

# **THE IMPLICATIONS FOR WALES OF THE PHILLIPS (BSE) INQUIRY REPORT**

## **A REPORT FOR THE NATIONAL ASSEMBLY FOR WALES BY THE HEALTH AND SOCIAL SERVICES COMMITTEE IN CONJUNCTION WITH THE AGRICULTURE AND RURAL AFFAIRS COMMITTEE**

### **CHAIR'S FOREWORD**

Following publication of the Phillips Inquiry Report in October 2000, The Health and Social Services Committee decided that it should consider and debate the issues arising from the Report that fell within the Committee's remit and consider evidence from appropriate parties.

This has been a difficult but significant piece of work for the Committee. It has been more difficult for many of the witnesses. On behalf of the Committee I should like to express thanks to all those who gave evidence, especially the families of BSE and vCJD victims in Wales and representatives of the Human BSE Foundation, who recounted their personal and tragic experiences with dignity.

**KIRSTY WILLIAMS AM**  
**Chair, Health and Social Services Committee**

### **1. INTRODUCTION**

1.1 The Phillips Inquiry Report was published on 26 October 2000, and included findings and recommendations for the conduct of business relevant to all UK Health and Agriculture Departments. The Report was made to the UK Government, but some of the issues on which it commented have been devolved and are now the responsibility of the National Assembly. Many of the findings are for the UK Government to lead in consideration and HM Government, in consultation with the devolved administrations, published its interim response on 9 February. The National Assembly is in close touch

with the work underway in Whitehall and elsewhere. An audit of the report has been prepared to identify areas that need to be addressed by the National Assembly.

1.2 The subject committees are able to consider and advise the National Assembly on whether appropriate measures are in place to address the concerns of the Phillips report in respect of devolved matters. They can also contribute to the framing of the response for Wales in an openly transparent way.

1.3 The Health & Social Services Committee has taken the lead in looking at protection of the human food chain and at the provision of care and support to victims and their families, whilst the Agriculture and Rural Development Committee has focussed on the agricultural and animal health issues. A joint meeting of the two committees was held on 24 January. It was agreed that the Committees' findings would be reported to the full Assembly to inform the wider plenary debate on the Assembly's response.

1.4 Except where stated, reference to "the Committee" in this report is to the Health and Social Services Committee. Reference to "the Committees" is to that Committee and the Agriculture and Rural Development Committee

## **2. APPROACH**

2.1 The Committee agreed that time should be allocated at its meeting on 6 December 2000 to begin consideration of the issues, and that the work should be Committee's priority for early meetings in 2001.

2.2 On 6 December, the following terms of reference were endorsed by the Committee:

"to complete an initial examination and report on key issues arising from the Phillips (BSE) Inquiry Report, in particular:

- a. the measures in place to protect the human food chain from the effects of BSE;
- b. the arrangements for caring for the victims of variant CJD; and
- c. the progress of the variant CJD epidemic and the way in which scientific advice is made available".

## **Evidence Gathering**

2.3 On 6 December, the Committee received oral evidence from:

- Dr Roland Salmon, Director of the Communicable Disease Surveillance Centre (CDSC) of the Public Health Laboratory Service (PHLS) in Wales, on the nature and progress of variant Creutzfeldt-Jakob Disease (vCJD) and the way in which scientific advice was made available;
- Members of the Human BSE Foundation on caring for sufferers of vCJD and their families;
- Joy Whinney, Director for Wales, Food Standards Agency (FSA) on protecting the human food chain; and

- Dame Deidre Hine, Chief Medical Officer for Wales 1990-97, who gave a brief account of the events that had taken place during that period.

2.4 Further oral evidence was received on caring for sufferers and their families on 24 January 2001 from:

- Gordon McLean, National Co-ordinator for CJD;
- Dr Marion Lyons, Consultant in Public Health at Bro Taf Health Authority; and
- Hugh Gardner, Chairman of the Association of Directors of Social Services (Wales) (ADSS).

2.5 In a joint meeting with the Agriculture and Rural Development Committee later that day, evidence was also received from:

- Professor Peter Smith, Acting Chair, Spongiform Encephalopathy Advisory Committee (SEAC) on the way in which scientific advice was made available; and
- Joy Whinney and Ann Hemingway of the Food Standards Agency;
- Chris Lawson, Acting Director, Meat Hygiene Service (MHS); and
- Tony Glacken, from the Society of Directors of Public Protection in Wales, on protecting the human food chain.

2.6 The Committee received written evidence from:

- Paul Boateng MP, Minister of State at the Home Office, about delays in holding inquests following the deaths of vCJD victims;
- Hugh Bayley MP, about fast tracking benefits to sufferers and their families; and
- Dr Terry Davies, Chairman, Royal College of General Practitioners on how GPs might be made more aware of the possibility of vCJD when patients present with relevant symptoms.

2.7 The evidence received is annexed to this report.

### **3. ARRANGEMENTS FOR CARING FOR SUFFERERS**

3.1 The Committee notes that the rarity of the disease meant that there was very little experience among medical, other health professional and social workers. The condition of sufferers can deteriorate quickly and structures are needed to ensure a quick response to the needs of sufferers from the disease and their families.

3.2 The Committee considers that many of the problems identified in caring for vCJD patients apply also to those who suffer from other rapidly degenerative diseases, such as motor neurone disease and AIDs.

### **Diagnosis of the disease**

3.3 The difficulty and sensitivity in diagnosing vCJD referred to in the evidence from the Chairman of the Royal College of General Practitioners (Wales) is noted. The Human BSE Foundation pointed to the distress caused to the victims and families when the true nature of the illness had not been identified. The response some of the victims and their families received indicated that some health professionals were unsympathetic to patients who presented with apparently psychiatric problems.

3.4 The Committee welcomes the research work that is being undertaken to develop diagnostic tests.

### ***Conclusions and recommendation:***

- *The development of an effective diagnostic test in the early stages of the disease is a priority*
- *GPs should be made more aware of the early symptoms and signs of vCJD and have access to guidance on diagnosis and care planning.*
- *The underlying causes of psychiatric symptoms should be investigated fully, whether or not vCJD is suspected.*

### **Further Guidance for Professionals on Care**

3.5 Guidance issued by the National Assembly in October 2000 for healthcare workers is being revised. The Committee considers that there should be effective networks for the sharing of experience and the development of best practice in care, and notes the role of the National Care Co-ordinator at the CJD Surveillance Unit.

### ***Recommendation:***

- *The National Assembly, working with the CJD Surveillance Unit, should ensure that comprehensive, multi-disciplinary guidance is disseminated and regularly updated.*

### **Mechanisms to Facilitate a Speedy Joint Response to Care Needs**

3.6 The Committee notes the view of Dr Marion Lyons that a standard for care could be developed in time, but that each case would have individual needs. The Health Service needs local plans to secure the necessary response and should maintain awareness among professionals and joint working across disciplines. Hugh Gardner told the Committee that care for victims of CJD should be a priority and included in the scope of implementing joint flexibilities between Health and Social Services. The Committee endorses the need for joint service planning.

### ***Recommendation***

- *Plans for meeting the needs of sufferers and their families should be an integral part of the joint working arrangements between the health service and social services.*
- *Victims and their families should be able to fast track access to the aids and adaptations they*

*need to help them to live as independently as possible.*

## **The Role of a Key Worker**

3.7 The Committee accepts the cases made by Hugh Gardner and Gordon McLean for a key worker. At a time when a family may be thrown suddenly into crisis a key worker would provide stability, building up trust and a relationship that could support the family through bereavement as well. A key worker would be able to liaise with other agencies so that the victim and the family would receive all the support they require at the appropriate time.

### ***Recommendation***

- *A key worker should be assigned to every vCJD case in consultation with the patient and his / her family or carers. The key worker should be responsible for drawing up and implementing the individual care plan with the patient and family or carers.*

## **Access to Care Budgets**

3.8 The Committee heard from some of the victims' families about delays in receiving care and aids and adaptations because of the slowness of bureaucratic processes. The pooling of care budgets might go some way in reducing delays, but rapid deterioration and change in a patient's condition often demanded an instant response.

### ***Recommendation***

- *The key worker should have a budget on which they are authorised to draw to meet patients' needs for care, aids and adaptations.*

## **Support for Families / Carers**

3.9 The Committee heard from Gordon McLean about the role of the National Care Co-ordinator in assessing and facilitating care needs and providing counselling and emotional support to the patients and their families. However, it notes that the involvement of the Care Co-ordinator is dependent upon the Surveillance Unit being advised of a suspected case. The Care Co-ordinator normally visits the patient within two weeks of notification, after initial inquiries of the family by the Unit.

3.10 The Committee takes the view that there is a need for the victims and families to receive counselling and support very quickly after the diagnosis has been made, to help them understand and cope with the disease. The special needs of children should receive attention.

3.11 The Committee commends the work of the Care Co-ordinator, and accepts that there are benefits in

centralising expertise. There is still uncertainty about how the vCJD epidemic will progress and therefore the capacity of the Co-ordinator to cope with demand needs to be kept under constant review. (Subsequent to its consideration of this issue the Committee has learned that a further care co-ordinator is to be recruited.)

3.12 The Committee was concerned to hear of the delays that some of the families had experienced in receiving advice on their entitlement to financial support. The Chair of the Committee wrote to the Department of Social Security Minister about the scope for fast tracking benefit advice and claims. The Minister, Hugh Bailey MP, responded with information on the National Benefit Enquiry Line and the special arrangements for processing claims from the terminally ill or their carer.

### ***Recommendations***

- *The National Assembly for Wales should monitor the incidence of vCJD in Wales and keep under continual review the capacity of the CJD Care Co-ordinator(s) to meet the needs of sufferers in Wales, their families and carers. If necessary it should consider whether a separate care co-ordinator is needed for Wales.*
- *It should be part of the key worker's role to make sure that victims and their families and carers have early advice on any financial benefits to which they might be entitled and are given any help they may need in making and pursuing claims for benefit.*

### **Palliative and Hospice Care**

3.13 The Committee heard from families of the victims that care is often needed for 24 hours a day. Domestic and family circumstances may preclude this being given in the patient's own home, especially as the disease progresses. Even where such care can generally be given at home there may be need for occasional respite care. However, most hospices cater exclusively for cancer sufferers. The committee takes the view that palliative care should be available for a wider range of care-intensive terminal illness.

### ***Recommendation***

- *The National Assembly should consider how palliative care for vCJD patients can be made available.*

### **Support for Families following the Death of a vCJD Patient**

3.14 Gordon McLean told the committee that the level of support for families after the death of the patient varied from area to area. The Committee considers that bereavement counselling should be made available as part of the care package for families and carers. The key worker should remain in touch with the family after the death to help them adjust and pick-up their lives. Again the needs for the counselling of children should be specifically addressed.

3.15 The Committee heard that there had been delays in holding an inquest. At the time of the evidence one family had been waiting five months. The Chair wrote to Paul Boateng MP, Deputy Home Secretary, seeking comments on whether such delays were commonplace and the action that might be taken to reduce delays and alleviate anguish for the bereaved. Mr Boateng replied that in the last five years there had been an increase in the percentage of cases that were taking over 6 months for an inquest hearing. The Home Office was monitoring these delays to establish the reasons. The Home Office had issued model charters for coroners and was encouraging them and their councils to adopt them. Mr Boateng was not aware of any particular delays in cases of deaths from vCJD.

### ***Recommendation***

- *Bereaved families should be offered counselling, with special arrangements for children where required.*
- *The services of the key worker should continue to be made available to the family to help them through the transitional period following the death of the patient. This should extend to helping them make any adjustments to their lifestyle resulting from reduced income, or securing help for carers to return to employment.*

### **Improving Public Information and Understanding**

3.16 It was clear from the evidence from a number of sources that there is still a lack of understanding among healthcare professionals as well as the general public about the nature of the vCJD epidemic and the symptoms and effects of the disease upon individuals.

### ***Recommendation***

- *The National Assembly should consider what more can be done to target information on the nature of vCJD.*

## **4. THE MEASURES IN PLACE TO PROTECT THE HUMAN FOOD CHAIN FROM THE EFFECTS OF BSE**

### **The Food Standards Agency**

4.1 The Committee has considered the evidence submitted by the Assembly Minister about the establishment of the Food Standards Agency (FSA) and its accountability to the National Assembly. It has also considered the evidence submitted by the Agency on the advice available to it, its research programme, the inspection of imported food and the development of its relationship with local authority public protection departments. The Committee notes that the FSA is still considering the lessons it can learn from the Phillips Report.

### ***Conclusion:***

- *The Committee applauds the FSA's aim to put the consumer first and to be transparent in its operations. It is early days to make firm conclusions on the FSA's effectiveness, but the Committee will continue to monitor its work.*

## **The Role and Effectiveness of Local Authority Public Protection Departments**

4.2 The Committee notes the role and responsibilities of local authorities as detailed in evidence supplied by the Society of Directors for Public Protection Wales. It was concerned to hear that the different structures of local authorities' public health work made it difficult to identify the resources allocated to food standards and safety and to compare performance between authorities. Members were also concerned to learn that additional money for improving local authorities' work on food standards had been made available through revenue support grant, but it had not been ring fenced. The Committee notes that the work is to be undertaken under a framework agreement with the FSA and that the FSA would be auditing local authorities' work in this area over the next three years. Audit report and action plans would be published.

### ***Recommendation***

- *Consideration should be given through the Partnership Council to ensuring that comprehensive information on local authorities' expenditure and performance on food standards work is published*

## **The Control of Imported Meat and Meat Products**

4.3 The Committee notes that beef labelling regulations in the EU are to be tightened in 2002 when the country of rearing and slaughter will be required to be specified on imported beef. It also notes that the Chair of the FSA was pressing the Commission to extend the country of origin requirements to all meat and meat products. The enforcement role of the Meat Hygiene Service is noted.

### ***Conclusions***

- *Both the Health and Social Services Committee and the Agriculture and Rural Development Committee are satisfied that the animal health controls now in place in the UK are adequate to deal with the known risks.*
- *Both Committees welcome the introduction of similar controls across the European Union and hope that they will be applied with sufficient vigour.*
- *The FSA should provide information on how intelligence is gathered on the safety of meat and meat products sourced from outside the European Union.*
- *The Agriculture and Rural Development Committee is concerned that imported meat should meet*

*the same high standards applied to beef produced in the UK, and that controls must be seen to be applied and enforced to ensure continued customer confidence.*

## **The Effectiveness and Enforcement of the 30 Month Rule**

4.4 The rule does not prohibit the import of beef from cattle over that age, only its use for human consumption. Thus it can be used for pet food. The Meat Hygiene Service advised the Committee that the rule was difficult to enforce as it was impossible to assess the age of meat off the bone, and with meat on the bone it was only possible to gauge whether it was from very young or very old animals. The importer was responsible for checking the documentation. The Service carried out checks at the eventual destination and the indications from their checks, and those of local authorities, were that there was a high level of compliance.

