# *Evaluation of a Screening Programme for Breast Cancer in Flanders*

## *Guest editorial*

by

Weyler J[1]

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Breast cancer screening programmes are widely implemented in developed countries and it is generally accepted that they do more good than harm. Nevertheless there is much confusion and misunderstanding with respect to what they really are and how they should be evaluated. Striking is the observation that the vast majority of 'scientific' researchers seems to consider these screening programmes as therapeutic interventions and as a result of this, they state that the ultimate evaluation is the 'randomised controlled trial'. A 'Cochrane meta-analysis' by Olsen and Gøtzsche, wherein is concluded that "there is no reliable evidence that screening for breast cancer reduces mortality," has fuelled the debate about whether mammography saves lives or not (1). Screening, however, is nothing more or less than a diagnostic activity, albeit (as it is the case in most diagnostic activities) with a view of treatment and be it that there is only a non-manifestational prompting for the pursuit of diagnosis (2). Cancer screening programmes can only be considered when there is scientific evidence for a better case fatality rate (or possibly for a better quality of life when case fatality is not improved) when an illness is treated in an early (non-symptomatic) stage. It is of course the stage-specific treatment that saves lives, not the diagnostic procedure. Therefore, the primary aim of a screening programme is to optimise the detection of this pre-symptomatic illness in an apparently healthy individual (a more appropriate term for screening is 'early diagnosis'). Once this becomes clear, it is obvious that such a 'screening programme' should be evaluated as a

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[1] Epidemiology and Social Medicine, Faculty of Medicine, University of Antwerp, Belgium

Correspondence address: Prof. dr. Joost Weyler, Epidemiology and Social Medicine, Faculty of Medicine, University of Antwerp, Campus Drie Eiken, Universiteitsplein 1, 2610 Antwerpen, Belgium, E-mail: joost.weyler@ua.ac.be

diagnostic activity. Evaluation should be focused on how the diagnostic activity succeeds in finding those lesions that in the absence of this activity would develop into 'dis-ease' caused by an underlying late-stage illness (with a high case fatality rate). The population 'effect' of the programme to be evaluated, is a shift in the stage distribution at the moment of diagnosis. Emphasis should of course not only be made on the benefits, but also on the drawbacks, side effects, costs,… and policymaking should be based on knowledge derived from evidence. With respect to 'costs', one of the most important elements at issue is (should be) the evaluation of economic consequences of pursuing this effect. The evaluation of such a screening programme is therefore not a scientific enterprise (and not leading to scientific evidence in its narrow sense) as it is concerned with the concrete (not abstract) facts about the way scientific knowledge is implemented, it is a matter of particularistic Health Services Research.

In Belgium, screening is implemented on a nationwide base since June 2001. In contrast to the southern part, in the northern part (Flanders) this implementation has been carefully prepared by a number of pilot studies (3). Nevertheless, the Health Care System has proven to be a major obstacle for optimal implementation of early detection. Though it was tried to adopt the European guidelines, some important deviations of proposed modalities have occurred. Pilot studies showed that the best attendance rate was reached when women were invited directly to a mammography screening unit. General Practitioners (GPs), however, claimed that before sending an invitation they should have the opportunity to discuss the benefits of screening, to explain the programme to their patients and to refer them to a radiology unit. The direct invitation therefore is only sent to women half a year after they reach the age for entering the programme (i.e. at 50.5 years of age) and/or half a year after each screening interval has been completed. As a result of this the screening interval in general exceeds the recommended two years by far. A second important deviation is the number of radiologists involved in the screening activities. Though a limited number of highly qualified screening radiologists was recommended, all radiologists were allowed to participate in the screening programme on the condition that they would make use of radiological equipment meeting the European quality standards and provided that they would follow a brief educational programme and succeed in a test on their first 30 mammograms. In the whole Flemish region (about 700,000 women in the age group 50-69) at present 170 radiology units and more than 500 radiologists are involved in the screening programme.

In this issue of the 'Archives of Public Health' five studies are presented showing the results of evaluative health services research on the first years of nationwide breast cancer screening. In the paper of

Vande Putte et al., emphasis is on the quality assessment of the offered screening (4). They conclude that the performance parameters fulfil the European standards for the most part. Given the high number of participating radiologists, the variability of these performance parameters, however, may be of concern. Reimbursement of the radiological test (screening and diagnostic) is mediated by the 7 different Belgian mutualities. The Intermutualistic Agency (IMA) analysed all diagnostic mammograms, screening mammograms, breast ultrasounds and magnetic resonances performed from 2000 to 2003 included. They found that within a two-year period (2002-2003), 33% of the target population in Flanders participated in the screening programme, while another 22% underwent a 'diagnostic mammography' (5). It is needless to say that most of these 'diagnostic mammograms' in fact are done with a purpose of screening. The reimbursement rate of the diagnostic examination, however, is higher and radiologists abuse the feeling of both women and GPs that doing more (more takes and an extra ultrasound) would be better. The authors conclude that the organised screening programme already reached a substantial proportion of the target group during its launch period. However, their participation rate is an underestimation of the true participation rate. As mentioned before, the average screening interval exceeds by far the proposed two years. Therefore, we calculated the participation rate in a different way. At present somewhat 875,000 women have been part of the target population since the beginning of the national programme in Flanders. From these women already 395,000 (45%) have been registered as participants in the programme (underwent at least one mammographic screening test). So, the willingness to participate in (any) mammographic examination is already quite high in Flanders (67% at least – 45% participation in the regular programme + 22% diagnostic mammograms). Question remains of course, whether adherence to the screening programme is high, as this is a prerequisite for optimal detection. In their paper, Van Landeghem et al. studied the determinants of reattendance in the Flemish mammography breast cancer screening programme (6). A somewhat worrying result is that re-attendance is negatively influenced by previous false positive findings. Furthermore, a wide variation in re-attendance rates was found among the radiology units that carried out the mammograms. Even when one might be optimistic concerning the already high participation rates, it is important to investigate why some women refuse to undergo a mammographic (screening) test. It is obvious that they should have the freedom not to participate, but they have to make their decision in full consent. In a fourth paper of this issue, Dierckx et al. studied the influence of district level characteristics on the participation rate in one of the major cities in Flanders (7). They found a 9.3% lower participation rate

in underprivileged areas as compared to privileged areas. Finally, Wouters et al. tried to disentangle some of the potential explanations for non participation (8). Based on a survey among participants and depth interviews among a number of non-participants, they found out that while a majority of women got into contact with the screening programme by the invitation letter, the general feeling was that GPs should introduce the benefits of early diagnosis (by organised screening). An intriguing finding of this study is the fact that all so-called non-participants had a diagnostic mammography performed. This seems to indicate that indeed women in Flanders in general do not refuse to undergo a mammographic test, but that key persons (e.g. GPs) should guide them towards the organised screening programme.

It is clear that the implementation of this nationwide programme could not be realised without difficulties. The main issue at present is however not a disappointing willingness to participate, but the optimisation of use of the regular programme. The need is not to reach more women but to guide these women towards the appropriate facilities. Health economical evaluation is now urgently needed in order to further strengthen the argumentation of those who advocate a well organised centralised breast cancer screening programme.

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