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Letter

The screening debates: time for a broader approach?

JK Morris [1], describing how conclusive evidence from two studies undertaken in Germany and Canada in the early 1990s, after the introduction of mass screening 20 years ago for neuroblastoma in children in Japan, showed that "neuroblastoma screening was not only worthless, but led to an "over-diagnosis" and must have identified tumours that would have spontaneously regressed." Morris commented: "Screening caused significant harm." The editorial concluded by stating that it is now time to withdraw such screening in Japan, acknowledging that such action is difficult, but that this should not be a reason for failure to act. Morris expressed hope that these lessons will be learned when considering the implementation of other screening programmes, for example, screening for prostate cancer (see also EJC news (*Eur. J. Cancer* 2002, **38**, 2201–2205)).

It is not difficult to imagine the outrage in the community that withdrawal of the neuroblastoma screening programme would cause, or the anguish and anger of parents of an unscreened young child diagnosed with neuroblastoma when they learn that a simple, inexpensive, non-invasive test is available that detects 90% of children with the disease. Media coverage of such cases fuels the demand for mass screening and reinforces reasons why the public is driven by the intuitively irresistible logic of 'finding it early'; avoidance of anticipated decision regret; the 'right' to obtain test information; and 'the right' to parity with other sections of the community [2] rather than by the logic of 'conclusive research findings'.

The exercise would be even more difficult in other adult disease areas with higher profiles in the public arena. The evidence for effectiveness of screening at reducing mortality for complex diseases with varied rates of progression, regression, or aggressiveness that mainly affect aging or elderly populations, such as prostate cancer or breast cancer, is difficult to disentangle from the effects of therapeutic advances and earlier presentation over the same two decades. David Spurgeon [3], commenting on the findings from the 13-year update of the Canadian Trial of mammography in women aged 40–49 years [4], concluded by quoting from the editorial covering its publication [5]: "There will come a time when all the study patients have been followed-up, all the analyses have been done, all the expert groups have met, and all the editorials have been written, and we still won't be sure how much benefit and how much harm are caused by mammography." This resonates very strongly with Professor Sir Richard Peto's view that he does not agree that those assessing the effect of screening on total mortality should base their conclusions on statistical analyses of total mortality in the trials. Peto believes that, for reasons of statistical powers, inferences about the effects of screening on total mortality should chiefly be made indirectly, from analyses of the mortality attributed to breast cancer. (Personal written communication 14 January 2003).

These difficulties inevitably lead to impassioned debate, polarisation of interpretation and opinion, and misrepresentation of findings, not only within the public domain [6,7], but also within the scientific and medical press [8,9]. Good quality, balanced media reporting can be more difficult to find [10–12]. The instantaneously offered loud clamour of 'believers' is easier for many to identify with, rather than the more difficult challenge to engage in consideration of well reasoned expert presentation of published debate [13]; or evidence concerning the effect of the National Health Service (NHS) breast screening programme on mortality in England and Wales [14], and questions in its covering editorial [15]; or other research evidence concerning reasons and comparisons of falls in mortality of breast cancer in Europe [16]; or within the USA [17]. It is interesting to note that there are five European countries where breast cancer mortality has fallen: UK (with the highest recorded fall in the world), Spain, Italy, Germany and Austria. These last four countries do not have organised public health programmes offering screening. In The Netherlands and Sweden, where mammographic screening has been on offer longer than in any other country, the mortality rate has not fallen [18]. Bearing in mind the risk factors for breast cancer which are increasing and not easy to change—earlier age of menarche, later menopause, later child-bearing, not helping women to breast-feed, increasing obesity in

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middle age onwards—the spectacular continuing fall is all the more remarkable.

Until the necessity for making serious attempts to achieve a convergence through careful examination of valid and legitimate lay and scientific views is acknowledged, the ‘eruptions’ [5] and ‘fuelling of the debate’ [19] will continue to cause divergence. This does not serve the citizens that public health programmes are intended to help. Goodman and Sox‘s editorials [5,19] in the *Annals of Internal Medicine* comment on the publication of the 13-year update of the Canadian National Breast Cancer Screening Study in women aged 40–49 years [4], which found no difference in mortality between the screened and unscreened groups. The same issue contained a synthesis of breast cancer screening evidence for the US Preventive Services Task Force [20]. This showed that the number that needed to be screened to prevent one death from breast cancer after 14 years of observation was 1224 in women 40–74 years of age. Amongst women younger than 50 years, the number that needed to be screened to prevent one death from breast cancer after 14 years of observation was 1792.

The main objective of screening individuals or populations has been to reduce mortality in a specific disease by offering a diagnostic test. Few tests, if any, are risk-free. They are imperfect with respect to their sensitivity and specificity. The ensuing therapeutic interventions, offered within or without trials to individuals diagnosed by these imperfect tests, carry their own burden of risk, not just against the disease they are treating, but also with respect to wider effects generally. This premature route to becoming a patient can lead to profound health, social, psychological and economic consequences [21,22] for many individuals whether or not mortality reductions for that disease are achieved in the population. Because the objective within the scientific community has been to attempt to reduce mortality *in a population* in the disease area in question, the determination of “success” or “failure” is usually judged against that objective by consideration of data from trials or systematic reviews. The hidden and unexpected repercussions suffered by unsuspecting and under-informed citizens can be profoundly damaging to them *as individuals* and to their trust in the medical profession [23].

Today, the forum for the ‘screening debate’ is wider, but disjointed and divergent, extending well beyond the scientific community with its opportunities in its journals, meetings and conferences. Most would agree that this opening up of the debate is right and proper, seeing that screening is frequently a public health intervention, and/or funded by the individuals who seek to obtain or weigh the benefits of it in order to make decisions. The ground rules for this debate were presumed at the outset to be at the jurisdiction of the health professionals and scientists. Accommodation, in those early days, for the views of citizens, the screened, or the medical ethicists, or the psychosocial researchers, or social scientists—all of whom have broader considerations in mind—was not foreseen or catered for. Little provision was made for their input that saw the need to widen the objectives against which acceptability, feasibility or success of an existing programme might be judged, or to contribute to governance decisions. Submissions from other viewpoints outside the perceived parameters, addressing additional aspects to the main objective, were deemed irrelevant, biased, or ‘one-sided’. Olsen and Goetszche’s systematic review of mammographic screening [24]—with its discussion of the associated morbidities, misleading outcome measures of breast cancer mortality, and resultant more aggressive treatments—was challenged within hours of publication by providers, charities and many others. This was in spite of pleas both by the authors of the review [25] and Richard Horton, Editor of *The Lancet* [26], who stated that the findings had substantial implications for women and for policy-makers that required careful consideration and discussion. Only later, did less hasty criticisms within the medical press follow [27].

Greater caution is becoming evident as health professionals deliberate about the introduction of screening programmes [28], now less provoked by criticisms of attempting to save money, or of gender discrimination. They rightly justify the introduction of risk management programmes instead of mass screening, supported by reference to the relevant evidence [29]. This is more in tune (in the UK at least) with the move towards encouraging citizens to take personal responsibility for health decisions after having taken account of the full range of potential for benefit, harm or consequences, and being aware of the inherent limitations. We all live in an increasingly risk-aware society that has its own justifications for demanding ‘their rights’ to available tests [2]. These apparently irrational views require proper consideration if we are to achieve better and more economical risk-management through readily available tests and screening modalities [30].

Uncertainty is unpalatable. N.H. Keeble’s statement that “the experiential fact of uncertainty is incontrovertible” reminds us that probability is all that is on offer [31].

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