### ***Conclusion and recommendation***

- *This is a potential weakness in the measures for public protection. Any instances of non-compliance should be pursued rigorously to prevent recurrence, and the effectiveness of the rule kept under constant surveillance.*

## **5. THE PROGRESS OF THE VARIANT CJD EPIDEMIC AND THE WAY IN WHICH SCIENTIFIC ADVICE IS MADE AVAILABLE**

### **Tracking the Trends of the Disease in Humans and Cattle**

5.1 The Committees heard from Dr Roland Salmon that it was still too early to know how the disease would progress in humans. Predictions were based on mathematical models and estimates of the eventual epidemic size ranged from hundreds of cases to hundreds of thousands. However, estimates at the top of the range incorporated long incubation periods which Dr Salmon considered improbable. Professor Smith advised the Committee that the current estimates of the risks to humans ranged from 100 to 100,000 new cases, but he pointed to uncertainties in the assumptions underlying those estimates.

### ***Conclusion***

- *The Committee agrees with Dr Salmon that it is too early to relax vigilance, and that planning should be based on a realistic assumption of the likely size range of the epidemic.*

5.2 Professor Peter Smith reminded the Committees that there was still no known cause for the first case of BSE, but that the most probable explanation for the subsequent epidemic was the feeding of infected cattle material to cattle. Members note that the incidence of the disease has declined since restrictions on feeding materials were introduced in 1996 and that scientists believe that the only means of infection now is by maternal transmission.

5.3 Professor Smith also told the Committees that there was strong circumstantial evidence that BSE and vCJD were caused by the same agent, that it was not clear how it was transmitted to humans, but eating infected beef was the most plausible explanation.

### ***Conclusion***

- *The Committees support the programme of continuing research into BSE and other Transmissible Spongiform Encephalopathies, including the work underway to develop a reliable diagnostic test for BSE in live cattle.*

### **The Value of Autopsies**

5.4 Dr Salmon advised the Committees that in most cases of vCJD there was an accepted set of criteria that if fulfilled would indicate vCJD as the probable cause of death. In some cases, such as in elderly people, the symptoms may not be so clear. In these cases a post mortem was necessary to identify the cause of death and thus increase knowledge about the disease.

### ***Conclusion and recommendation***

- *The Committee notes that some doctors may be reluctant to seek a post mortem in order to save relatives from further distress. However, doctors should be encouraged to discuss the importance of establishing the cause of death with the bereaved relatives if they suspect that vCJD may be the cause.*

### **The Relationship between the National Assembly Professionals, National Assembly Ministers, Whitehall, SEAC, the FSA and Other Sources of Scientific Advice.**

5.6 Considerable progress has been made since 1996 in exchange of information between Departments and access to scientific advice. The FSA has been established as an independent body with clear lines of accountability to the National Assembly and a commitment to transparent working arrangements.

5.7 The terms of reference of the Spongiform Encephalopathy Advisory Committee have been revised to provide scientifically based advice to government, including the devolved administrations. The Committee notes that officials may attend meetings as observers, receive papers and are involved in administrative arrangements such as the appointment of new members. It is aware that SEAC members are appointed for their scientific expertise. However if the position of the National Assembly is to be protected there may be a case for further formalising the arrangements for observer status.

5.8 The committee notes that the Chief Medical Officer, Dr Ruth Hall is satisfied with the current arrangements for access to scientific advice.

5.9 The Committee heard with interest from Dame Deirdre Hine, former Chief Medical Officer, who

gave evidence to Lord Phillips's Inquiry. Dame Deirdre considered that the Welsh Office had benefited from the structure of the Health Professional Group prior to re-organisation in response to the Hart report. The group had been able to provide multi-disciplinary support and advice and she considered that the case for restoring it should be examined.

### ***Conclusions and Recommendations***

- *The National Assembly should work to develop a multi-disciplinary public health protocol for the assessment and management of risks to food safety and the response to outbreaks of human disease derived from food. This should embrace the Assembly's relationship with Whitehall and the other devolved administrations as well as its partners within Wales.*
- *The current arrangements for receiving scientific advice appear to be working, but should be kept under review and evaluated.*
- *The National Assembly should consider pressing for further formalisation of the arrangements for sending observers to SEAC meetings. Similar arrangements might be appropriate for other scientific advisory committees.*
- *The independent role of the Chief Medical Officer in providing objective advice on public health matters should be safeguarded.*
- *The National Assembly should consider the benefits of re-instating the Health Professionals Group that existed prior to the implementation of the Hart report.*

February 2001

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5. Letter to [Jeff Rooker](#) MP and response from Hugh Bayley MP (Department of Social Security) regarding the 'Phillips Report on the Emergence and Identification of BSE and vCJD.
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## **Health And Social Services Committee**

**HSS-19-00(p.6)**

Date: 8 November 2000

Venue: Committee Room 2, National Assembly for Wales

Title: **HANDLING OF THE PHILLIPS (BSE) INQUIRY REPORT**

### **Purpose**

1. The purpose of the paper is to identify issues which the Committee may wish to examine in the light of the publication of the Phillips Inquiry Report.

## **Recommendation**

2. The Committee is recommended to:-

- a. consider measures now in place to protect the human food chain by inviting the Food Standards Agency to explain its approach and the emerging issues it is dealing with;
- b. consider arrangements for caring for the victims of variant CJD by inviting representatives of the Human BSE Foundation to give the victims' perspective and the care co-ordinator from the CJD Unit in Edinburgh to explain his work; and
- c. to consider the progress of the variant CJD epidemic and the way in which expert scientific advice is made available by discussing this with representatives of the key independent advisory body, the Spongiform Encephalopathy Advisory Committee (SEAC).

3. Rural Affairs Committee has decided that it will consider the agricultural issues arising from the Phillips Inquiry Report. Given that there is common ground, it is further recommended that discussions with SEAC and the Food Standards Agency should be held jointly with that Committee.

## **Timing**

4. It is intended that there should be a Plenary Debate of the implications raised by the Phillips Inquiry Report before the end of January. The Committee will wish to have completed this first round of work before that.

## **Background**

5. The Phillips Inquiry Report was published on Thursday, 26<sup>th</sup> October. It runs to 4,000 pages in 16 volumes. Copies of Volume 1 (Findings and Conclusions) and Volume 9 (Wales, Scotland and Northern Ireland) are being made available to Committee members. The Members' Library has copies of the full report available (in both hard copy and CD-rom). The text of the Report is available also on the MAFF website.

6. The Report includes findings and recommendations for the conduct of business relevant to all UK Health Departments. Many of these can be best addressed on a pan-UK basis and National Assembly officials are closely in touch with the exercise which is getting underway in Whitehall. Devolved Authorities are being fully involved in this process.

7. National Assembly Subject Committees have an important part to play in satisfying themselves that, in relation to those matters that are now devolved, all appropriate measures for Wales are in place. Committees also have a role to play both in contributing to the framing of the response for Wales and in

ensuring that the process is taken forward openly and transparently.

8. The Rural Affairs Committee had an initial discussion of the Report and its handling when it met on Thursday, 2 November. The Committee resolved that it wishes to examine the animal health and agricultural implications of the Report and to co-operate with the Health and Social Services Committee where there was an interface between those issues and human health matters.

## **Consideration**

9. Lord Phillips of Worth Matravers was asked:

"To establish and review the history of the emergence and identification of BSE and new variant CJD in the United Kingdom, and of the action taken in response to it up to 20 March 1996; to reach conclusions on the adequacy of that response, taking into account the state of knowledge at the time; and to report on these matters to the Minister of Agriculture, Fisheries and Food, the Secretary of State for Health and the Secretaries of State for Scotland, Wales and Northern Ireland".

10. Formally, the Report is not made to the National Assembly for Wales, but many of the issues on which it comments have been devolved and now fall to the National Assembly to deal with. Many of the findings are for the UK Government to lead consideration and the Government intends to produce its initial response and soon as possible. The interests and responsibilities of the Devolved Authorities are being recognised in that process and National Assembly officials are in close touch with the work underway. An audit of the report will be prepared to identify areas requiring action by the National Assembly.

11. However, ahead of this we have identified a number of key issues arising from the Report and, in particular, from the emergence of the variant CJD epidemic that fall squarely in the Health and Social Services Committee's area and where action is required both now and in the future. These include:-

### The care of victims of variant CJD

a. So far 85 victims of variant CJD have been identified and of these 81 have died. In Wales, there have been 4 victims of whom 3 have died. There is no cure for variant CJD and it has proved difficult to diagnose the disease until it is well advanced. The CJD Surveillance Unit in Edinburgh employs a care co-ordinator who visits every victim in order to secure appropriate care from both NHS and Social Services. There have been difficulties in the care of victims, which the Committee will wish to note.

In presenting the Phillips Inquiry Report to Parliament, the Minister of Agriculture announced arrangements for an enhanced care package for victims, which, as well as improving physical care, would address the financial implications for dependants and families. The detail of these arrangements is still being worked through in discussion with the families of victims themselves. It is recommended that

the Committee invites representatives of the Human BSE Foundation to give the victims' perspective and, also, the care co-ordinator from the CJD Unit to explain his work.

### Measures to Protect the Human Food Chain

b. The vesting of the UK Food Standards Agency in April 2000, as an independent Department to assure food safety, has been a major reform. The FSA has specific reporting arrangements to the National Assembly and also has an Advisory Committee for Wales appointed by the Assembly. The Report points up difficulties in communication between Government Departments which the creation of the UK Agency with direct reporting lines to both UK Government and the devolved authorities should overcome. It is important to note that the Agency is committed to operating openly and transparently. It is recommended that the FSA be invited to explain to the Committee the way it is approaching its work.

### The progress of the epidemic and the role of expert advice

c. UK Departments and the Devolved Administrations receive independent expert advice from the Spongiform Encephalopathy Advisory Committee (SEAC). The Committee advises on the need for research, the implications of new findings, the need for new precautions and the expected progress of the epidemic. SEAC gave evidence to the National Assembly beef on the bone inquiry and it is suggested that they are again invited to attend in order to explain the current position on variant CJD.

### **Compliance**

12. The powers of the Assembly relevant to these issues are the Ministry of Health Act 1919, which covers action conducive to the health of people and the National Health Service Act 1977, which covers services related to health. Powers for both have been transferred to the National Assembly. The Government of Wales Act 1998 provides the Assembly with the power to do anything to facilitate, or conducive or incidental to, the exercise of any of its functions (section 40). The Food Standards Act 1999 deals with the National Assembly's powers in relation to food safety. The relevant powers are delegated to the Minister for Health and Social Services. The paper raises no issues of regularity or propriety.

### **Financial Implications**

13. The paper does not raise any financial implications.

### **Cross-cutting themes**

14. The Phillips Inquiry Report raises issues across a very wide area and in preparing a response the National Assembly's wider duties to local government, business and the voluntary sector will be taken into account. The Compliance Unit has seen this paper and is content.

## **Action**

15. The Committee is invited to consider the recommendations at paragraph 2 and 3.

**Jane Hutt**  
**Minister for Health and Social Services**

Contact Point: Public Health Division.

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## **Extract from Minutes of 8 November 2000**

**Paper: HSS-19-00(min)**

Item 4: Handling of the Phillips (BSE) Inquiry Report

Paper: HSS-19-00(p.6)

4.1 The Committee agreed that time should be allocated at its meeting on 6 December to begin consideration of this extremely important issue, and that the work should be Committee's top priority for meetings in the new year. . It was also agreed that the Chair should write to Dame Deidre Hine acknowledging her work on BSE when she had been Chief Medical Officer and inviting her to meet the Committee to discuss future safeguards.

## Action

- Clerk to advise on revised agenda for 6 December.
- Chair to write to Dame Deidre Hine.

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**Health & Social Services Committee**

**HSS-21-00 (p.1)**

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Date: 6 December 2000

Venue: Committee Room 2, National Assembly for Wales

Title: **THE PHILLIPS (BSE) INQUIRY REPORT**

## **Purpose**

1. The purpose of this paper is to set out the background to issues which the Committee will wish to discuss with witnesses in considering the ramifications for Wales of the Phillips (BSE) Inquiry Report.

## **Recommendation**

2. The Committee is recommended to endorse the draft terms of reference at paragraph 5 and to examine the way in which arrangements now differ from those extant during the period (i.e. up to 20 March 1996) considered by the Phillips (BSE) Inquiry, looking at:

a. with a representative of the Communicable Diseases Surveillance Centre (CDSC), the progress of the variant CJD epidemic;

b. with representatives of the Human BSE Foundation, who have been invited to attend, the arrangements for caring for the victims of variant CJD;

c. with the Food Standards Agency (FSA), the measures now in place to protect the human food chain; and

d. with Dame Deirdre Hine, formerly Chief Medical Officer for Wales, who has been invited to attend to give her reflections on her experiences in relation to the events considered by Lord Phillips;

3. The Rural Affairs Committee will consider the agricultural issues arising from the Phillips Inquiry Report. Given the common ground, a joint meeting with that Committee will be held on 24 January 2001 to allow further discussions with the FSA and, also, with representatives of SEAC (the Spongiform Encephalopathy Advisory Committee - the specialist advisory body).

## **Timing**

4. It is intended that there should be a Plenary Debate of the implications raised by the Phillips Inquiry Report early in the New Year, probably in February. The Committee will wish to have completed its work before the debate takes place.

## **Draft Terms of Reference**

5. The following draft terms of reference are proposed for the Committee's examination of this issue:

"to complete an initial examination and report on key issues arising from the Phillips (BSE) Inquiry Report, in particular:-

- a. the measures in place to protect the human food chain from the effects of BSE;
- b. the arrangements for caring for the victims of variant CJD; and
- c. the progress of the variant CJD epidemic and the way in which scientific advice is made available".

## **Background**

6. The Phillips Inquiry Report was published on Thursday 26 October. It runs to 4,000 pages in 16 volumes. Copies of Volume 1 (Findings and Conclusions) and Volume 9 (Wales, Scotland and Northern Ireland) have been made available to Committee members. The Members' Library has copies of the full report available (in both hard copy and CD-rom). The text of the Report is available also on the MAFF website.

