ticipating, or planning to participate, in the study. To produce reliable evidence to guide the future treatment of many millions of women with breast cancer there is an ethical and scientific imperative to continue recruitment into the aTTom study and other studies of the optimum duration of tamoxifen treatment.

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Multicentre trial should be welcomed

EDITOR,—R D Bulbrook's concern about the multicentre adjuvant tamoxifen trial¹ is misplaced. This trial seeks to address the vexed question of the optimum duration of adjuvant treatment with tamoxifen. The trial randomises patients who have been taking adjuvant tamoxifen for at least two years either to stop at this point or to continue for a further three years. There is no question of the trial embracing very long periods of treatment such as the 10 years referred to in Bulbrook's editorial. It is regrettable that this editorial may discourage recruitment to this extremely useful and pragmatic trial.

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Clinicians must share knowledge with their patients more readily

EDITOR,—Women will welcome the end of the uncertainty over the duration of treatment with tamoxifen.¹ The question to address now is the optimum duration between two and five years. But trials should build in measurements of quality of life as well as survival as end points.² For a singer, loss of top notes would mean the end of a career³; for a proofreader, retinopathy could spell redundancy⁴; for a young mother, brittle bones might be disastrous. For sexually active women, dyspareunia could threaten relationships. For any woman, the prospect of exchanging one cancer for another, or risking thromboembolism, is not to be relished.

It is also time that women were routinely offered simple hormone tests in Britain (as they are in North America). At the moment "oestrogen receptor status is available for less than 10% of women."⁵ This means that tamoxifen is given to

Kathleen Ferrier, the contralto, who refused an oophorectomy for her advanced breast cancer after being advised by a laryngologist that it might have a disastrous effect on her voice

many women who are unlikely to benefit: indeed, in large trials tamoxifen is given to all women, regardless of their oestrogen receptor status or menopausal status. Examples of such trials are the aTTom (adjuvant tamoxifen treatment offer more) trial, the adjuvant breast cancer trial, and the international breast cancer intervention study (a prevention study). The information thereby obtained is crude and does not help individual women; nor is the expense of inappropriate treatment justified.

Women are no longer ignorant of these issues, which are discussed in the national and women's press. The information is available on the Internet. Clinicians must now share knowledge more readily with their patients, so that women themselves can make decisions about their treatment that genuinely reflect their personal values.

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Creutzfeldt-Jakob disease and bovine spongiform encephalopathy

Scientists who inflame public anxieties must share responsibility for resulting panic

EDITOR,—Recent editorials on the danger of bovine spongiform encephalopathy causing Creutzfeldt-Jakob disease in humans confirm that academic scientists are as much in the grip of the irrationality of the mad cow panic as is the public.^{1,2} Paul Brown recalls his judgment of last November that the available evidence suggested "a negligible risk to humans,"³ only to confess that "it now appears that I was wrong."⁴ However, he adduces no new evidence to justify this about turn, simply repeating the now familiar refrain that "no better explanation is presently forthcoming."

Being unable to advance a better explanation than that offered by a hypothesis for which there is only the weakest circumstantial backing is a dubious basis for endorsing that hypothesis. Yet,

within a few sentences, Brown is raising the spectre of "a potential medical catastrophe." If an eminent scientist can swing in four months from characterising bovine spongiform encephalopathy as a negligible risk to warning of potential catastrophe is it any wonder that the public is confused and frightened?

With rhetorical flourish, Sheila M Gore demands, "let us have done with misleading the profession, the public, and the press" and insists that "all evidence must be quantified."⁵ As there is no evidence for a link between bovine spongiform encephalopathy and Creutzfeldt-Jakob disease it cannot be quantified; what is misleading is to imply that the link is something more than the weakest of hypotheses. Yet this is exactly the effect of the statement that there is "no better explanation" or that this is "the most likely" cause. Echoed in parliament and the press, such statements have fuelled the mad cow panic. Gore's powerful metaphors about British beef consumers continuing "to play Russian roulette" can only contribute to the hysteria.

