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Determinants of successful implementation of population-based cancer screening programmes

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ABSTRACT

To facilitate the future implementation of population-based cancer screening programmes in European countries, we summarised the experience 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 general and is applicable to breast, cervical and colorectal cancer screening. It 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 seven phases: (1) before planning, (2) planning, (3) feasibility testing, (4) piloting or trial implementation, (5) scaling up from pilot to service, (6) running of full-scale programme, and (7) sustainability. For each phase, a substantial number of specified conditions have to be met. Successful implementation of a cancer screening programme requires societal acceptance and local ownership along with the best evidence-based practise and verification of adequate performance in each phase of implementation.

1. 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 2003 recommendation of the Council of the European Union (EU),[1] many European countries have implemented screening programmes for some or all of these three cancer sites. Additional programmes are currently being planned or established.

In principle, a good screening test should be simple and easy to use. However, the full preventive potential of screening tests will only be realised within a good screening programme, and such a programme is a 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

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auspices of the European Science Advisory Network for Health, and this paper reports on the outcome of this work.

The aim of cancer screening is to reduce the mortality from the disease screened for. When pre-cancer lesions are detected and treated, the incidence of the disease should also be reduced. For cancer screening to achieve its aim, a number of conditions need to be fulfilled. This report sets out the key 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 following 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.[2–4]

The list follows the steps in programme implementation; from the societal deliberations about new cancer-control measures to the sustainability of a well-implemented screening programme. Successful implementation of cancer screening encompasses many steps, here these are grouped into: before planning, planning, feasibility, piloting, roll-out (scaling-up from pilot to service and running a full-scale programme) and sustainability. The points are general and are applicable to breast, cervical, and colorectal cancer screening. In a few cases, points have been repeated if they are of prime importance in more that one phase.

2. Determinants

2.1. *Before planning*

The starting point must always be to promote professional and public understanding of the purpose, the benefits and the risks of screening. This implies that one has to organise a societal debate. The next step is to review existing evidence-based recommendations and guidelines taking into account the local setting. During the whole process international exchange of experience is encouraged. Key points at this stage are:

- Review of scientific literature.
- Collection of information on disease incidence, stage distribution, and survival.
- Collection of information on availability and quality of cure offered.
- Understanding the potential role of screening in cancer control.
- Assessment of evidence for adding screening to existing cancer control measures.
- Collection of experience from other countries.
- Building up professional and public understanding of the benefits and risks of screening.
- 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.

2.2. *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 cover the entire multidisciplinary screening process and the organisational aspects and will help to avoid unnecessary delays and costs later on.

The feasibility of screening models should be tested before detailed planning of pilot studies can begin. Planning should include: professional performance, organisational and financial aspects, as well as the scope and content of a comprehensive quality assurance programme. The initial plans should also consider the time frame within which the various issues need to be further developed. Key points at this stage are:

- Creation of professional dedication (understanding).
- Planning of infrastructure.
- Establishing of coordinating office with supervision mandate.
- Ensuring that screening is seen as a process.
- Designation of 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 plan, including technical QA.
- Adoption of approved QA plan.
- Definition of performance parameters and acceptable levels, including standards for health professionals.
- Contracts with health care providers.
- System for auditing, training and re-training.
- Assessment tools to exclude bad performers.
- Consideration of accreditation system or other comprehensive systems for ensuring competent service delivery.

2.3. *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 should be tested in small-scale studies that 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. Key points at this stage are:

- Scientific and ethical review of feasibility protocol.
- Correct and balanced information on 'benefit and risk'.
- Development of communication strategy.
- Societal input.
- Clearance of data protection and confidentiality issues.
- Creation of formal oversight for screening programmes.
- Scientific publication of feasibility results.

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

In England and many other European countries, implementation of breast, cervical and colorectal screening programmes started in pilot areas, and based on this experience the programmes were scaled up to national coverage.[5] In Finland, implementation of the programmes started in randomly selected cohorts, and was gradually extended to all targeted age groups.[6] This allows the outcome to be evaluated as a randomised controlled trial (randomised health policy).[7] The Finnish approach requires a national decision on screening implementation and the availability of a national population register. The approach permits evidence-based modification of the programme before it extends to the entire country.