7. The Report includes findings and recommendations for the conduct of business relevant to all UK Health Departments. Many of these can be best addressed on a pan-UK basis and National Assembly officials are closely in touch with the exercise underway in Whitehall to prepare the Government's response. The Devolved Authorities are being involved fully in this process.

8. The Rural Affairs Committee had an initial discussion of the Report and its handling when it met on Thursday 2 November. The Committee resolved that it wished to examine the animal health and agricultural implications of the Report and to co-operate with the Health and Social Services Committee where there was an interface between those issues and human health matters.

## **Consideration**

9. Lord Phillips of Worth Matravers was asked:

"To establish and review the history of the emergence and identification of BSE and new variant CJD in the United Kingdom, and of the action taken in response to it up to 20 March 1996; to reach conclusions on the adequacy of that response, taking into account the state of knowledge at the time; and to report on these matters to the Minister of Agriculture, Fisheries and Food, the Secretary of State for Health and the Secretaries of State for Scotland, Wales and Northern Ireland".

10. Formally, the Report is not made to the National Assembly for Wales, but many of the issues on which it comments have been devolved and now fall to the National Assembly to deal with. Many of the findings are for the UK Government to lead consideration and the Government intends to produce its initial response as soon as possible. The interests and responsibilities of the Devolved Authorities are being recognised in that process and National Assembly officials are in close touch with the work

underway. An audit of the report is being prepared to ensure that those areas either requiring action by, or of key interest to, the National Assembly are addressed.

11. There are a number of issues arising from the Report and from the emergence of the variant CJD epidemic which the Committee will wish to examine. These are:

#### The progress of the variant CJD epidemic

a. Annex A provides an analysis of the progress of the epidemic and the way in which it is tracked. A representative of the Communicable Diseases Surveillance Centre (CDSC) will offer further explanation.

#### The care of victims of variant CJD

b. Annex B sets out issues around the care of victims of variant CJD. The Committee is expected to have the opportunity to consider the experiences of victims and their families with representatives of the Human BSE Foundation who have been invited to attend.

#### Measures to Protect the Human Food Chain

c. The vesting of the UK FSA in April 2000, as an independent Department to assure food safety, has been a major reform. The FSA has specific reporting arrangements to, and an Advisory Committee for Wales appointed by, the National Assembly.

The Phillips Report points up difficulties in communication between Government Departments which the creation of the UK Agency with direct reporting lines to both UK Government and the Devolved Authorities should overcome. The FSA's Director for Wales will be available to explain the approach being taken by the new Agency.

#### The lessons for Wales from the Phillips Inquiry Report

d. Annex C sets out some themes from the Report. One important change since the period under report is that SEAC's terms of reference now require it to report to the National Assembly. However, the Committee will wish to consider the experience of the former Chief Medical Officer for Wales, Dame Deirdre Hine who has been invited to attend.

### **Compliance**

12. The powers of the Assembly relevant to these issues are the Ministry of Health Act 1919, which covers action conducive to the health of people and the National Health Service Act 1977, which covers services related to health. Powers for both have been transferred to the National Assembly. The Government of Wales Act 1998 provides the Assembly with the power to do anything to facilitate, or conducive or incidental to, the exercise of any of its functions (section 40). The Food Standards Act

1999 deals with the National Assembly's powers in relation to food safety.

The relevant powers are delegated to the Minister for Health and Social Services. The paper raises no issues of regularity or propriety.

### **Financial Implications**

13. The paper does not raise any financial implications.

### **Cross-cutting themes**

14. The Phillips Inquiry Report raises issues across a very wide area and in preparing a response the National Assembly's wider duties to local government, business and the voluntary sector will be taken into account. The Compliance Unit has seen this paper and is content.

### **Action**

15. The Committee is invited to consider the recommendations at paragraph 2.

**Jane Hutt**  
**Minister for Health & Social Services**

Contact Point: Public Health Division.

**Annex A**

## **Progress of the variant CJD epidemic and the way in which it is tracked**

### **Introduction**

1. Variant CJD was first reported in 1996. The initial 3 cases were diagnosed in 1995 but the possible association with BSE was not made until 1996. The association is now accepted; BSE and vCJD are caused by the same infecting protein (prion).

### **Definite and probable cases in the UK**

2. The table below gives all CJD types since 1985. The highlighted columns are for variant CJD. The total for 2000 currently stands at 29 when the probable diagnoses are included.

Year	Referrals	Sporadic	Iatrogenic	familial	GSS	vCJD probable still alive	vCJD probable deaths awaiting p.m. results	NvCJD confirmed*	Total
1985	-	26	1	1	0	-			28
1986	-	26	0	0	0	-			26
1987	-	23	0	0	1	-			24
1988	-	22	1	1	0	-			24
1989	-	28	2	2	0	-			32
1990	53	28	5	0	0	-			33
1991	75	32	1	3	0	-			36
1992	96	43	2	5	1	-			51
1993	78	38	4	2	2	-			46
1994	116	51	1	4	3	-			59
1995	87	35	4	2	3	-		3	47
1996	134	40	4	2	4	-		10	60
1997	161	59	6	4	1	-		10	80
1998	154	63	3	3	1	-		18	88
1999	169	61	6	2	0	-	-	15	83
2000*	151	30	0	1	0	4	4	21	60

\* To 3 November 2000. Total number of definite and probable cases of vCJD = 85.

\* including 7 probable deaths from vCJD where neuropathological confirmation will never be possible.

The next table will be published on Monday 4th December 2000.

## Tracking the epidemic

3. The epidemic surveillance is co-ordinated by the CJD surveillance unit in Edinburgh. They receive notifications (referral column above) from principally neurologists. Epidemiologists from Edinburgh interview the relatives/doctors associated with cases and collect a large amount of information to assist in assessing the national picture. Figures as above are published monthly and discussed by SEAC and other groups associated with CJD/BSE issues.

**Annex B**

## Diagnoses and care of victims of variant CJD

1. Best practice guidance on healthcare for CJD patients was published in October 2000, to complement guidance on social care produced in 1998 by the CJD Support Network in collaboration with the Association of Directors of Social Services Professionals. The guidance draws on the experiences of families and professionals, and represents a guide to best practice in caring for patients with all types of CJD. It stresses the importance of a multi-disciplinary approach to care, which needs to be co-ordinated and regularly reviewed because of the rapidity with which patients can deteriorate. The role of a key worker is very important to ensure a range of services come together in a co-ordinated and timely way. It is the implementation of this guidance that the Assembly is promulgating

### **Diagnoses and Clinical features**

2. CJD is invariably fatal. The illness usually has a short duration after the onset of progressive symptoms but varies according to the type of CJD. The median illness duration is approximately 3-4 months in classical CJD, 14 months in vCJD and 2-5 years in inherited forms. The rarity of the disease and the lack of a simple diagnostic test mean that it is often difficult to confirm the diagnosis. Many patients' families are angry that their relatives have been given a psychiatric diagnosis and managed in a psychiatric setting.

3. Diagnosis usually involves an intrusive and distressing process for patients and their families. It may include: lumbar puncture, EEG, CT & MRI scans, tonsil biopsy, brain biopsy and genetic testing.

### **Care requirements and co-ordination**

4. The rarity and special features of the disease mean that local care services will need specialist support and advice. Patients with terminal or degenerative conditions benefit from co-ordination of care and the identification of a key worker. Partnership arrangements are the most appropriate, in the circumstances of vCJD, as they allow the speed and co ordination needed to respond to needs.

5. Support and advice for families in Wales is provided by the National CJD Case Co-ordination Project run by the CJD Support Network. From January 2000 the National CJD Surveillance Unit has employed a national care co-ordinator to provide specialist expertise in CJD and act as an information resource for carers and professionals. These arrangements provide detailed advice to local agencies on the likely progression of the disease and the range of care services that may need to be put in place. They will emphasise the importance of appointing a key worker at the earliest stage to co-ordinate a speedy response, tailored to meet the needs of the patients and their families.

6. The Department of Health has also given financial support to the Human BSE Foundation, a voluntary organisation run by and for families affected by variant CJD to offer help, support and practical advice.

## **Some Themes from the Phillips Report**

Lord Phillips has made the point that the report needs to be considered in its entirety. However the following themes may be of particular interest to the Committee:

- the way that policy measures were developed. The Report identifies a certain "lack of rigour" in tackling some issues although the policy responses developed are seen as having by and large been on the right lines;
- delays in taking action at various points in the BSE story, including the absence of contingency planning in the period of a few weeks in early 1996 when it seemed increasingly likely that a scientific view that vCJD was probably derived from eating BSE infected meat was imminent;
- concerns about the way that messages about BSE were conveyed to the public. The Inquiry concludes that Government had tried hard to counter negative treatment in the media. There was a lack of openness and over-management of information;
- the Trust that the public has in Chief Medical Officers is precious and should not be put at risk;
- any advice given by a Chief Medical Officer or advisory committee should be, and be seen to be, objective and independent of Government;
- Government expected its scientific advisory committees to shoulder too much of the responsibility for policy matters;
- there was a collective failure to revisit key scientific assumptions about BSE on a sufficiently regular basis – policy measures might have had a firmer basis if key people had stopped to take another look at assumptions underpinning new decisions;
- the Welsh Office medical team is commended for "the quality of its independent thinking" and for following up its concerns with Whitehall. The team did their best to register valuable insights which they had to offer for national policy development. The Welsh Office response is presented as a good example of multi-disciplinary working;
- concern about the effectiveness of communication between Departments. Without access to basic information, Territorial Departments had to rely on judgements already made.

### **Extract from Minutes of 6 December 2000**

**Paper: HSS-21-00(min)**

Item 2: The Phillips (BSE) Inquiry Report

Paper: HSS-21-00(p.1)

### **Terms of Reference**

2.1 It was confirmed that the Health & Social Services Committee would take the lead in relation to protecting the human food chain and the provision of care and support to victims and their families, whilst the Agriculture and Rural Development Committee would focus on the agricultural and animal

health issues. There would be a joint meeting on 24 January and both Committees would report to plenary in February.

2.2 The Committee endorsed the draft terms of reference.

### Nature and Progress of vCJD

2.3 The Committee welcomed Dr Roland Salmon, Director of the Communicable Disease Surveillance Centre (CDSC) of the Public Health Laboratory Service (PHLS) in Wales.

2.4 Members asked the following questions to which Dr Salmon replied:

Q What were the early symptoms of vCJD and how did the disease manifest itself in sufferers as it developed?

A Typically, in the first six months, symptoms of vCJD were extremely non-specific and predominantly psychiatric. After approximately six months, specific signs related to the nervous system appeared, such as clumsiness and lack of balance or co-ordination. This would be followed by the onset of dementia and eventually the person became, frequently, bedbound, unable to walk, speak, see or hear. From the first symptoms to the final stages could take up to three years.

Q Was it correct that sporadic CJD did not have such a long gestation period as nvCJD?

A Yes. The median length of the disease in vCJD was approximately 12 months and it was six months before any signs were apparent. By contrast the length of illness in sporadic CJD was frequently less than 6 months in total.

Q When CJD was suspected a number of investigations were carried out (lumbar puncture, EEG, CT scan, MRI scan, tonsil biopsy, brain biopsy and genetic testing). At what stage would this help inform diagnosis?

A In general, all tests started to show as positive once a clinical diagnosis could be made. The general view was that there was little that could be done to firm up the diagnosis in the early stages, before clinical diagnosis.

Q Did the medical profession generally know enough to identify possible vCJD?

A Dr Salmon believed that generally there was enough knowledge available but that, in specific instances, knowledge may not be accessed and deployed at the appropriate time.

Q What resources were being deployed in developing schemes to diagnose vCJD?

A A large research programme, jointly driven by the Department of Health, Ministry of Agriculture, Research Councils and the Wellcome Foundation, had been set up and one of their priorities was the development of diagnostic tests.

Q Was there any evidence of the disease being masked by other diseases and not diagnosed?

A In the case of young people it was very difficult to find any evidence of under diagnosis but in older people it could be more problematic as dementia was a common symptom. The problem was compounded by fewer post mortem examinations.

Q Should there be more post mortems where there was a possibility of CJD?

A It was felt that there was much to be learned in general from post mortems and coroners should be encouraged to have them carried out.

Q Was it correct that the median illness time for classical CJD, which affected the elderly, was 3 to 4 months?

A Yes.

Q The median duration for vCJD is 14 months. Was there any danger that in current procedures an illness of that length could be described as classical? Was it possible to distinguish between various forms of CJD?

A It was possible to make a distinction using chronology, MRI scan and histopathology.

Q How could the public be better informed about infectious disease?

A A great deal was being done to enhance people's understanding of the science surrounding the work of the CDSC, including collaboration with organisations like Techniquet to hold briefing sessions for school children to explain infectious diseases.

Q Was it possible to confirm diagnosis of CJD without a post mortem?

A In humans there was an accepted set of criteria which, if fulfilled, would deem CJD as the probable cause of death. It was more difficult in cases, such as might occur in elderly people, that did not exhibit typical symptoms. In these cases a post mortem was necessary to identify the cause of death and to increase knowledge, in general, of the epidemic.

Q Was it intended to issue any guidance to clinicians to assist early diagnosis?

A It was recognised that early diagnosis was difficult, if not impossible, in practice. It was felt that media reporting not been helpful. Given the similarity of the early symptoms to psychiatric disorders it was not unreasonable for a doctor to make a psychiatric referral in the first instance, given that much psychiatric illness is treatable but CJD is not.

Q Given that the early perception was of psychiatric illness, was there a case for providing public information on the early symptoms?

A Public education campaigns were effective when there was action the public could take to improve their health or prevent illness, although, even then, such campaigns could have unanticipated consequences. It was not clear that there were such specific actions in the event of CJD and much anxiety could result among a wider public. Once diagnosis had been made, however, information needed to be made available to families as quickly as possible.

Q What research had been done on linked cases and clusters? What was the progress of the disease to date?

A The Department of Health had issued the latest numbers of known cases of vCJD disease on 4 December. The number of definite and probable cases in the UK was 87. The number of cases this year represented a significant advance on last year and the expectation was that it may increase further next year. It was known beyond any reasonable doubt that the infection in humans was the same as in cattle and cats but it was not clear how it actually got from one to the other. The investigation of clusters would provide an opportunity to examine what might be the relevant links between cases.

Q Was there any significance in the increase of cases this year and the fact that cases now existed outside the UK.