Gore emphasises the need to learn the lessons of the AIDS crisis. Back in 1987 I argued that there was no evidence to justify the promotion of fears of an imminent explosion of HIV infection among heterosexuals in Britain.⁶ Now, nearly a decade later, we have a health scare not about a disease but about the possibility of a disease. Scientists who inflame public anxieties about uncommon or rare or possibly non-existent diseases (like bovine Creutzfeldt-Jakob disease) must take their share of the responsibility for the resulting panic and its consequences.

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Doctors and scientists must be able to communicate degree of risk . . .

EDITOR,—The handling of the issue of bovine spongiform encephalopathy¹ is an example of the consequences of poor communication about risk. Risk management and the communication of risk are not new, and it is disappointing that the principles of the communication of risk have not been applied. The Environmental Protection Agency in the United States has published a set of rules and guidelines, most of which seem to have been ignored in the past few weeks²: accept the public as a legitimate partner; listen to your audience; be honest, frank, and open; meet the needs of the media; speak clearly and with compassion; coordinate and collaborate with other credible sources; and plan carefully and evaluate performance.

Analysis of the problems encountered in terms of the sources of information on bovine spongiform encephalopathy and Creutzfeldt-Jakob disease, the means of communication, the messages that have been given, and the people receiving the information is revealing. There is a general lack of trust in the responsible authorities; there has been disagreement among scientific experts; the reporting of the issues in the media has dramatised events and emphasised the conflicts; and it has been difficult to explain the scientific uncertainties to a lay public that has inaccurate perceptions of risk and demands scientific certainty.

While the finger of blame will be pointed at the government, none of us can afford to be

complacent. As doctors or scientists we are asked to give opinions about a range of issues, not all of which lie within our area of expertise. We will probably also be asked about issues that are at the boundaries of medical and scientific knowledge and about which considerable uncertainty exists. It is incumbent on us to be aware of all the arguments and to be able to communicate the levels of uncertainty associated with them in an understandable fashion. We need to work with the media so that we remain in control of the debates, and, above all, we must preserve our professional credibility at a time when those around us are losing theirs.

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... but members of the public make up their own minds about risks

EDITOR,—The government's recent statement on bovine spongiform encephalopathy has focused media interest on its potential impact on consumer behaviour.¹ The general public's response to media reports on "mad cow disease" and how this might have affected their behaviour already have not been well documented. In a survey among nurses 5% reported avoiding beef and a further 58% said that they would do so if cross species transmission was confirmed.²

Before the government's most recent statement we interviewed 155 members of the general public in three south London boroughs to assess their knowledge of bovine spongiform encephalopathy and how this related to changes in beef consumption. Twenty one general practitioners also completed the questionnaire.

Overall knowledge of bovine spongiform encephalopathy was good, with 147 of the members of the general public being aware of the disease. Their assessment of the risk of Creutzfeldt-Jakob disease was accurate, with 129 saying that it was either rare or extremely rare and 120 correctly estimating the number of deaths in Britain each year as 50 or fewer.³ Altogether 134 reported that the media were their source of information, with only five having consulted their general practitioner.

Eighty one (55%) members of the public thought that humans could get the disease by eating cow products, compared with 12 (57%) general practitioners. Sixty (41%) members of the public and 14 (67%) general practitioners had reduced their beef consumption. The public tended to avoid all beef products, whereas general practitioners were more likely to refrain selectively from eating offal products (39 of the public avoided all beef and 21 were selective, compared with four and 10 general practitioners respectively; $\chi^2=6.2$, $df=1$, $P=0.01$).

Generally the public were true to their beliefs and changed their behaviour accordingly. Forty (49%) of those who believed that transmission was possible had reduced their beef consumption, compared with 14 (29%) who were unsure about transmission and none who thought that transmission was impossible ($\chi^2=17.2$, $df=2$, $P=0.002$).

We also identified a subgroup of 59 people who had consistently changed their diet in response to previous media reports, such as the scares over salmonella and listeria in food. Of these, 34 (58%) had decreased their beef intake, compared with only 25 (28%) who had not previously changed their behaviour ($\chi^2=12.6$, $df=1$, $P=0.0004$).

