3. Establishment of the CJD Surveillance Unit

Introduction

3.1 This chapter deals with the establishment of the CJD Surveillance Unit (CJDSU) at the Western General Hospital in Edinburgh, under the direction of Dr Robert Will. It addresses the terms of reference, funding, and monitoring of the work of the CJDSU. Details of the consideration given to possible involvement of the Public Health Laboratory Service (PHLS) are included.

Establishment

3.2 On 5 December 1989, Dr Will, then a consultant neurologist and a senior lecturer at the Department of Clinical Neurosciences, Western General Hospital, submitted an application to DH for a research grant for a project on CJD surveillance over a period of four years. The application was for funding for a research registrar, a secretary, equipment and running expenses.

3.3 Prior to this formal application, the Tyrrell Committee had already considered and approved Dr Will’s proposals. In addition, DH had previously agreed that they should fund the CJD surveillance project. Consequently, after the surveillance methodology had been submitted to the Department of Health’s Research Division, Dr Will’s programme ‘was duly accepted’.

3.4 The CJD surveillance project began on 1 May 1990 at the Western General Hospital in Edinburgh. The project was funded jointly by DH and the Scottish Office Home and Health Department (which contributed 10 per cent of the total costs). Funding covered the costs of establishment of the Unit and running costs for Dr Will’s project. However, additional projects, for example, molecular biology studies, were not within the remit of the DH/Scottish Office grant and it was thus necessary to obtain alternative funding for work of this sort.

Terms of reference

3.5 The main objectives of the CJDSU study were:

i. to identify any change in the epidemiological characteristics of CJD; and

ii. to assess the extent to which any such changes were linked to the occurrence of BSE.
3.6 The CJDSU was expected to document and publish any changes in the clinical or other characteristics of CJD, or in the epidemiology of CJD, and conduct investigations into the cause of these changes.

**Funding and resources**

3.7 Initially, it was agreed that the CJDSU would be funded from 1990 to 1994. However, DH recognised that it might be necessary for the project to continue beyond this.\(^75\) In the event, DH continued to provide funding after the initial four years, although the responsibility for funding eventually moved from the Research and Development Division to the Health Aspects of the Environment and Food Division in 1996, as the activities of the CJDSU were considered to be inherently surveillance rather than research.\(^76\)

3.8 Extra funding for specific developments was awarded in 1991 by DH to set up a neuropathology laboratory and to appoint additional staff to free Dr Will from some of his other commitments. MRC funding was later provided for the strain typing\(^77\) of the CJD cases in farmers, and DH funded the strain typing experiments on the teenage CJD victims in March 1996.\(^78\)

3.9 An estimate of the total cost of the work at the CJDSU from 1990 to 1996 is £1.8 million, with DH contributing 90 per cent of the funding (see also vol. 10: *Economic Impact and International Trade*).

3.10 Although Dr Will found the funding for the basic surveillance activities of the CJDSU adequate, the funding from DH and the Scottish Office for epidemiological investigations and statistical analysis was limited, and he had to seek additional funds for these activities.\(^79\)

**Review of the CJDSU by the Allen Committee**

3.11 The work of the CJDSU was reviewed by the MRC Allen Committee, chaired by Professor Ingrid Allen, which met four times between 1991 and 1995. This Committee was established on the basis of concerns raised by Professor Allen at a meeting of the MRC Coordinating Committee for Research on Spongiform Encephalopathies in Man (The Murray Committee; see vol. 2: *Science*) in October 1990. She considered that the design of Dr Will’s study could mean that atypical features of dementia, like those exhibited by patients developing CJD as a result of treatment with human growth hormone, might fall outside the study. A Clinical Subcommittee was therefore established to coordinate and facilitate studies relating to the epidemiological monitoring and neuropathological definition of human SEs, to monitor patients at risk of iatrogenic infection and to apply new methodologies.