A The increase in cases had been the subject of an article in the Lancet on 5th August. The first French case had been reported in 1996/97. It was understood that there was no evidence that the victim had been a regular visitor to the UK, although a lot of British offal had been exported to France during the early 1990's so that did not preclude a link to the UK. One of the vacuums in understanding CJD was a lack of detailed knowledge of the transmission route from cattle to humans and this made a rational approach to prevention very difficult.

Q Early on, vCJD had been portrayed as a young person's disease. Could it now be assumed that the whole population was at risk?

A It was Dr Salmon's opinion that the whole population was at risk and CJD was not just a young person's disease, although the fact that predominantly young people had been victims of vCJD might produce some interesting insights into how it was acquired. Whilst it was clear that genetics played a part in susceptibility to the disease, there was no reason to assume that the rest of the population would not be susceptible.

Q What should the Assembly's approach be to public health and prevention?

A Dr Salmon felt that the way in which the Assembly conducted its business was encouraging, with open Committee debate and publication of documents. However, he pointed out that many believed that in government, generally, at all levels there was even more emphasis on information management (something criticised by Lord Phillips) than there was in the early 1990s. He was critical of the role played by the media in informing the public of the details of the issue so that the public could engage in the wider debate. He also questioned the lack of effective democratic scrutiny at the time and hoped this would no longer be the case.

Q Would the Welsh Office have been more likely to have issued a statement cautioning against the safety of beef if there had there been an Assembly in 1990, and had the Welsh office applied good public health principles?

A There had been a great deal of concern amongst officials in the Welsh Office at the categorical nature of the advice being issued by Whitehall. Welsh Office advisers had considerable, relevant professional experience. It was possible that the existence of an Assembly might have altered how the issue was handled.

Q Concern was expressed about the protection of healthcare workers.

A The Advisory Committee on Dangerous Pathogens had looked at occupational protection several times over the last ten years and had issued advice which would eliminate most of the risk.

Q Incidence of vCJD was increasing, what was the likely outcome and what was happening to rare and sporadic forms?

A Although the incidence of Sporadic CJD had increased this was due to an increase in diagnoses among the elderly, believed to result from better ascertainment. It did not appear that the disease was at substantially different levels from those known in the past. GSS (Gertsman-Straussler-Scheinker) disease was predominantly genetic and only found worldwide in certain family groupings. It would remain rare. For vCJD it was too soon to know how it would progress. Predictions were based on mathematical models and estimates of the eventual epidemic size ranged from hundreds to hundreds of thousands of cases. Scenarios that gave very large numbers tended to be based on mathematical models that incorporated in their calculations long average incubation periods, which appeared, to Dr Salmon, improbable. If so, and it was too early to relax our vigilance, the figures would, hopefully, be at the lower end of those estimates.

### The Arrangements for Caring for Sufferers

2.5 The Chair welcomed members of the Human BSE Foundation, all of whom had cared for family members suffering from vCJD, and thanked them for coming to share their experiences with the Committee.

2.6 Nigel Beavon described the onset of the disease in his wife Karen and the treatment she had received. He outlined the difficulties he had experienced in trying to obtain support, particularly from social services. Karen had been denied access to a community practice nurse because she was seeing a counsellor and was told that she could not see both. Once vCJD had been diagnosed, three weeks before his wife's death, funding for hospice care was not available because the committee that approved the funding only met once a month and a meeting had taken place just before the application was made. Karen had died in July and an inquest had still not been held, nor had the family received a death certificate.

2.7 John Williams' experience had been slightly more positive and he had received more support, particularly from his GP. His daughter Alison had been the first victim of vCJD in Wales and the biggest difficulty he had encountered was the lack of knowledge and understanding of the disease.

2.8 Malcolm Tibbert, Chairman of the Human BSE Foundation, said that Nigel Beavon's experience was not peculiar to Wales, but he was very disappointed that five years after the first case of vCJD had been diagnosed such problems were still in evidence. It also highlighted the difficulty in obtaining the necessary level of high dependency care because there were no facilities in the UK for young terminally ill people, and a large number of hospices accepted only cancer patients.

2.9 In discussion, members of the Human BSE Foundation made the following points:

- It was important that families were given the choice of providing care at home or in a hospital or hospice setting;
- Care packages should be tailored to meet the individual needs of the patient and carer in each case. A general care package was not suitable as symptoms and family and domestic needs varied.
- There was not perceived to be a conflict between medical confidentiality and the need to secure good services, as the local health authority would be in possession of the victim's details.
- A fast track system for access to support, both care and financial, was essential.
- The CJD Unit in Scotland employed the only Care Co-ordinator in the UK. It was suggested that having one based in Wales would relieve some of the pressure from him.
- Consistency of approach was essential to ensure everyone had access to the same level of care;
- It was acknowledged that health professionals were still learning about vCJD but it was felt that information was not shared widely enough. vCJD was a problem throughout the whole of the UK and a common information source was needed.
- The Foundation operated a helpline. They also had a website which was currently being developed further to provide more information to those seeking advice.

2.10 Assembly members raised the following points:

- There was a need for a change in attitude towards provision of support to people with psychiatric disorders, whether or not they were related to CJD;
- Effective joint working between specialties and different tiers in the health service and between health and social care was critical;
- General practitioners and other clinicians needed to be more alert to the early symptoms of vCJD, and social services more responsive to the needs of CJD patients;
- The Assembly's guidance for healthcare workers should be made available to anyone who might be involved in caring for a victim of vCJD.

2.11 Dr Ruth Hall, Chief Medical Officer, said that the discussion had highlighted the need for increased awareness and education of professionals, and she had raised the possibility of setting up a professional network to share expertise across the UK with her colleague Chief Medical Officers. She said that epidemiologists did not need access to victim's personal information, but it was essential that clinicians had access to the best possible information. The patients and their families required comprehensive care packages. She confirmed that the Assembly's guidance for healthcare workers was to be revised and would be informed by the issues that had been raised.

2.12 The Minister thanked everyone for sharing their experiences with the Committee. She said she realised how distressing it must have been, but hoped that the families recognised the importance the Committee placed on taking this forward and getting it right and the important part their experiences would play in that. There would be a UK response to the Phillips Report which Wales would feed into and the Committee would also prepare a report to the Assembly on their findings and recommendations.

The report would include the key issues raised by the families and the lessons to be learnt from their experiences.

### Key lessons to be learnt from the Report

2.13 Joy Whinney, Director for Wales, Food Standards Agency (FSA), gave a brief background to the establishment of the FSA and the measures in place to protect public health (see Annex A). She said that one of the most important lessons to be learnt from the Phillips Report was the need to end the culture of secrecy that had existed. The FSA's core values were to put the consumer first and be open and accessible. One of the FSA's first tasks had been to review BSE controls and it would not be recommending any immediate changes. It would be recommending a ban on recycling blood, gelatine and tallow and that research was needed to develop rapid diagnostic tests for BSE in abattoirs. A report of the recommendations would be published before Christmas.

2.14 In response to questions from members, Joy Whinney gave the following responses:

- Setting up the FSA would not mean there would never be another emergency but it would be handled in an open and transparent way;
- Any advice to Ministers or information passed on to the public should be based on scientific evidence.
- The FSA was reviewing its research programme and how it set its research priorities. It would ensure proper co-ordination between research funding bodies, and commission research to fill gaps.
- The FSA had inherited its research budget from the Ministry of Agriculture, Fisheries and Food (MAFF) and the Department of Health (DoH). There was also BSE research being funded by MAFF and a joint funding group.
- The FSA had access to a range of experts to provide advice on food safety issues, including the Spongiform Encephalopathy Advisory Committee (SEAC), and it also had a number of scientists on its Board.
- Largely, the same standards applied to imported foods as those produced in the UK and the European Commission Food and Veterinary Office carried out regular checks in EU countries. It recognised that there could never be 100% certainty about the control in other countries, but it was also the case that there could not be 100% certainty that standards were adhered to in Britain. The important issue was making enough information available to allow the consumer to make an informed choice and the FSA were pressing for better country of origin labelling.
- It was accepted that the public might have suspicions that standards were not applied as rigorously in other countries but the FSA carried out inspections of imported foods and any problems were thoroughly investigated.
- The FSA was considering the provision of epidemiological research and advice in its consideration of the Phillips Report. It was stressed that much closer relationships existed with the Public Health Laboratory Service (PHLS) than had previously been in place.
- The commitment of local authority officers was recognised. More control was being given to local authorities and this was subject to regular review. An accountability framework had been

drawn up with local authorities to set out more clearly what the FSA expected them to provide in terms of food safety and standards. A report on the achievement of these standards would be publicly available and the FSA would work with local authorities to address any areas of concern.

- The UK coverage of the FSA ensured consistent risk assessment across the UK.
- The FSA intended to produce a database of establishments that had broken the law in terms of food safety.
- It was important to make the public aware of the FSA and its role and responsibilities.

2.15 The Chair welcomed Dame Deirdre Hine, now Chairman of the Commission for Health Improvement, to the meeting. Dame Deirdre had been Chief Medical Officer for Wales from 1990-97 and gave a brief account of the events that had taken place during that period.

2.16 In response to questions from members, Dame Deirdre made the following comments:

- It had been purely lack of evidence to challenge DOH and MAFF that had prevented her recommending to Ministers that they make a public statement on the safety of British beef.
- With regard to the statement at Chapter 9, section 5.16 of the Philips' report, it was not normal for the Welsh Office to endorse, or otherwise, statements made by the Chief Medical Officer in England but it was expected that Directors of Public Health in Wales would ask and it was in that context that the suggestion was made not to directly endorse it.
- The relationship with DoH had always been good and they had always been receptive to the Welsh perspective. The DoH partnership with MAFF may have led to the different attitude over BSE.
- It would not have been helpful to have brought the concerns into the public domain as there had been no hard evidence to corroborate them.
- The establishment of the FSA was welcomed and it was believed that the difficulties encountered would not have occurred in the context of the FSA, with its climate of openness.
- It was believed that the Health Professional Group as it had existed prior to the Hart report had been an extremely valuable source of multi-disciplinary support and advice and consideration should be given to restoring it.
- The public health approach was very important, as was having a sufficient cadre of trained public health professionals to safeguard the health of the people of Wales.

2.17 The Minister thanked Dame Deirdre for sharing her experiences and views with the Committee.

## Conclusions

2.18 The Minister asked members to consider who else they would like to invite to put their views to the Committee. Suggestions included environmental health representatives from local authorities, Benefits Agency, Health & Safety Executive, carers, and the CJD Care Co-ordinator. It was agreed that these suggestions be discussed at the next Party Spokesperson's meeting. Because of the timescale involved in preparing a report for plenary, a balance between oral and written evidence would need to be achieved

and this would also be discussed with party spokespersons.

## **FEED CONTROLS**

### **Basis of UK feed controls**

The aim of the feed ban is to eliminate the incorporation of potentially infective material into feed for ruminants. If there is no other significant route of infection, this measure alone would eventually eradicate BSE from UK cattle.

### **Feed controls since 1988**

In the UK a ban on feeding ruminant protein to ruminants was originally introduced in 1988. However, cattle born after this date continued to be affected by BSE. It is thought that this was, at least in part, because of cross contamination of ruminant rations from other livestock feeds.

Since June 1994, the EU has prohibited the feeding of mammalian protein to ruminant species in all member states including the UK. Our UK feed controls were extended in March 1996, on the advice of SEAC, to prohibit the feeding of all mammalian MBM to all farmed livestock, in order to avoid any possibility of its getting into feeds for ruminants. From 1 August 1996, the possession of mammalian MBM was banned from farms and feed premises. A feed recall scheme was conducted to ensure that residual stocks were removed from farms. It is believed that from this date the feed controls in the UK became fully effective.

### **EU-wide controls**

The Agriculture Council of 4-5 December 2000 concluded that there should be a temporary ban on the feeding of meat and bonemeal to farm animals from 1 January 2001.

### **Monitoring and enforcement**

To monitor compliance with the feed controls, the Government has in place a feed sampling programme. This programme, conducted by the SVS since February 1996, takes around 20,000 samples annually, and includes around 3,000 premises. Each positive or inconclusive result is followed up with a full investigation.

### **Over Thirty Month Cattle Slaughter Rule (OTM rule)**

#### **The rule**

The OTM rule, with some exceptions, prohibits the sale of meat for human consumption from cattle aged over 30 months at slaughter. It is implemented by the Fresh Meat (Beef Controls)(No2) Regulations 1996, which came into force on 1 September 1996. The Regulations continued a provision made earlier that year which made it an offence to sell over age bovine animals slaughtered on or after 29 March 1996.

At the time of its introduction, the Rule used the number of an animal's teeth as an approximate physiological means to determine age.

On 21 September 1997, the Animal By-Products (Identification) (Amendment) Regulations 1997 tightened the controls by requiring that beef shall be treated as a by-product (not sold for human consumption) if the animal from which it came has been shown to be more than 30 months old at the time of slaughter for human consumption.

From 1 January 1999, the Cattle Identification Regulations 1998 have required all 30 month and younger cattle to have a passport. Since then, older animals have been excluded from the food chain either because the cattle passport showed them to be over 30 months of age at slaughter or because they lacked a passport.

#### Basis for the rule

The rule was introduced after the SEAC had considered 10 cases of Creutzfeldt-Jakob Disease and concluded, in March 1996, that a previously unrecognised and consistent disease pattern had been identified. SEAC advised in a statement on 20 March 1996, to prevent further exposure to this risk, that carcasses from cattle aged over 30 months must be deboned in licensed plants supervised by the MHS, and the trimmings must be classified as Specified Bovine Offals"

It proved impractical to implement the deboning recommendation and so it was decided that, with some exceptions, meat from both home-killed and imported animals aged over 30 months at slaughter should be prevented from being sold for human consumption.

Exemptions are for specialist beef herds registered with the Beef Assurance Scheme, which may be sold for consumption at up to 42 months of age, and meat imported from 14 countries that traditionally supplied the UK and in which there is no history of BSE.

#### Planned EU-wide controls

At the Agriculture Council of 4-5 December, new EU-wide controls were agreed. The measures include a ban on cattle over thirty months old entering the food chain unless they have tested negative for BSE. Member states also agreed to speed up moves to implement comprehensive labelling for beef and beef products.

## **Specified Risk Material (SRM)**

### **What are the controls?**

The current controls on SRM are laid down in the Specified Risk Material Regulations 1997 (as amended) and the Specified Risk Material Order 1997, which came into force on 1 January 1998. The essential purpose of this legislation is to ensure that SRM is excluded from the human food and animal feed chains and cannot be used for any other purpose which might put human or animal health at risk.