Thus, before the recent statements, the general

public seemed to have picked up on the uncertainty about the scientific evidence portrayed in the media, made up their own minds, and acted accordingly. The public are more sophisticated than we give them credit for; public health messages should take this into account. If people are given absolute answers to questions for which the evidence is uncertain they seem not to believe the message.

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Advisory committee's conclusion was based on "absence of any credible alternative"

EDITOR,—On 20 March the Spongiform Encephalopathy Advisory Committee in Britain issued a statement regarding 10 cases of Creutzfeldt-Jakob disease that showed a previously unrecognised and consistent pattern of disease.¹ The committee concluded: "in the absence of any credible alternative the most likely explanation at present is that these cases are linked to exposure to BSE [bovine spongiform encephalopathy] before the introduction of the SBO [specified bovine offal] ban in 1989." How can a committee of scientists come to a conclusion on the basis of no credible alternative? Why exposure to bovine spongiform encephalopathy and not to microwave ovens, high voltage power lines, or organophosphorus sheep dips?

These few words have caused an epidemic of hysteria across Europe and paralysed the British beef industry at home and abroad. Pharmaceutical companies are being besieged by patients concerned about the possible risks of medicines of bovine origin. For example, diabetic patients are asking whether they should continue to take beef insulin (in the case of the pharmaceutical company to which I am a medical adviser the insulins are made from pancreases from cattle outside the British Isles).

Another concern is that the suicide rate in British farmers—which is currently among the highest by occupation in Britain—will increase and that the increase will exceed the number of deaths from Creutzfeldt-Jakob disease over the coming months. All this when, in the committee's own words, "there is no direct evidence of a link."

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Government policy has failed

EDITOR,—Several weeks ago two of us expressed concern about the credibility of government advice on public health.¹ The issue of bovine spongiform encephalopathy has confirmed the disbelief with which some government pronouncements on public health are regarded in Britain and worldwide. If this situation is not to be repeated lessons must be learnt from three failures of policy.

The deregulatory culture in Britain contributed to the failure to regulate recycling of sheep remains until 1989, although the Royal Commission on

Environmental Pollution had expressed concern about this in 1979.² Ministers have taken minimal action, which has consistently been based on the most optimistic scenarios.³ Deregulation is justified largely on financial grounds. Comparison of the total costs that will be incurred in Britain with those of more regulatory policies elsewhere shows that this is not tenable. Amazingly, the government confirmed its intention to relax further regulations on food hygiene immediately after a worldwide ban on the export of British beef was proposed.⁴ But food safety is not the only aspect of public health affected by deregulation: there are concerns about the effect of deregulation in, for example, the water, nuclear, and transport industries.

The second failure of policy was the way in which the Spongiform Encephalopathy Advisory Committee worked, and this was compounded by the absence from the committee, until recently, of specialist public health scientists. In the face of uncertainty, traditional methods of assessing evidence should be supplemented with techniques such as modelling of the consequences of best and worst case scenarios. Had the committee done this it might have placed less faith in the species barrier, given that many human infections originated in animals. It might also have questioned the official confidence in the implementation of precautions, given extensive evidence that they are not being taken. It also failed to appreciate how risk is perceived, which led to a patronising impression, characterised by the secretary of state's statement that "it is the public who are mad rather than the cows."

The third failure arises from the relation between the government and business in Britain. The Ministry of Agriculture, Fisheries and Food continues to resist proposals for an independent food standards agency,⁵ giving the impression that commercial interests come before those of the public. A national food policy council is also needed to coordinate the many interests involved. There are many other issues, such as the presence of pesticide residues in fruit and vegetables, on which consumer opinion will demand a source of authoritative, independent advice. The public is concerned that intensive farming has cut corners in cutting costs. On grounds of public health and confidence in governance this cannot continue.

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Risk to human populations is remote

EDITOR,—Many commentaries on bovine spongiform encephalopathy have focused concern on recent unusual cases of Creutzfeldt-Jakob disease, an apparently important increase in the incidence of the disease, and statistical accretions in particular age and occupational groups. A link between the two diseases raises the possibility (even if not the probability) of risk to large numbers of people.¹ Indeed, the standardised mortality ratios for