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\(^{75}\) YB92/5.1/2.1  
\(^{76}\) YB94/4.18/1.1; YB95/9.11/3.1  
\(^{77}\) Strain typing studies – different strains of TSE agent (for example, sCJD, vCJD, scrapie, etc) can be distinguished on the basis of their incubation period in host species, on the pattern of disease caused in the brain, and on the basis of certain biochemical characteristics. Strain typing experiments generally involve the inoculation of experimental animals with infective material and subsequent observation of these characteristics to identify the strain of agent  
\(^{78}\) S60 Ironside paras 2–3; S61 Will para. 5; YB96/4.4/2.1–2.5  
\(^{79}\) S61 Will para. 5
and technologies to refine the definition and improve diagnosis of SEs. The Allen Committee had powers to co-opt relevant experts when necessary. Dr Will was a co-opted member of the group.

4 April 1991

3.12 At their first meeting on 4 April 1991, Dr Will presented a paper on the CJD surveillance project at the CJDSU. This covered the objectives and the criteria for referral of ‘suspected CJD’ cases. It was agreed that the clinical criteria for referral should be sufficiently broad-based so that atypical cases would not be missed. Classification would be based on the neuropathological findings obtained post-mortem. The criteria adopted by Dr Will were:

- **Definite CJD** – neuropathologically confirmed spongiform encephalopathy in a case of progressive dementia with at least one of the following features:
  1. myoclonus;
  2. cortical blindness;
  3. pyramidal, cerebellar or extrapyramidal signs;
  4. akinetic mutism; or
  5. characteristic EEG.

- **Probable CJD** – neuropathologically unconfirmed cases with at least two of the features mentioned above and the characteristic EEG.

- **Possible CJD** – progressive dementia plus three of the above clinical features but either an uncharacteristic EEG or no EEG recording.

All ‘possible CJD’ cases were excluded from analysis (but not from surveillance) in Dr Will’s study and in the studies that Professor Matthews had carried out between 1970 and 1985.

3.13 The Subcommittee did not identify any compelling clinical reason to modify the clinical criteria for referral, which were essentially the same as in the Matthews study. Indeed, it was considered advantageous to be able to use the Matthews study as a baseline for the current study. However, it was recognised that the criteria might need to change as scientific developments dictated.

3.14 The biochemical aspects of CJD were also discussed, including the prion protein gene mutations that had been linked with familial CJD. The CJDSU were collaborating with The Prion Disease Group, St Mary’s Hospital, London, who undertook the screening of patients for familial mutations.
3.15 It was also agreed that the biochemical methods for detecting abnormal forms or distributions of prion protein were not yet sufficiently well developed to be used in the diagnosis or classification of CJD by the CJDSU. The Committee members agreed that they should review the methods for the ‘potential molecular or histochemical definition of CJD’ annually.

1 July 1991

3.16 The second meeting of the Allen Committee took place on 1 July 1991 as a joint meeting with the MRC Murray Committee. Dr Will updated the members on the progress made in the surveillance of CJD. Presentations were also given by Dr John, Dr John Collinge and Dr Mark Palmer (St Mary’s Hospital, London) on the genetics of human TSEs, and by Dr Gareth Roberts (St Mary’s Hospital, London) on biochemical diagnosis. Although much progress had been made in the area of molecular genetics and immunocytochemical techniques, those present at the meeting ‘reaffirmed their view that clinical neuropathology remained the best anchor point for diagnosis’.

22 February 1993

3.17 The third meeting of the Committee took place on 22 February 1993. It had been called in response to Dr Will’s concerns about the ethical problems arising from the identification of genetic mutations in individuals with sporadic CJD. Standard procedures were agreed. Prior consent from the GP/clinician of the patient and the patient’s closest relative should be obtained before the genetic analysis of blood samples. The relative should also be asked whether they would like to know the results of the test and any feedback requested should be given by the clinician/GP.

3.18 By the time of this meeting, even more progress had been made in the biochemical detection of prion protein (PrP) and so the Allen Committee decided to organise a workshop to achieve a consensus on the techniques used, in an attempt to coordinate the work in this area, including that of the CJDSU. The workshop took place on 23 April 1993 during which all the techniques were discussed and it was then agreed that the next step was to run a multi-centre study to compare and optimise the methods for detection of PrP.