SRM is those tissues of cattle sheep and goats which are known to, or might potentially, harbour detectable BSE infectivity in infected animals. Since the controls on SRM were first introduced (in 1989 in respect of cattle and in 1996 in respect of sheep and goats) they have been regularly reviewed and strengthened on the basis of developing scientific evidence.

### **Controls in respect of food**

The rules prohibit the sale of SRM, or any food containing SRM, for human consumption. They also prohibit the use of SRM, or sale of SRM for use, in the preparation of food for human consumption.

Under fresh meat hygiene rules, animals for sale for food must be slaughtered in a licensed slaughterhouse, all the SRM must be removed as soon as it is reasonably practicable after slaughter, be stained blue and consigned to approved premises for disposal.

The SRM rules also provide that mechanically recovered meat (MRM) may be produced only in premises which have been registered with the FSA and prohibit MRM production from ruminant vertebral column.

### **Controls in respect of animal feed**

As for food, the rules prohibit the use of SRM, or sale of SRM for use, in the preparation of any feeding stuff and the sale of SRM, or any feeding stuff containing SRM, for feeding to any creature.

### **Basis for the controls**

The controls are based on advice from the Spongiform Encephalopathy Advisory Committee (SEAC). Tissues in which BSE infectivity in cattle has been found are covered by the SRM rules except for bone and dorsal root ganglia. The Beef Bones Regulations 1997, which prohibited the sale of bone-in-beef to the ultimate consumer and the use of bone-in-beef in the preparation of any food for sale direct to the consumer, were intended to protect public health from the risk from those tissues. The controls on bone-in beef were lifted from 17 December 1999, except in relation to bones for manufacturing food products.

The controls on sheep and goats were introduced later, when concern about the possibility that BSE might have been transmitted to sheep began to emerge. They are precautionary, as no evidence that BSE is present in the national flock has yet been found, and are considered to represent the minimum measures which should prudently be taken against that risk. It is, however, recognised that, if evidence that BSE was present in commercial sheep were to be found, these risk reduction controls would not be sufficient.

## **EU wide controls**

A Commission Decision on EU-wide SRM controls has been adopted, requiring all member states to remove and dispose of SRM with effect from 1 October 2000. Before the introduction of EU-wide measures, a number of member states had national SRM controls in place. The UK amended its previous national rules to conform with the EU Decision from 1 October 2000.

New measures announced following the Agriculture Council on 4/5 December will require all bovine intestines to be classified as specified risk material and therefore be removed at slaughter.

[France has deferred implementing its unilateral ban on sale of beef on the backbone - T-bone steak - pending further assessment of the risk by the EU's Scientific Steering Committee.]

## **Enforcement**

The SRM controls are supervised and enforced in licensed premises by the Meat Hygiene Service (MHS) an Executive Agency of the FSA. Supervision includes "a detailed final inspection of every carcass before it is stamped to ensure that after completion of dressing all visible traces of spinal cord have been removed from the spinal canal together with any debris that might obscure the spinal cord and there is no visible evidence of contamination by SRM on any part of the carcass."

In all other premises which handle SRM, the controls are enforced by local authorities.

In addition, the State Veterinary Service carries out regular unannounced independent audit visits to all premises which handle SRM to monitor the extent of compliance with the controls and to monitor MHS enforcement. The results of the SVS audit, which are published in the monthly BSE enforcement bulletin, indicate a high level of compliance in all types of premises. In slaughterhouses only a very few breaches of the rules relate to a failure to properly remove SRM from a carcass destined for human consumption (4 in 1999).

Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff CF99 1NA

Eich cyf / Your Ref  
Ein cyf / Our Ref HSS-Phillips

December 2000

Jeff Rooker Esq MP  
Minister of State  
Department of Social Security  
Richmond House  
79 Whitehall  
London SW1A 2NS

## **PHILLIPS REPORT ON THE EMERGENCE AND IDENTIFICATION OF BSE AND vCJD**

The Health and Social Services Committee of the National Assembly for Wales is considering the implications of Phillips' report during the course of several meetings. Its terms of reference are:

"to complete an initial examination and report on key issues arising from the Phillips (BSE) Inquiry Report, in particular:-

- a. the measures in place to protect the human food chain from the effects of BSE;
- b. the arrangements for caring for the victims of variant CJD; and
- c. the progress of the variant CJD epidemic and the way in which scientific advice is made available".

At its meeting on 6 December the Committee heard from members of the BSE Foundation, all of whom had cared for family members suffering from vCJD. One of the major concerns that they passed on to the Committee was the problems they experienced in getting advice on benefits to which they as carers, or the victim, might be entitled and in having their claims processed quickly. As you will appreciate the

distressing nature of the disease and the problems of providing care compounded their problems.

It was suggested that, as part of the overall care package for CJD patients, there should be a fast-track to benefits that carers could access. Before coming to a view on this, the Committee would welcome your views on this and on the availability of advice on benefits to people who find themselves in these unfortunate circumstances.

The committee will be taking further evidence at the end of January and it would be helpful to have your response by 17 January.

I am copying this letter to David Hanson, Parliamentary Under Secretary of State for Wales.

**Kirsty Williams AM**  
**Chair**

***Text of reply from Hugh Bayley MP***

"Thank you for your recent letter to Jeff Rooker suggesting that the Department of Social Security (DSS) should consider whether there was any opportunity to consider a fast track benefit information and claim processing scheme for carers of CJD sufferers. As the DSS Minister with responsibility for disability benefits I have been asked to reply.

I am sorry to hear that members of the BSE Foundation have experienced problems in obtaining information and making DSS benefit claims for themselves or those they are caring for and it may help if I describe what provisions we already have for providing information and how the benefit system works in circumstances such as those experienced by this group of people.

On a general level the National Benefit Enquiry Line (BEL) is a Social Security benefit helpline for people with disabilities, their carers and representatives. Confidential advice and information on all Social Security benefits and how to claim them is offered and advice can also be given on Local Authority benefits, Working Family and Disabled Persons Tax Credits and disability linked organisations. In addition to giving advice, BEL are also able to send out an extensive range of leaflets and claim packs to customers.

Advisers are trained in all Social Security benefits but the most common benefit advice is provided on

those relating to sickness and disability. However, advisers are only able to provide general advice and have no access to personal records. Advice can also be provided to help complete certain disability related claim packs over the telephone and advice can be given in Braille and large print if required.

Turning now to the specific position, you may be aware that entitlement to the disability benefits is not based on particular diagnosis but is determined by the effects that any disability has on an individuals care needs.

The Department makes every effort to process all claims as quickly and as accurately as possible and with the disability extra costs benefits, Attendance Allowance (AA) and Disability Living Allowance (DLA), special procedures already apply to people who are diagnosed as terminally ill. Our arrangements recognise the particular difficulties faced by people who have only a short time to live and such people are awarded AA or the highest rate of the care component of DLA automatically without having to serve a qualifying period. This means that, if they claim straight away, they can get benefit as soon as they have been diagnosed as being terminally ill. The arrangements ensure that claims are dealt with quickly and sensitively. Similar special arrangements exist in the Invalid Care Allowance Unit. When the Invalid Care Allowance (ICA) Unit receive a claim from the carer of a disabled person who is terminally ill the fact is identified at the initial processing stage. A check is then carried out against the AA/DLA computer systems. The ICA system is marked up accordingly and the ICA claim processed as a priority.

When devising these special arrangements, it was recognised that it is impossible to determine accurately what a person's life expectancy may be and that is why our legislation defines a person as terminally ill if "*he suffers from a progressive disease and his death ... can reasonably be expected within 6 months*". It is for the decision maker - who decides individual claims - to consider, in the light of all the evidence before him, what is the reasonable expectation.

I hope that you find this helps to explain that whilst there are no specific rules for people suffering from CJD because our benefits are not based on particular illnesses or diseases, special arrangements already exist to provide a fast tracked service where appropriate."

Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff CF99 1NA

Paul Boateng Esq MP  
Deputy Home Secretary and Minister of State  
Home Office  
50 Queen Anne's Gate  
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Eich cyf / Your Ref  
Ein cyf / Our Ref HSS-Phillips

December 2000

## **DELAYS IN CORONERS' COURTS**

The Health and Social Services Committee of the National Assembly is currently looking at the implications for Wales of the Report by Lord Phillips into the emergence and identification of BSE and vCJD and the action taken in response to it up to 20 March 1996.

The Committee's terms of reference include the arrangements for caring for the victims of variant CJD and the Committee has heard from the families of victims of the disease. Among the problems encountered by the families was a delay in the inquest on one victim who had died in July but, at the time of the Committee meeting on 6 December, a death certificate had still not been issued because the inquest had not been held.

Before coming to a view on this issue, the committee would appreciate your comments on

- the reasons why there might be such a delay and whether it is commonplace;
- whether action should be taken to reduce delays of this length; and
- how the anguish for bereaved families can be alleviated in such circumstances.

The committee will be taking further evidence at the end of at the end of January and it would be helpful if you could let me have your comments by Wednesday 17 January.

I am copying this letter to David Hanson, Parliamentary Under Secretary of State for Wales.

**Kirsty Williams AM**

**Chair**

***TEXT OF RESPONSE FROM RT HON PAUL BOATENG MP***

Ms Kirsty Williams AM

Chair

Health and Social Services Committee

The National Assembly for Wales

Cardiff Bay

Cardiff

CF99 1NA 15 January 2001

Thank you for the letter you sent me last month about the work you are doing in considering the implications of the report by Lord Phillips on BSE and your concern about the delay to an inquest into a death apparently due to variant CJD.

The general position is that just under half of all inquest cases are completed in less than three months, with one in five cases taking more than six months. The situation has unfortunately been deteriorating in recent years (in 1995, for example, only 10% of cases were taking longer than 6 months). The reasons for the increasing delays in general are not entirely clear but we are monitoring these with coroners. The main causes of delay in arranging inquests appear to be the need to await relevant reports from the police and pathologists, and in obtaining the results of other specialist examinations or tests. Other factors may be at work in individual cases, but we are not aware of any particular delays in cases of variant CJD deaths.

Coroners are well aware of the need to hold inquests as soon as possible and that delays are likely to be distressing to the families of the deceased. We are anxious to improve the service to the bereaved, and in 1999 we issued a model coroners' court charter which includes provision for local performance data of this nature to be set out. We have encouraged all coroners and their Councils to adapt the model charter for local use.

I cannot comment on why the inquest has been delayed in the case you mention, but if you were to send me further details I would be happy to make enquiries.

I am copying this reply to David Hanson.

Pwyllgor Iechyd a Gwasanaethau Cymdeithasol  
Health and Social Services Committee

Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff CF99 1NA

Ms Nicola Peachey  
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Eich cyf / Your Ref  
Ein cyf / Our Ref HSS-Phillips HSS

14 December 2000

## **PHILLIPS REPORT ON THE EMERGENCE AND IDENTIFICATION OF BSE AND vCJD**

The Health and Social Services Committee is considering the implications of Phillips' report during the course of several meetings. Its terms of reference are:

"to complete an initial examination and report on key issues arising from the Phillips (BSE) Inquiry Report, in particular:-

- a. the measures in place to protect the human food chain from the effects of BSE;
- b. the arrangements for caring for the victims of variant CJD; and
- c. the progress of the variant CJD epidemic and the way in which scientific advice is made available".

At its meeting on 6 December the Committee heard from members of the BSE Foundation, all of whom had cared for family members who had suffered from vCJD. One of the major concerns that they passed on to the Committee was the distress caused by the difficulty in diagnosing vCJD. In the early stages of

vCJD the symptoms may be mistaken for those of psychiatric disease or dementia.

The Committee would welcome the written views of the Royal College on how GPs might be made more aware of the possibility of vCJD when patients present with relevant symptoms.

I should be grateful if you would let the Clerk to the Committee, Jane Westlake, have your comments by Wednesday 17 January.

**Kirsty Williams AM**  
**Chair**



Jan 17<sup>th</sup> 2001

Dear Kirsty

Thank you for asking us to comment on the issue of BSE and vCJD.

This is an extremely difficult and sensitive issue to address. Currently, I suspect that some GPs in Wales have patients they are seeing with a variety of non-specific symptoms, who could possibly, in due course turn out to have vCJD, whilst other GPs are totally unaware of the possibility. Certainly, I have such cases and until there is a specific and sensitive enough test to identify the condition in vivo, the uncertainty remains. vCJD is not alone in this category of course. Many other illnesses can have a lead in period with a variety of non-specific symptoms and signs, before a firm diagnosis can be established, including AIDS, motor neurone diseases and multiple sclerosis. The clinical reality is that at present, nothing can be done to treat vCJD, so it could be argued in pure academic terms, does it matter whether the diagnosis is made early anyway? In fact, there may be a case for protecting the patient from harmful

information and the distress, caused by introducing vCJD as a *possible* diagnosis in these circumstances.

The situation is an extremely sensitive and difficult one to address. On the one hand, does the GP share his or her uncertainty with the patient at an early stage and if the diagnosis of vCJD is eventually confirmed, he or she is safeguarded? The likelihood is that the patient will not have vCJD and consequently, much unneeded anxiety has been caused. On the other hand, does the GP protect the patient by keeping the possible diagnosis to him/herself and run the risk of derision, breakdown in the vital patient/doctor relationship and even litigation if diagnosis of vCJD is eventually made? To complicate matters further, the consequent loss of intellectual ability which is inherent in vCJD, will make it difficult in the issue of confidentiality - with whom does the GP share his problem, the patient or the putative carer?

The College quite rightly advocates a patient centred approach and the probable practical, though compromise, approach, is to establish trust and be able to continue a good relationship with the patient, whilst sharing a degree of uncertainty regarding the diagnosis, probably without being explicit, unless directly asked. When a condition is extremely rare and not treatable, this type of approach is probably reasonable. However, this position could change if the disease became more common or if a test for early diagnosis and/or a treatment became available.

To explicitly answer your question about increasing GPs awareness, would be to prepare and distribute a synopsis of vCJD, which would include symptoms and signs of the condition as well as a diagnostic/care plan. A regular update on incidence and current thinking would also be helpful. The mechanisms are already in place to circulate practices in Wales with important clinical data, but an occasional article in the medical 'tabloids' might also be helpful. We, as RCGP (Wales) would, I'm sure, be prepared to assist.

Thusfar, vCJD remains an extremely rare condition and predictions of future cases in the UK are in the range 63 to 100,000. GPs deal in probabilities, but need to be aware of possibilities.

