**Date:** **28th February 2001, 14.00 pm to 17.20 pm**

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

**Title:** **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 Committee***s***" 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 multiple sclerosis, 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:***

- *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 properly, 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.*

**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 the 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 were 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 ever 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.

***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. This might be in the range of 500 to 5,000 cases in the UK.*

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 National Assembly should consider the benefits of re-instating the Health Professionals Group that existed prior to the implementation of the Hart report.*

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