Screening mammography: scientific knowledge, dispute and uncertainty.

Communication for an informed decision

Turin, 25 September 2013

A statement from GISMA - ONS

GISMA ¹ and ONS ² are Italian organizations dedicated to the design, monitoring and evaluation of programmes of service screening oncology in Italy. The Italian Group for Mammography Screening (GISMA) is the multidisciplinary society for breast cancer screening professionals, and the National Centre for Screening Monitoring (ONS) is an initiative of the Ministry of Health which is committed to quality improvement and the evaluation of the performance and outcomes of cancer service screening in Italy. In September 2013 GISMA and ONS jointly convened a workshop, held in Turin, for professionals working in the ambit of breast cancer service screening in Italy, to discuss and formulate their common position in the debate about the efficacy of screening for breast cancer, particularly in the light of two important recent publications which have addressed the balance of benefits and harms of screening mammography. The reports' principal findings are presented in terms of estimated mortality reduction and the ratio of estimations of those whose lives are saved to those who are harmed, i.e. have false positive mammograms or are diagnosed with breast cancer but would not have been so-diagnosed during their lifetimes in the absence of screening (overdiagnosis).

The later of the two publications is the report by the Independent UK Panel on Breast Cancer Screening. This report, commissioned by government, analyses the randomized controlled trials conducted in the USA and Europe in the 1990s whose results formed the scientific basis for the implementation of service screening mammography programmes. The report finds that service screening programmes 'extend lives', 'confer significant benefit' and that 'the greater the proportion of women ... screened, the greater is the benefit to population health in terms of reduction in mortality from breast cancer' and concludes that the UK's service screening programme should continue.

The earlier publication reports findings of the Euroscreen working group. The Euroscreen group was formed in 2010, thanks to international cooperation promoted by ONS, and is composed of experts operating at various levels of research and service in the European screening oncology sector. Their aim was assessment, in line with the EU recommendations, of the impact of service screening on mortality due to breast cancer and to study the relation between harms and benefits. To this end, the group only considered European observational studies of active screening programmes published in peer-reviewed journals evaluating efficacy, over-diagnosis and false positives. Their report reconfirms the beneficial impact of service screening mammography programmes in reducing mortality due to breast tumours and gives results which are consistent with those previously observed in the randomized clinical trials. Its estimate of harms leads to the conclusion of a favourable benefit-harm ratio for service screening programmes.

The difference between the methodologies of the Euroscreen group and the Independent UK Panel serves only to bolster the importance of their similar conclusions and the need to discuss future challenges and improvement.

GISMA and ONS, with their considerable experience of the design, monitoring and evaluation of screening oncology programmes, not only for breast cancer, believe that the time has come to reaffirm their commitment to programmes of service screening mammography.

GISMA and ONS believe that, in regard to communication and future challenges:

- 1. programmes must be supported in developing, testing and implementing communication strategies for delivering comprehensive and balanced messages, and stakeholders, particularly women, must have the opportunity to participate to ensure that information is imparted, as far as is possible, in ways that help them in making an informed choice.
- 2. screening professionals who provide information to women and other stakeholders must be assisted in their assimilation, understanding and elucidation of the methodology of screening programme evaluation, particularly the choices made and the estimates produced, in order that they make proper use of them in their discussions with stakeholders, particularly women
- 3. the presence of widespread opportunistic screening in Italy, even though of high quality in some areas, does not constitute a substitute for service screening because, being free of a quality

- control system and without periodic monitoring and collection of data, opportunistic screening can heighten the risks and adverse side-effects of screening
- 4. continuing research, whether it is in ways to identify over-diagnosis or to reduce the extent of treatment in specific cases or to continue the impact studies for mortality and over-diagnosis, is an absolute requirement that must be considered in the national and regional planning for screening programmes
- 5. it is fully appropriate that those who are involved in screening carry out research and enquire into screening itself through studies conducted with transparency and with the rigour of scientific method and, furthermore, that it is important, right and useful that public health operators working in screening actively participate in research at all levels, including the evaluation and improvement of information about screening and its limitations
- 6. it is essential that researchers from outside of the orbit of screening programmes study the methodology of evaluation and participate in the research process because their work is most likely to be impartial and unbiased
- 7. it is essential that researchers are assisted by making readily available the case data of cancer registries and the personal data collected by screening operators (service and opportunistic), the linking of which is fundamental to the evaluation of populational impact. This development of scientific information must be matched with data usability for the various interested parties and at all times greater transparency in communications
- 8. it is important to strengthen and promote alliances with professional groups, including women's associations, so as to widen the debate about the appropriateness of screening interventions and the cultural difficulties of coping with the limitations of medicine and prevention, which screening shares with other health care sectors and society.

¹ The Italian Group for Screening Mammography www.gisma.it

² The Italian National Observatory for Screening www.osservatorio nazionalescreening.it