The pilot implementation model starts with selection of one or a few pilot regions. 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 serves as a testing ground for the legal framework. The pilot outcome should be reported in the scientific literature and 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. Key points at this stage are:

- Budgeting.
- Ensuring financial commitment.
- Supervision and coaching of screening staff.
- Testing the legal framework.
- Ability to exclude bad performers.
- Scientific publication of outcome.

2.5. *Scaling up from pilot to service screening*

This is the actual implementation of the piloted intervention. All the points above need to be scaled-up to the size of the full programme. Effective communication of the experience gained to date in the implementation process should help to develop societal confidence in the programme. Key points at this stage are:

- Defining and contracting the local, regional and national programme teams, defining responsibilities.
- Setting-up infrastructure for coordination within health care settings.
- Identifying possible obstacles.
- Developing a plan for evaluation.
- Availability of staff (professional skills and numbers).
- Multidisciplinary case management.
- Special training, reference centre.
- Comprehensive information system, covering all steps in the screening process.
- Collaboration between screening, treatment and IT systems.
- Technical quality assurance.
- Reduction of barriers to participation.
- Tools to encourage compliance.
- Advocacy and collaboration with local civil society organisations.
- Population confidence.

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

Maintaining high-quality of the screening service requires continuous supervision and rigorous scientific reporting. Attention must be paid to performance at each step in the screening process from information and invitation to performance of the screening test, assessment of abnormalities, and diagnosis and treatment of lesions detected in screening. Key points at this stage are:

- Supervision of all steps in the screening process.
- Ability to exclude bad performers.
- Testing grounds for new technologies.
- Monitoring the benefits and harms of screening.
- Scientific publication of outcome.

2.7. *Sustainability*

Sustainability is essential to achieve the potential impact of screening on the burden of disease in the population. This requires adequate, continuous financial support for preserving high programme quality. To maintain societal support, adequate communication of programme performance and impact is essential. This requires long-term evaluation in adequately planned studies with high-quality testing, reporting of performance and follow-up of screening outcomes. Key points at this stage are:

- Accurate and accessible communication of screening outcome.
- Population confidence.
- Organisational anchoring.
- Ensuring adequate financial resources and political commitment.

3. Discussion

The importance of screening as a tool for 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'.[8] The need for organisation of screening into population-based programmes was stressed in the first quality assurance guidelines on breast[9] and cervical[10] cancer from 1993, and further developed in the preparatory work for the recommendation on cancer screening of the Council of the EU in 2003.[11] In the Council Recommendation, the EU Member States unanimously agreed on standards and principles for implementation of breast, cervical, and colorectal cancer screening programmes.[1]

However, the actual implementation of population-based screening programmes in the EU is still far from complete. By 2007, opportunistic cervical cancer screening was still the only available option for nearly half of the European target population, and 30% (8% without service and 22% outside groups served) of the women and men in the European target population were not offered colorectal cancer screening,[12] Table 1. The coverage by colorectal cancer screening programmes has, however, improved after 2007. For example, in Italy by the end of 2008, 36% of 50–69 year old men and women were invited to biennial screening with faecal occult blood test, and 1,171,000 persons were screened, attendence rate 47.5%.[13] The programmes in France and England became nationwide in 2009, and roll-out of programmes in the Netherlands and Denmark will start in 2013 and 2014, respectively. Furthermore, the screening activity is not yet standardised across the EU according to the European recommendations. For example by 2009, the lifetime number of recommended screening tests for cervical cancer varied from 6 to 50+ across the EU countries.[14]

Various obstacles in health care systems and in setting political priorities can inhibit the implementation of population-based screening. In 'new' Member States (that acceded to the EU after 2003), lack of resources is a serious problem. Adequate budgeting is a prerequisite for a successful programme as illustrated by recent experience from Poland.[15]

In 'old' Member States, organisation of screening may conflict with a traditional fee-for-service payment system. To decrease the number of opportunistic smears, the Netherlands stopped reimbursement of preventive smears taken outside the organised programme in 1996.[16] In England, target payments were introduced for general practitioners in 1990 to encourage them to include their female patients in the screening programme. There was no payment if the coverage was below 50%, a small payment if the coverage was between 50% and 79%, and a higher payment when the coverage reached 80%.[17]