We have not met formally as a Welsh Council since your request and the views expressed are based on informal discussions with College colleagues.

Yours truly

Kind regards and best wishes

Dr Terry Davies  
Chairman RCGP Wales

Date: 24 January 2001

Venue: Committee Room 3, National Assembly for Wales

Title: **The Phillips (BSE) Inquiry Report**

## **Purpose**

1. The purpose of this paper is to summarise what has come out of the Committee's work so far and to set the scene for further evidence.

## **Recommendation**

2. The Committee is recommended to continue to examine the way in which arrangements now differ from those extant during the period (ie up to 20 March 1996) considered by the Phillips (BSE) Inquiry, looking at:

- a. with the CJD Unit Care Co-ordinator, representatives of the NHS and Social Services, the arrangements for caring for the victims of variant CJD;
- b. with the Chair of SEAC (the Spongiform Encephalopathy Advisory Committee), arrangements for providing scientific advice; and
- c. with the Food Standards Agency (FSA) and a representative of Directors of Public Protection, the measures now in place to protect the human food chain, in particular the Agency's review of BSE controls.

## **Timing**

3. It is intended that there should be a Plenary Debate of the implications raised by the Phillips Inquiry Report, probably in March. The Committee will wish to have completed its work before the debate takes place.

4. The Committee will wish to note the UK Government's position in responding to the Report. This is set out by Mr Nick Brown MP in answer to a Parliamentary Question on 21 December 2000. The text is at Annex A. A separate paper has been prepared to inform the Agriculture and Rural Development Committee's participation in the Inquiry. This sets out the Phillips findings and a provisional reaction to them for Wales.

## **Terms of Reference**

5. The following terms of reference have been agreed for the Committee's examination of this issue:

*"to complete an initial examination and report on key issues arising from the Phillips (BSE) Inquiry Report, in particular:-*

- a. the measures in place to protect the human food chain from the effects of BSE;
- b. the arrangements for caring for the victims of variant CJD; and
- c. the progress of the variant CJD epidemic and the way in which scientific advice is made available".

## **Background**

6. At its meeting on 6 December, the Committee heard from:

- Dr Roland Salmon, CDSC
- Human BSE Foundation
- Joy Whinney, Director FSA (Wales)
- Dame Deirdre Hine, formerly CMO (Wales)

Some key themes emerging were:

- Speed of diagnosis and care needs
- Tracking the epidemic - autopsies
- Getting the right messages across - media reporting
- Informing professionals
- A new openness - Devolution/creation of the FSA
- The place of Health Professionals in the National Assembly organisation
- The need for further guidance (on diagnosis and care)

## **Consideration**

7. The meeting on 24 January will allow members to meet representatives from the following:

- UK CJD Unit (Care Co-ordinator)
- National Health Service
- Social Services
- Local Authority Directors of Public Protection
- SEAC
- FSA

The Committee has requested written evidence from:

- The Benefits Agency
- The Home Office
- The Royal College of General Practitioners

## **Care Arrangements**

8. Representatives of the CJD Unit, the NHS and Social Services will be able to discuss the practical issues surrounding the delivery of care to victims of variant CJD and the problems that families have faced. The need for an enhanced care package was referred to in a statement by the Minister for Rural Affairs in the National Assembly's Plenary Session on 31 October. Work continues on these arrangements and the representatives of the families of victims have been kept closely involved. The Minister for Health and Social Services has indicated that the guidance issued to health care workers on 26 October will be updated in the light of the Committee's Inquiry.

## **Provision of Scientific Advice**

9. The Chair of SEAC will be able to explain to the Committee the role that his Committee fulfils. The Clerk has asked that SEAC provides a background note for Members ahead of the meeting. The session will be taken jointly with the Agriculture and Rural Development Committee.

## **Protection of the Human Food Chain**

10. Representatives of the FSA will be able to discuss further the measures now in place to protect the human food chain from BSE. The Agency published its Review of BSE Controls on 20 December and this is available on the FSA website [www.bsereview.org.uk](http://www.bsereview.org.uk). The Agency has provided a separate paper to aid members. A representative of the Society of Directors of Public Protection Wales will be able to discuss the role of local authority Environmental Health Officers in enforcing the regulations designed to protect consumers. This session will be taken jointly with the Agriculture and Rural Development Committee.

## **Compliance**

11. The powers of the Assembly relevant to these issues are the Ministry of Health Act 1919, which covers action conducive to the health of people and the National Health Service Act 1977, which covers services related to health. The Government of Wales Act 1998 provides the Assembly with the power to do anything to facilitate, or conducive or incidental to, the exercise of any of its functions (section 40). The Food Standards Act 1999 deals with the National Assembly's powers in relation to food safety. The relevant powers are delegated to the Minister for Health and Social Services. The paper raises no issues of regularity or propriety.

## **Financial Implications**

12. The paper does not raise any financial implications.

## **Cross-cutting themes**

13. The Phillips Inquiry Report raises issues across a very wide area and in preparing a response the National Assembly's wider duties to local government, business and the voluntary sector will be taken into account. The Compliance Unit has seen this paper and is content.

## **Action**

14. The Committee is invited to take forward its Inquiry in line with the recommendations at paragraph 2.

**Annex A**

## **BSE**

Maria Eagle: To ask the Minister of Agriculture, Fisheries and Food what action he is taking to implement the recommendations of the BSE inquiry report. [142346].

Mr Nick Brown: I intend to publish at the end of January the Government's interim response to the report. Lord Phillips' findings go to the heart of what is good governance, including properly informed policy-making; joined-up Government; best use of advisory committees and expert advice; timely decision-taking; a consistent and proportionate approach to risk management and precaution-especially when dealing with uncertainty; and effective implementation of policy decisions. The report's conclusions also emphasise the need for openness and better communication with the public about scientific knowledge and risk to inform consumer choice.

The interim response will focus on actions already taken on these key themes, as well as addressing how we will deal with the 160 plus detailed lessons that the report identifies. It will form the basis of consultations and discussions, enabling all those interested to contribute to the final response that the Government will make later next year.

In my statement on 26 October, I said that I and my right hon. Friend the Secretary of State for Health would commission an independent assessment of current scientific understanding, including emerging findings, of the origins of the BSE epidemic. We have now asked Professor Gabriel Horn to chair this review.

Date: 24 January 2001

Venue: The National Assembly for Wales

Title: **National Creutzfeldt-Jakob Disease Surveillance Unit**

### **NATIONAL CARE CO-ORDINATOR**

In February 2000 Gordon McLean was appointed (in response to concerns regarding care issues and CJD) as the National CJD Care Co-ordinator based within the National CJD Disease Surveillance Unit in Edinburgh.

Part of the co-ordinator's role is to offer to meet with the patient, their family, carers and health care workers on a regular basis in order to optimise the care, as well as ensuring that access to the services required is timely throughout the illness. To achieve this Gordon travels to any part of the country where his assistance is needed. He is available on an ongoing basis by telephone. He can also give information about charitable organisations which are dedicated to helping people affected by CJD.

As well as liaising closely with the Department of Health, Gordon is available as a valuable source of information for patients, families and health care workers.

Since October 2000 a care package has been set up for people with CJD to help ensure any shortfalls in care provision are met. Part of the role of the care co-ordinator will be to monitor the response of the authorities providing care in order to identify areas that may require improvement.

### **Duties and Responsibilities of the Post**

1. Provision of information and advice to professions and to the relatives of patients with CJD and vCJD on a national basis.
2. Liaison with professionals especially the key worker/care manager caring for patients with CJD and vCJD on a national basis.
3. Liaison with both the CJD Support Network and the Human BSE Foundation.
4. Provision of information and advice on:
  - a. The clinical features, investigations, diagnosis and prognosis of CJD and vCJD

- b. Co-ordination of care in and between different settings
- c. Nursing care
- d. Assessment and reassessment of patients and families care needs
- e. Financial help and benefits
- f. Counselling and emotional support
- g. Palliative care
- h. End of life decisions and funeral arrangements
- i. Continuing support after the patient dies
- j. Care package and the accessing of
- k. Pooling health and social service funds.

5. Answering questions on putative areas of risk, including: social and personal contact with patients, blood and blood products, surgical instruments and risk to other family members.

6. Advice and information, including that derived from the experience of the family of previous cases, on media contacts.

7. Liaison with other members of staff at the National Surveillance Unit.

8. Participation and presentation at conference, production of journal articles and overall development of expertise of the care of a patient with CJD and their family.

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**Health and Social Services Committee**

**HSS-02-01(p.1c)**

Date: 24 January 2001

Venue: Committee Room 3, The National Assembly for Wales

Title: **Variant Creutzfeldt Jakob Disease - The contribution of Social Services to Care**

## **Background**

It is hard to establish a clear picture about the scale of involvement by Social Services Departments in Wales because of the very small number of cases. It would appear however that there has been limited involvement to date. This low frequency in itself presents problems in establishing good practice and points to the need to share experience. The guidance issued by the Chief Medical Officer provides a very helpful framework together with the information from the CJD Support Network. The principles of good

practice established in the care of other degenerative conditions provides a relevant foundation, for example, in stressing the importance of good communications, co-ordination and the support that a key worker can provide.

The most likely contact will be through a hospital-linked social worker in the Mental Health Service or general hospital, although referral could come from Primary Health Care Teams. A wide range of services could be appropriate and it is likely that in most cases shared care arrangements involving both Health and Social Services would be appropriate, working in close co-operation with the family. The key worker could come from Health or Social Services and this may be influenced by whether there is already involvement and a working relationship as well as availability and appropriate skills. It is important that the family has a good working relationship with the key worker and is happy with the arrangements.

## **Services**

A wide range of possible involvement could occur from general advice and support which could include provision of information and access to other support from carers services and advice on benefit entitlement as well as trying to resolve other pressures that may be on the family. Assistance with lifting and handling techniques, provision of specialist equipment and temporary adaptations could play a part alongside the provision of domicillary care and respite breaks for the family with sitting services or in specialist residential care settings. Enabling the family's wishes, for example, to provide care at home or close to home in a non-hospital setting requires close collaboration to ensure a comprehensive co-ordinated package of sufficient care.

The guidance and studies indicate the importance of support and counselling for families especially after the death. The rapid progression and the very distressing nature of the disease for family members and staff who also need support, is very demanding.

There are a number of special features of the disease that pose a particular challenge for services:

- Family ambivalence at becoming engaged with Psychiatric Services because of the initial phase of the illness with changes in personality and presence of psychiatric conditions.
- The rapid changes and decline means that there is a need for a parallel, quick and co-ordinated response from services with regular reviews and timely changes to care arrangements. This may lead to a rapid shift in the balance of responsibility between social care and health services but with continued joint involvement.
- Fear of strangers adds further importance to ensuring there is a small familiar care team who can provide continuity of care.
- High media interest heightens the importance of confidentiality in record keeping and communication but also support to families in dealing with possible enquiries or concern about possible publicity. The sensitive political context for the condition can add suspicion and mistrust of the response of statutory services.

- The very small number of cases means the scope for support from other families with the same experience is more difficult to provide.

## Conclusions

Services are at the early stage of the process of coming to terms with dealing with this condition. In this situation it is particularly important that skills and insight is shared from those with experience. Special efforts are going into establishing these kinds of network arrangements within Wales and the opportunity can be taken by ADSS in its meetings to draw Directors attention to the guidance and identifying contact points to assist Departments when new cases arise. The management of v.CJD cases is likely to pose a particular problem for local continuing care arrangements. Use of the new flexibilities will enable simplified and more integrated care arrangements. A significant increase in numbers would indicate the need for more formal awareness raising and training on an all Wales basis.

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**Health and Social Services Committee**

**HSS-02-01(p.1d)**

**Date:** 24 January 2001

**Venue:** Committee Room 3, The National Assembly for Wales

**Title:** **SEAC'S relationship with the National Assembly for Wales**

1. Before the establishment of the devolved administrations in the United Kingdom, SEAC's role was to provide advice to the Ministry of Agriculture, Fisheries and Food, the Department of Health and the then territorial Departments. SEAC's terms of reference have now been amended and are as follows:

*'To provide scientifically based advice to the Ministry of Agriculture, Fisheries and Food, the Department of Health, their counterparts in Northern Ireland and devolved administrations and the Food Standards Agency on matters relating to spongiform encephalopathies, taking account of the remits of other bodies with related responsibilities.'*

2. The SEAC secretariat is provided jointly by MAFF, the Department of Health and the Food Standards Agency. Although there are no specific Welsh representatives on SEAC or its secretariat, officials from the National Assembly attend meetings of the committee as observers, receive papers and are involved in its administrative procedures, such as the appointment of new members. The same is true for the Devolved Administrations in Scotland and Northern Ireland.

3. The new terms of reference enable the National Assembly to request advice direct from SEAC if this

is appropriate, without consulting Government Departments in London first. In practice, though, it is likely that most matters considered by SEAC will have application to the whole of Great Britain or the United Kingdom rather than to the constituent countries.

SEAC Secretariat

January 2001

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**Health & Social Services Committee**

**HSS-02-01(p.1e)**

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Date: Wednesday 24 January 2001

Venue: Committee Room 3, National Assembly for Wales

Title: **BSE INQUIRY - FOOD STANDARDS AGENCY**

### **Handling**

1. The FSA Board will discuss the lessons to be learned from the Report at its open meeting on 8 February, and is contributing to the Government's response to the Inquiry's findings.
2. The BSE Inquiry was set up to review the BSE story up to 20 March 1996. So all of its comments relate to the period before the Agency was set up. We have no comments on the report's criticisms or otherwise of the decisions and actions taken in the period under review. Our concern is to learn the lessons of history and try to do better in future. Questions of who did what, when, are not the concern of the Agency. Our focus is on what we are doing now and what we shall do; we look to the Inquiry Report to see what lessons we can learn.
3. The Phillips report identifies about 166 "lessons to be learnt". Agency officials are studying the details of the report to see what are the specific lessons that we, the Agency, can learn. Amongst the key issues we clearly need to look at are openness and communication, the handling of risk and uncertainty, effective enforcement, working with other bodies and how to make the most appropriate use of our scientific advisory committees.

4. The creation of the Food Standards Agency as an independent body is in itself the most concrete example of the lessons already learnt from the epidemic. The Agency is an independent body, which puts the interests of consumers first and is committed to working as openly as possible. However, we are not complacent.
5. Implications of the Inquiry's findings are being discussed with all staff of the Agency.

