ACKNOWLEDGEMENT

We are indebted to Susanne V Allander, Ahti Anttila, Magdalena Bielska-Lasota, Dorine Coenen, Thomas Davidson, Euzebiusz Dziwinski, Karl Freese, Louise Gunning, Monica

Hultcrantz, Gunta Lazdane, Sue Moss, Måns Rosén, Leo van Rossum, Chris de Wolf, and Maja Primic Žakelj for discussion on this paper.

The research leading to these results has received funding from the European Union's Seventh Framework Programme [FP7/2007-2013] under agreement number 229716.

Preparation of this report has also been supported by the project entitled "European Cooperation on Development and Implementation of Cancer Screening and Prevention Guidelines (ECCG-ECN)", grant agreement no. 2006322 that has received funding from the European Union in the framework of the Public Health Programme. The views expressed in this report are those of the authors and do not necessarily reflect the official position of the European Commission.

REFERENCES

1. European Union. *Council recommendation of 2 December 2003 on cancer screening* (2003/878/EC).
2. Perry N, Broeders M, de Wolf C, Törnberg S, Holland R, von Karsa L (Eds.). *European guidelines for quality assurance in breast cancer screening and diagnosis*. Fourth edition. Luxembourg: Office for official publications of the European Communities, 2006.
3. Arbyn M, Anttila A, Jordan J, Ronco G, Schenck U, Segnan N, Wiener HG, Herbert A, Daniel J, von Karsa L (Eds.). *European guidelines for quality assurance in cervical cancer screening*. Second edition. Luxembourg: Office for official publications of the European Communities, 2008.
4. Segnan N, Patnick J, von Karsa L (Eds.). *European guidelines for quality assurance in colorectal cancer screening and diagnosis*. Luxembourg: Publication office of the European Union, 2010.
5. The UK CRC Screening Pilot Evaluation Team. *Evaluation of the UK colorectal cancer screening pilot. Final report*. February 2003, revised May 2003. <http://www.cancerscreening.nhs.uk/bowel/pilot-evaluation.html> [Accessed 3 March 2011]
6. Chiu SY, Malila N, Yen AM, Anttila A, Hakama M, Chen HH. [Analytical decision model for sample size and effectiveness projections for use in planning a population-based randomized controlled trial of colorectal cancers screening](#). *J Eval Clin Pract* 2011;17:123-9.
7. Sweet D, Vanvossel A (Eds.). *Europe against cancer. Public health: initiatives and texts adopted in 1990*. Luxembourg: Office for Official Publications of the European Communities, 1990.
8. Kirkpatrick A, Törnberg S, Thijssen MAO. *European guidelines for quality assurance in mammography screening*. Luxembourg: Office for Official Publications of the European Communities, 1993.
9. Coleman D, Day N, Douglas G, Farmery E, Lynge E, Philip J, Segnan N. European guidelines for quality assurance in cervical cancer screening. *Eur J Cancer* 1993;29A(Suppl 4):138.
10. Advisory Committee on Cancer Prevention. Recommendations on cancer screening in the European Union. *Eur J Cancer* 2000;36:1473-8.
11. von Karsa L, Anttila A, Ronco G, Ponti A, Malila N, Arbyn M, Segnan N, Castillo-Beltran M, Boniol M, Ferlay J, Hery C, Sauvaget C, Voti L, Autier P. *Cancer screening in the European Union*. Luxembourg: European Communities, 2008.
12. Anttila A, von Karsa L, Aasmaa A, Fender M, Patnick J, Rebolj M, Nicula F, Vass L, Valerianova Z, Voti L, Sauvaget C, Ronco G. Cervical cancer screening policies and coverage in Europe. *Eur J Cancer* 2009;45:2649-58.

Table 1. State of cancer screening in 27 member states of the European Union by 2007 (adapted from 11)

| | Breast cancer | Cervical cancer | Colorectal cancer |
|---|-------------------|-------------------|---------------------------|
| European recommendation* | Women, aged 50-69 | Women, aged 30-60 | Women and men, aged 50-74 |
| EU Target population | 59 mio | 109 mio | 136 mio |
| Proportion of target population covered by: | | | |
| - population-based, rollout complete | 41% | 22% | 0% |
| - population-based, roll-out ongoing, piloting, planning | 50% | 29% | 43% |
| - non-population-based | 6% | 47% | 27% |
| - excluded from the regions and/or age groups offered screening | 2% | 2% | 22% |
| - no service | 2% | <1% | 8% |

* Target ages recommended for breast and colorectal cancer screening recommended by (1), minimum target age recommended for cervical cancer screening by (3)

The EuSANH-ISA project is supported by funding under the Seventh Framework Programme of the European Community under grant agreement number 229716.