Several countries have encountered problems with data confidentiality despite the fact that the EU directive on data protection[18] allows for linkage of health services data. The performance indicators listed in the EU guidelines may be used to monitor the programmes. However, it is clear that these indicators can be calculated only if access is provided to the necessary data. For example, calculation of the 'interval cancer rate as proportion of the underlying, expected, breast cancer incidence rate in the absence of screening'[2] requires access to data on all women with a normal screening mammogram and the individual follow-up of each of these women for incident breast cancer, death and emigration. Furthermore, a population-based breast cancer incidence rate for the period prior to initiation of screening must be available. It is encouraging that this indicator has been calculated for several European breast cancer screening programmes.[19]

Evaluation might also require the merging of datasets that have been separate in the past. In Sweden, the responsibility for cervical cancer screening rests with the counties that also keep the respective records. In order to perform a national audit of the screening programme data were retrieved and merged from 30 pathology and cytology laboratories throughout Sweden, and local cytology codes were converted to a common nomenclature.[20] Once national datasets have been established it is also possible to identify regional differences in screening uptake and outcome; a routine practise in the English[21] and Italian[22] programmes. Centralisation of activities also facilitates monitoring. The EU obligation to invite tenders for provision of large scale services has, however, in some cases impeded centralisation such as in the case of cytology services.

Local ownership and appropriate adaptation to the local health care system are important factors for success. In France, widespread opportunistic mammography screening was the norm until the organised programme became nation-

Table 1 – State of cancer screening in 27 Member States of the European Union by 2007 (adapted from von Karsa et al.[12]).

European recommendation* EU Target population	Breast cancer Women, aged 50–69 59 mio	Cervical cancer Women, aged 30–60 109 mio	Colorectal cancer Women and men, aged 50–74 136 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 European Union,[1] minimum target age recommended for cervical cancer screening by Arbyn et al.[3]

wide in 2004. The organised screening programme has therefore encompassed some of the features from the opportunistic practise. For example, a screening examination includes a clinical examination, a minimum of two views per breast, and a supplementary view if needed; all undertaken by an accredited radiologist.[23] In England, the organised programme started much earlier, in 1988. A radiographer with special training in mammography takes two views of each breast, and the whole visit lasts about half an hour.[24]

The comparison of performance indicators from different countries serves as a tool to monitor possible consequences of adapting screening programmes to local health care systems. For example, results from selected European breast cancer screening programmes showed that the cancer detection rate divided by the background incidence rate was somewhat higher in Copenhagen, 3.2, where the programme resembles the English set-up, than in Marseille, 2.5, and in Strasbourg, 2.9.[25]

To ensure the sustainability of a screening programme new evidence concerning screening methods should be reviewed regularly and the potential implications for programme policy should be considered, e.g. with regard to new technologies as flexible sigmoidoscopy,[26] or combination of screening with other preventive measures as human papillomavirus (HPV) vaccination.[27] Evidence-based guidelines should therefore be updated regularly.

Broad societal understanding of the benefits and risks of screening is also essential to the sustainability of an effective screening programme. Many of the performance parameters in the European guidelines are designed to provide an early indication of the benefits and risks of screening. However, long-term follow-up is needed to accurately assess both the benefit in reducing cancer specific mortality and the risk of over-diagnosis. The methodological challenges of such long-term studies using observational data[28] make it all the more important to provide sustainable support for accessibility and management of individual data.

Given the large number of individuals attending screening programmes, it is of utmost importance to avoid risks of low-quality screening. To ensure public confidence in the programme, it should be possible to identify and exclude poor performers. This is challenging because no screening service is infallible. A good example is the actions taken in England following identified failures in the cervical cancer screening programme.[29] Where resources are limited, it is better to implement one cancer screening programme at a time, than to start screening for all three cancer sites at once. Prioritisation may be based amongst other things on the number of cases, political will, and the availability of professional expertise and dedication. The detailed lists provided in this paper can serve as a guide to a gradual and successful implementation.

4. Conclusion

Screening programmes must be implemented effectively and operated in accordance with societal values and priorities. Prerequisites for a successful screening programme are societal acceptance, local ownership, and effective coordination along with the best evidence-based practice.

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

Conflict of interest statement

Elsebeth Lynge: 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.

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Nereo Segnan: I participated to 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. I asked and received the formal permission by my employer, the S. Giovanni University Hospital of Turin.

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