### **Findings and Lessons to be Learned**

6. There is nothing in the report to suggest that current controls are not adequate to protect the public from the risks of BSE in cattle.
7. The report emphasises the important role of scientific advisory committees but makes a number of comments as to how the Government should use them. The review of food safety advisory committees earlier this year by Sir Robert May (assisted by the CMO England and the FSA Chairman) drew very similar conclusions. Advisory committees should undertake/advise on risk assessment but not be asked on risk management if they do not have the expertise to do so. In our review of the BSE controls, we were quite clear about the distinction. SEAC and the other scientific experts were offering advice on risk assessment, while options for risk management were being discussed by the wider stakeholder group.
8. It is the responsibility of the Agency to formulate advice to Ministers on the best way to manage risks. We have published a draft statement of policy on our approach to risk which we believe is entirely consistent with the conclusions of the Inquiry; it has recently been out to consultation and we shall revise it if necessary.
9. Phillips lays great stress on the need to take precautionary action when the risk is uncertain, and the need to ensure that that action is implemented and enforced effectively. This has always been the Agency's policy and we shall continue to apply it.
10. There is nothing in the Phillips report to suggest that either the remit or the composition of the Agency is flawed.
11. We have a unique position in government both in terms of our relationship with Ministers and the fact that we are a UK body advising Ministers in all 4 governments. The Agency is directly accountable to the National Assembly for Wales in respect of its activity in or on behalf of Wales and reports via the Minister for Health and Social Services.
12. The report says that openness is essential within government and between government and the public. Openness is one of our core values: the Board meets in public and we routinely publish our advice to Ministers. The Agency is establishing 'whistle-blowing' procedures within the Meat Hygiene Service and the rest of the Agency, to ensure that relevant information is not withheld at any level of the

organisation.

13. The report says that effective enforcement is essential to ensure food safety. The Agency now has direct control of the Meat Hygiene Service and we not only have new legal powers in relation to Local Authority enforcement but also have developed a Framework Agreement to ensure close working with LAs to improve both legislation and enforcement. All Welsh local authorities will be audited by the Agency over the next three years and the resulting audit reports and action plans published.

14. The Inquiry found that the Welsh Office did not have access to all the information necessary on the science of BSE; did not receive copies of SEAC minutes and was not able to influence the agenda of investigation. Since devolution, the terms of reference of specialist advisory committees on food safety have been widened to give them a UK-wide remit. The Agency itself advises Government in all four countries of the UK and ensures that the four administrations receive papers from the Committees which advise the FSA. The devolved authorities are able to request consideration of issues via the FSA secretariat.

15. These and other issues will be discussed in more detail when the Board meets on 8 February.

## **BSE CONTROLS REVIEW**

1. The Agency recently carried out a review of whether the BSE controls were adequate to protect the public, whether they were proportionate to the risk, and to look also into the future, to consider whether, and if so under what circumstances, the controls might need to change.

2. As this was one of the Agency's first major tasks, we took it as an opportunity to break with the past and do things in a totally different way that emphasised our commitment to access, transparency and evidence. The review was drafted by FSA staff supported by external advisors, who included the acting Chairman of the Government's Spongiform Encephalopathy Advisory Committee and other experts from the UK and from overseas. Throughout the process, from before the first draft and through each subsequent version of the review we exposed our findings to a group of about 30 stakeholders meeting in public. The stakeholders were drawn from a wide cross-section of consumer groups, science, health and veterinary professionals, government departments, the National Assembly, and the meat industry. The public, including notably representatives of the Human BSE Foundation, participated fully in the discussions of the stakeholder group. We also organised a further public meeting in October and established an interactive website which has been visited by over a third of a million people with over 2,400 copies of draft reports being downloaded. The review report was submitted to Health and Agriculture Ministers across the UK in December and has been sent to Committee members.

3. The review dealt with the three principle control measures: the over thirty month rule, which keeps older cattle out of the food chain; the specified risk material ban, which keeps those parts of the body that might harbour infectivity out of the food chain; and the meat and bone meal ban, which prevents recycling of the disease and its potential amplification to create future problems.

4. The draft report says at the outset that BSE is an area in which there is still great scientific uncertainty. The clear consequence of this is that whatever measures are put in place to protect the health of the public, they are intended to manage risk in the face of uncertainty. They reduce risk to a low level, rather than completely eliminating the risk.

5. Enforcement of control measures is the key to the protection of health. The UK is now coming to the end of the BSE epidemic. In the year to November there had been about 1100 cases, set against a total of 179,000 since 1986, and the figure for 2000 is about 40% of that for 1999. But even though the numbers are declining rapidly, it must be borne in mind that we still have a higher incidence by quite a long way than other countries with BSE.

6. In light of all the uncertainties about the science of BSE, our review emphasises that the current precautionary approach should be continued. Summary findings in relation to the main measures are below.

### **The Over Thirty Month (OTM) rule**

7. The OTM rule is the first line of defence. The point of the OTM rule is to remove from the food chain almost all the cattle that are close to developing clinical symptoms of BSE, and therefore potentially carry infectivity. The rule is based on the fact that clinical symptoms do not generally develop until an animal is about 35 months old, with an average of 60 months. Thirty months was chosen as a safe, precautionary cut-off age, and in the two years before it was introduced there had been only three cases of clinically identified BSE in animals younger than 30 months.

8. The OTM rule does not remove all potentially infective cattle from the food chain. That is effectively impossible. But by setting the limit at 30 months we estimate, using the model developed by the Wellcome Trust Centre in Oxford, that an average of 1.2 cattle close to clinical symptoms will enter the food chain in the year 2000, out of roughly two million slaughtered for food.

### **SRM Controls**

9. The controls on specified risk material provide the second line of defence, by removing more than 96% of the infectivity of any animal that enters the food chain. The risk material are tissues like brain, spinal cord and intestines: tissues in which experiments have indicated the infectivity seems to be concentrated.

### **The Feed Ban**

10. The feed ban is not directly aimed at protecting public health, but at eliminating or reducing the incidence of the disease in livestock. It has been estimated that the feed ban has eliminated 90% of the transmission of BSE. (The other 10% results from maternal transmission to calves.)

11. The BSE controls review does not recommend relaxing any of the controls in the immediate future. Further, we suggest that the feed ban might be extended to cover all intra-species recycling, especially to herbivores. The feed ban also should be applied in other countries where there is a risk of BSE, because experience in the UK has shown that a partial feed ban (allowing meat and bone meal to be fed to pigs and poultry) results in cross contamination from kind of livestock to another. As a result of decisions at the Agriculture Council in December, such measures are now being brought in across the EU.

12. Our report also emphasises that the current SRM controls would be inadequate for sheep if BSE were discovered in the national flock. At the moment we know that sheep can be given BSE under experimental conditions, but no cases have been detected on farm. Detection, however, would not be straightforward, partly because sheep suffer from a similar disease, scrapie, that is apparently harmless to human health but that has symptoms in animals that are similar to those of BSE. There is a possibility, therefore, that BSE is present in sheep but is masked by the much greater incidence of scrapie. In order to reduce uncertainty about the possibility of BSE in sheep, there needs to be a much more extensive screening programme. This, linked with the rapid implementation of a plan to get rid of all transmissible spongiform encephalopathies (BSE and scrapie are both TSEs) from sheep, would be an important cautionary step in enhancing consumer protection.

13. Quite apart from ensuring that current procedures are as good as they can be for protecting human health, the BSE control review has shown many direct benefits. In addition to greater transparency of the process of decision making, and ownership of the conclusions by most (if not all) of the stakeholders, the direct debate among stakeholders has benefited from the additional challenge to assumptions that has come from the public. Our ability to communicate risk and uncertainty through public discussion has also improved the level of debate.

Date: 24 January 2001

Venue: Committee Room 3, The National Assembly for Wales

Time: **Society of Directors for Public Protection in Wales (SODPPW) :  
The Phillips (BSE) Inquiry Report**

## **Background**

1. Local Government reorganisation in 1996 generally brought together the Environmental Health and

Trading Standards services into new Public Protection departments within the Unitary Authorities. The professional representation of each prior to reorganisation was through separate Chief Officer groups. These groups came together to form the Society of Directors with representation from each of the twenty two Councils in Wales.

2. The purpose of the Society is to provide advice and guidance to each local authority, assist with the production of uniform policies and procedures, be a reservoir of expertise to respond to consultation documents and advise the local government association in Wales. The society is also heavily committed to the public health agenda and partnership working, a clear example of this is the Collaboration of Health and Environment, a partnership with other key players in the health field.

3. Local authorities have a regulatory enforcement role to play in respect of Trading Standards and Environmental Health functions, especially with regard to animal health and welfare. This enforcement responsibility is complemented by offering advice on legal requirements to the agricultural sector.

4. Many councils have adopted the Enforcement Concordat agreed by central and local government and promoted by the Cabinet Office. The concordat details what businesses and others, who have to comply with the regulations, can expect and advocates the establishment of transparent and clear policies of enforcement to ensure a level playing field is created for business operators including the agriculture sector.

5. The introduction of Best Value, as part of the local government modernisation agenda is a commitment to ensuring the councils are responsive to the changing needs and expectations of local people. It aims to ensure that councils consistently meet challenging performance targets and that services are effective and efficient.

6. Best Value also requires that elected members and local authority employees continuously review and improve a council's performance, both in terms of quality and value for money and also publish comparative data on their performance.

7. The Local Government Benchmarking Reference Centre in Pembrokeshire has been assisting Local Authorities in Wales in benchmarking elements of the Trading Standards and Environmental Health services, including food safety and animal health and welfare functions. This study has included process benchmarking, the promotion of best practice guides, and assistance in the development of local performance indicators.

8. The Local Authorities Co-ordinating body on Food and Trading Standards (LACOTS) has pioneered the Home Authority principle, where Authorities prioritise surveillance of the practices and policies of businesses based in their area. It aims to prevent infringements by offering advice and guidance at source, in order to maintain high standards of public protection, and enables businesses to reduce compliance costs and implement the law in a spirit of consultation rather than confrontation. Good enforcement practices are also effective in minimising duplication and reducing public expenditure.

9. The issues above are intended to give an understanding of the infrastructure of the Society and the professions it represents and its preparedness to respond to threats to public health.

## **The Role of Local Government and BSE**

10. Essentially the controls, which fall to local authorities to enforce are principally the responsibility of either Trading Standards or Environmental Health Officers. These generally lie within two areas:-

Food Safety

Animal Health & Welfare.

11. Food Safety legislation, principally Food Safety Act 1990 is enforced to:-

- prevent food poisoning
- ensure food is safe
- provide proper information to consumers
- protect public health

12. Animal Health and welfare legislation is enforced to:

- prevent, control and eradicate animal disease;
- protect the welfare of animals on agricultural holdings, in transit and at markets;
- safeguard human health from transmitted disease.

13. The concerns of BSE have been around for almost ten years and EH and TS professionals have been enforcing relevant legislation within their responsibility during this period. However the changing attitude by successive Governments to enforcement has not always made the role easy. Furthermore the sometimes conflicting approaches by Government departments has created confusion and uncertainty for local authority enforcement.

14. The advent of the Food Standards Agency (FSA) in relation to more recent concerns about BSE have meant a single body co-ordinating controls centrally, a situation welcomed and endorsed by enforcement officers.

15. Guidance has been issued by the FSA to all local authorities in Wales directing them to undertake detailed checks on all premises where imported meat is offered for sale. This work has been undertaken, in a diligent manner, by all local authorities and indeed monitoring forms have now been issued by the FSA to record the work undertaken to date. There is also a recognition by the FSA that this unfunded extra work requirement will have an adverse effect on other targeted work.

16. Local authorities are last in the chain of information and action and consequently there are some

practical difficulties historically and currently:-

- Legislation issued for local authorities to enforce in response to matters such as BSE often create local enforcement problems because the practical implications have not always been addressed. A case in point is the Beef on the Bone Regulations, which were almost impossible to enforce.
- Food Safety legislation applied across the UK but because of devolution brought in at different times, again often creates enforcement problems particularly for border authorities dealing with small businesses whose premise may be in both England and Wales yet less than a mile apart. The same issue occurs across Wales with National Multiple retailers. The Butchers Licensing Regulations is another case in point, implemented in Scotland and England some months ago but only in Wales from the end of December.
- There is a lack of clarity about the controls applicable to the Intervention Board, which supplies beef in the UK. Clear guidance needs to be issued to local authorities to ensure there are no lacunas in the controls.
- Correspondence initially issued by the FSA was not always consistent across the UK requiring, particularly Welsh Local Authorities, to seek further clarification.

### **Controls Enforced by Local Authorities**

17. Farmers have to keep detailed records of bovine animal identification, their movements, and births, to satisfy the requirements of the Cattle Identification Regulations 1998; the Sheep and Goats (Records, Identification and Movement) Order 1996; and the Pigs (Records, Identification and Movement) Order 1995. Keeping accurate bovine records is essential to ensure the traceability of animals, to enhance confidence in the beef industry and to qualify for subsidy payments under the various schemes. The crucial importance of traceability has also been highlighted by the measures taken to control Bovine Spongiform Encephalopathy, including the Selective Cull Scheme and verifying that animals are under 30 months of age and can enter the food chain. The cattle passports required for animals born or imported after 1 July 1996 have assisted in this process.

18. Farm visits including checks on flock and herd records are usually carried out by local authority inspectors as part of a comprehensive animal health check.

19. The contact by Environmental Health Departments with the agricultural industry can involve virtually all the public health controls enforced by local authorities, including pollution control, general public health, health and safety/licensing and food hygiene.

20. Local authorities also have responsibilities for food safety/inspection, although this area has undergone major change, as already stated, with the formation of the Food Standards Agency.

21. The introduction of the Hazard Analysis Critical Control Point (HACCP) principles into the inspection process of food premises has incorporated training and advice being given to all butchers in the production of this essential food safety management documentation. All "butchers" which includes farm sales of unwrapped raw meat, operating in the principality should now have such documented systems. Environmental Health Officers also inspect small scale turkey slaughtering at Christmas, where the Food Safety [General Food Hygiene] Regulations 1995 are enforced.
22. Private kills by farmers is a matter for local authority enforcement but is currently subject to some uncertainty and further advice is awaited from the FSA.
23. Various Acts supplemented by Regulations, control the quality, marking and sampling of those products used to produce human foods. Local Authorities have a duty to enforce the 1970 Agriculture Act and do so by the taking of samples and submitting them for analysis. Samples can also be taken following a complaint made by purchasers.
24. Fertilisers and feeding stuffs are analysed to ensure that the prescribed information, referred to as the Statutory Statement, is correct within certain tolerances. Where samples are found to be outside the prescribed limits of error, and are to the prejudice of the purchaser, enforcement action is taken by the Authority, which may include prosecution of the producer concerned.
25. Local authorities also enforce the Feedings Stuffs (establishment and Intermediaries) Regulations 1998. The Regulations implement Council Directive 95/69 laying down the conditions and arrangements for approving and registering certain establishments and intermediaries in the animal feed sector.
26. The Regulations made under the Food Safety Act 1990 require records to be kept to enable farmers to ensure that withdrawal periods for animal medicines are observed. In addition the Regulations prohibit the sale, possession or administration to animals of specified unauthorised substances and prohibit the possession, slaughter or processing of the meat of animals intended for human consumption which contains, or which have been administered with such unauthorised substances. They also prohibit the sale or supply for slaughter of animals if the appropriate withdrawal period has not expired and generally prohibit the supply for slaughter, or the sale, of animals or the sale of animal products which contain unauthorised substances or an excess of authorised substances.
27. Trading Standards Officers deal with the labelling of food and its composition. Increased consumer awareness has led to demands for more product information to enable reasoned choices to be made. Recent legislation has included the labelling of food produced by genetic modification, and the labelling of fresh and frozen beef. The Food Labelling (Amendment) Regulations 1999 provide for the enforcement of the EC Regulation and penalties for non-compliance. Any new GM Foods would need approval under the EC Novel Foods Regulation 258/97, which include labelling requirements. In introducing the requirements for catering and other appropriate premises, the Regulations provide flexibility in the way that the information is made available and allowed a six-month lead-in time for businesses in order to reprint menus.

28. The Beef Labelling Scheme is intended to give consumers accurate information about the beef they buy so traceability is a key requirement of the scheme. Under the scheme any retailer giving consumers anything more than basic information about beef must get prior approval and have in place arrangements to guarantee that the beef is what the label say it is. A community-wide system of compulsory beef labelling has been agreed by the EU Agriculture Council. This will ensure that beef described as being of British origin is what it purports to be and that beef originating elsewhere is clearly labelled as such. It is likely that this agreement will come into force in September 2000, subject to approval by the European Parliament.

## **Conclusion**

29. Local authorities are keen to work in partnership with the FSA in ensuring public health is protected and the relationship with FSA Wales is generally developing well and with confidence. However enforcement officers are dependent upon quality, accurate and timely information from Government and its advisors if they are to be effective at a local level. Therefore there should be no overlap in communication, roles should be clearly defined and legislation must be capable of effective enforcement if consumer confidence is to be built and maintained.

Report Author

Allan Davies

Chairman of the Society of Directors for Public Protection Wales.

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**Extract from Minutes of 24 January 2001**

**Paper: HSS-02-01(min)**

Item 2: The Phillips (BSE) Inquiry Report

Paper: HSS-02-01(p.1)

2.1 The Chair welcomed Gordon McLean, National Co-ordinator for CJD; Dr Marion Lyons, Consultant in Public Health at Bro Taf Health Authority and Hugh Gardner, Chairman of the Association of Directors of Social Services (Wales) (ADSS).

## 2.2 In response to questions from members, Gordon McLean made the following points:

- Support for families was improving although there was still some way to go. The level of support and input varied from area to area, and best practice occurred in areas where health and social services worked together.
- The difficulty in diagnosing variant CJD was highlighted, although techniques were improving with the use of MRI scanners.
- Depending on the symptoms, a patient could be referred to a neurologist or psychiatrist. Referral to a neurologist resulted in a quicker diagnosis, but symptoms could point to the involvement of a psychiatrist. It was therefore essential that information on the symptoms and nature of the disease be widely disseminated
- Families felt unsupported until a diagnosis had been made.
- The provision of a key worker who remained with the victim and family throughout the illness was vital.
- Post-bereavement counselling and care varied from area to area but ideally should be automatically available if the family required it.
- As CJD was not a notifiable disease under statute, the CJD Surveillance Unit relied on notification from a neurologist of a suspected case. Following this, a researcher from the Unit would visit the family and carry out a questionnaire. Then, if the family so wished, the Care Co-ordinator would become involved. This would take place within two weeks of the Unit being made aware of a suspected case.
- The main differences between caring for CJD victims and other degenerative illnesses were the much younger age group affected by CJD and the rapidity of the disease.
- The pooling of funds between health and social services was important.
- At the moment, the main role of the CJD Surveillance Unit was disseminating information to professionals involved in caring for patients and their families, although it was envisaged that, as more time became available, this would be widened to include other groups.
- The difficulty in getting a hospice place for a patient with a neurological disease was highlighted and it was suggested that there was an imbalance between funding and provision for cancer patients and funding for neurological patients.
- Access to MRI scans varied across the country. A fast track system that enabled immediate referral of a suspected patient was needed.

## 2.3 Dr Marion Lyons said:

- Because of the low level of incidence it was highly unlikely that a GP would see a case during his/her career but the possibility should always be considered as part of differential diagnosis.
- All GPs would have received a copy of the Assembly's guidance for healthcare workers and work was ongoing within health authorities to prepare local plans to implement this, although raising awareness should be an ongoing process.
- The early symptoms of the disease could mimic many other conditions so it was often difficult for a GP to decide where to refer the patient.
- In her opinion, a Welsh standard for care would be developed in time but each case would have

different needs. The ground rule should always be joined-up service provision.

- Because CJD was not a notifiable disease it was possible that the health authority might not be aware of a case in its area and this could contribute to patients not receiving the best care available. (Dr Ruth Hall said that it was not simply a question of adding CJD to the statutory list of notifiable diseases - where notification allowed action such as contact-tracing, sensitivity to the confidentiality of a victim's identity was vital.)
- Whilst early mis-diagnosis in the elderly was possible, as the full range of symptoms presented, CJD would normally be identified.

## 2.4 Hugh Gardner:

- Acknowledged that, due to the rapid progression of the disease, some authorities might be seen as slow in responding to patient needs. He therefore believed that CJD should be treated as a special category with priority for response.
- There was a lot of experience of joint working to deliver care for people with degenerative conditions.
- The review of continuing care arrangements should be a priority in implementing the joint flexibilities, and care for victims of CJD needed to be included. Pooled funding arrangements and lead commissioning could also have a role.
- The concept of a key worker was established where multiple contributions were necessary to the package of care. It was likely that the key worker would not be a budget holder and accessing funds needed further consideration.
- Within the ADSS, the need to share best practice and learn from others was recognised and improvement was being made.
- There had been progress in joint working including with other agencies in both the hospital setting and primary care.

2.5 The Chair thanked everyone for their contributions. She asked that the Committee be provided with further information on access to MRI scanners, availability of hospice facilities and details of a pilot project operated in Yorkshire which enabled the families of victims of Huntington's Chorea to manage the budget provided for their care.

## **Item 4: The Phillips (BSE) Inquiry Report**

### **Paper: HSS-02-01(p.1)**

4.1 The Chair welcomed members of the Agriculture and Rural Development Committee. Apologies were received from Delyth Evans, John Griffiths and Huw Lewis.

4.2 The following interests were declared:

Mick Bates, partner in a farming business;  
Glyn Davies, farmer

Peter Rogers, farmer.

4.3 The Chair also welcomed representatives from the Spongiform Encephalopathy Advisory Committee (SEAC), the Food Standards Agency (FSA) and the Society of Directors of Public Protection in Wales.

4.4 In response to questions from members, Professor Peter Smith, Acting Chair of SEAC, made the following points:

- SEAC had no financial resources other than the expenses needed to run the Committee, but did have substantial resources in terms of scientific expertise. The Committee was able to secure money for its work and could commission risk assessments with resources provided by sponsoring departments.
- SEAC was an independent Committee of experts and all new appointments followed the Nolan procedures. Members were appointed for their expertise and some members were from outside the UK. The Committee's advice was made public and members were asked to declare any commercial or other interest prior to taking part in discussions.
- The Food Standards Agency (FSA) was represented at meetings.
- The devolved administrations were able to seek advice from the Committee and observe at meetings, although most of the issues addressed were of relevance across the UK.
- The Phillips Report related to the period up to March 1996 and substantial changes in membership had taken place since that time, there was more expertise in epidemiology.
- The cause of the first case of BSE was not known but the most probable explanation for the BSE epidemic was the feeding of infected cattle material to cattle.
- It was believed that maternal transmission was the only route of infection since the ban on feeding bovine meat and bone meal to cattle in August 1996. The incidence of BSE had declined since 1992 to 1000 cases. All but one of these had been infected prior to 1996. If the number of new cases increased significantly it would disprove this theory.
- Current estimates of the risk to humans ranged from 100 new cases of vCJD to over 100,000. This was based on a number of uncertain assumptions, for example it was not known what the critical dose was for a human to become infected and what the average incubation period of the disease was.
- It was estimated that last year one animal in the final year of the incubation period of BSE entered the food chain, this year it would be less. All the material where it was thought infectivity was concentrated was removed from those animals. The only remaining risk was dorsal root ganglia.
- Although it was circumstantial, the evidence that BSE and vCJD were caused by the same agent was extremely strong. A lot of work had been undertaken to identify the strain typing and they were virtually indistinguishable. How the agent got from cattle to humans was less clear. It had not been possible to work out the definitive route of transmission, although eating infected beef was the most plausible explanation.
- CJD could be contracted in other ways, such as use of infected growth hormones, but this was not the same as vCJD and there was no known cases of vCJD having been contracted from growth

hormones.

- There had been concern about BSE in other species. Concern remained about sheep, as it was known that sheep had been fed the same infected material as cattle. However, strain typing of scrapie in sheep indicated that it was not caused by the same infective agent as BSE in cattle. Research was, however, continuing and specified risk material controls were in place for sheep.
- It was considered extremely unlikely that organophosphates had contributed to the BSE epidemic.
- It was believed that the risk of BSE infecting the food chain had been reduced to a low level in the UK although concern remained about other European countries.
- It was known that sporadic CJD could be transmitted from person to person through contaminated surgical instruments. Whilst there was no direct evidence to suggest that vCJD was also transmissible from person to person, it was a potential risk that needed to be addressed.

4.5 When asked about the difficulties experienced by the Welsh Office in obtaining scientific advice outlined in the Phillips Report, Dr Ruth Hall, Chief Medical Officer, said that the right of the devolved administrations to access to advice had been built into SEAC's terms of reference and she and her colleagues had already made use of this. She was content that a framework was in place that would enable her to seek advice as necessary and that full co-operation would be forthcoming.

**Food Standards' Agency (FSA), Meat Hygiene Service (MHS), Society of Directors of Public Protection (Wales) (SoDPPW).**

4.6 The following responses were given to points and questions raised by members:

4.7 Joy Whinney said that the same standards on the safety of food imports applied across the European Union (EU). The safeguards existed, but the Agency recognised that enforcement was not straightforward. The Food and Veterinary Office of the European Commission checked standards and enforcement in approved premises across the EU and in third countries exporting to the EU. The FSA operated within the EU framework.

4.8 The FSA had recommended banning the recycling of gelatine in feeds, but the use of gelatine in animal medicines was being looked at with the industry. Most of the gelatine imported into the UK was derived from pigs or fish. She undertook to provide further information on the sources of imported gelatine.

4.9 Tony Edwards said that the ban on fishmeal for animal feed in the EU arose from concerns that fishmeal had been contaminated by ruminant meat and bonemeal, and not because of concern about fish.

4.10 Ann Hemingway explained that the FSA had inherited a portfolio of research work from the Ministry of Agriculture Fisheries and Food. It was reviewing this portfolio and current contracts, with a view to filling gaps. The underlying principle was to protect the interests of the consumer. It was a public review and there would be consultation on the contract process. Research on BSE was not

confined to the UK.

4.11 The FSA was independent and non-political. It would ensure a wide research data base and advice from across the spectrum would be available to inform judgements. The Agency was determined to retain its independence and to use its powers to bring issues into the public arena. There would be a public meeting with stakeholders in Wales shortly to elicit feedback on the Agency's performance.

4.12 Joy Whinney said that the FSA was reviewing the burdens of regulation on small businesses including abattoirs. The Agency was required to act in a manner proportionate to the risk, hence would not be over-regulatory, but consumer safety came first.

4.13 She said that the beef labelling regulations required country of slaughter labelling of imported beef. This would be extended across the EU in 2002 to require the country of rearing to be specified on labels. The chair of the FSA had written to commissioner Byrne pressing for the extension of labelling of the country of origin to be extended to all meats/meat products.

4.14 Chris Lawson said the MHS had been established in 1995 and had been complimented in Lord Phillips's report on the improvements that it had secured. It was continually auditing and tightening controls on UK abattoirs.

4.15 Tony Glacken said that the Port Health Authorities, which were not all local authority controlled, could check documentation accompanying imports. Local authorities also undertook sampling and checks.

4.16 Joy Whinney said that the FSA monitored the incidence of BSE in all countries and provided current information on the Internet.

4.17 She said that local authorities played an essential role in ensuring food safety. The National Assembly had made additional funding available through the Revenue Support Grant for continued improvements in local authorities' food standards work under a new FSA Framework agreement, but this was unhypothecated. The FSA did not have any information on local authorities' actual spend, but would be auditing local authorities' work in this area over three years. Audit reports and action plans would be published. The Chair of the Committee welcomed this development.

4.18 Tony Glacken said that the different structures of local authorities' public health work would make it difficult to disaggregate expenditure and compare performance. SoDPPW welcomed the increased focus on food safety, but this was only one of local government's statutory functions. There was an argument that food standards should be brought into the health and well-being element of the Assembly's policy agreements with local government.

4.19 Asked whether the FSA would have made a difference to handling if it had been in existence at the height of the BSE epidemic, Ann Hemmingway said that the FSA's open agenda would have brought

the issues into the open. The FSA board had not yet discussed the Phillips report but it was embracing Lord Phillips's recommendations.

4.20 Chris Lawson said that the over 30-month rule did not prohibit the import of beef from cattle over that age. It only banned its sale for human consumption. It could be imported for pet food. The rule was difficult to enforce. It was impossible to assess the age of meat off the bone, and possible to assess the age of meat on the bone at the extremes, ie to say whether it was from very young or very old animals. The importer was responsible for ensuring that the ban was not contravened. This was done through documentation. The MHS carried out checks at the eventual destination, not at the port of entry. The indications from MHS and local authority checks were that there was a high level of compliance.