19 July 1995

3.19 A report of the multi-centre study was presented to the Allen Committee on 19 July 1995, and although final results had not been published, it was felt that the study had been extremely successful. The results from the second and third CJDSU reports, along with the preliminary data from the draft of the fourth report, were discussed. The questionnaire used to ascertain putative risk factors for CJD in
the case-control study was also discussed. The introduction of a supplementary questionnaire aimed at investigating more fully possible links to diet or occupational exposure was suggested. The Allen Committee supported a proposal that the CJDSU undertake genetic analysis of CJD cases in-house rather than having to rely on their London colleagues, and recommended that the Health Departments ensured that the CJDSU was ‘appropriately’ resourced.

Public Health Laboratory Service involvement

3.20 The CJDSU was established expressly to undertake CJD surveillance rather than following the usual route of disease surveillance and control by the Public Health Laboratory Service (PHLS), which did not become involved in CJD surveillance until after 20 March 1996.

3.21 The PHLS is an executive non-departmental public body with responsibility for providing a microbiological and epidemiological service to health authorities and local authorities for the diagnosis, control and prevention of infection and communicable disease.98 In 1986, it comprised a network of 52 diagnostic laboratories throughout England and Wales with headquarters at Colindale in London. It was, and continues to be, supported by two surveillance centres, the Communicable Diseases Surveillance Centres, or CDSC, which are based in London and in Wales and by a specialist research establishment, the Centre for Applied Microbiology and Research, at Porton Down. Since the PHLS operated only in England and Wales, it was not considered to have a role in UK-wide CJD surveillance,99 although precedents for UK-wide surveillance by PHLS do exist.100 Details of the Welsh PHLS and the mechanisms of disease surveillance in Northern Ireland and Scotland can be found in vol. 9: Wales, Scotland and Northern Ireland.

3.22 The CDSC served as the epidemiological arm of the PHLS by keeping human infectious diseases under surveillance. The Centres worked with other PHLS units to provide expert epidemiological support for the study of infectious diseases including the investigation of outbreaks. Their surveillance function was based upon regular returns of diagnostic data from the PHLS laboratories, supported by other information, including reports from clinicians and others. 101

3.23 Strong links existed between PHLS and its sponsor Department, DH. Members of the PHLS board which determined policy included a Deputy Chief Medical Officer (DCMO) and a DCMO from the Welsh Office (until July 1989), and other DH staff attended as observers.102 In addition, the PHLS was required to produce an annual Accountability Review for discussion at a meeting with Health Ministers. The Review included a Corporate Plan produced in the light of regular dialogue between DH and Welsh Office officials and the PHLS.

3.24 From 1988 onwards, annual ‘Customer Liaison’ meetings were held between the PHLS, DH and Welsh Office officials and served to discuss progress on the PHLS’s ongoing work and concerns. In addition, there was day-to-day contact

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98 M39 tab 1 p. 105
99 T66 p. 87
100 T67 p. 42
101 S181 Smith para. 6
102 S181 Smith para. 9
between PHLS and DH scientific and medical staff, particularly in relation to current outbreaks of infectious disease.

PHLS and CJD surveillance

3.25 Before 20 March 1996, several discussions had taken place between PHLS and DH officials about the possible assistance the PHLS might be able to provide in CJD surveillance. One of the surveillance options initially proposed by Dr Pickles to the CMO on 2 March 1989 in response to the recommendations of the Southwood Report, was for the CDSC to undertake surveillance of CJD (see paragraph 2.31). However, Dr Pickles did not approach the CDSC for help and this option was not pursued.103 Nevertheless, the PHLS was concerned about the risks to humans from BSE and their 1989 Corporate Plan, which was prepared in mid-1989, highlighted the need for continued surveillance and research to evaluate these risks.104

3.26 However, on 12 December 1989, ‘a formal decision not to involve CDSC was taken at the PHLS Accountability Review meeting’.105 The CMO’s speaking notes for that meeting indicate DH’s reasons for not involving the CDSC at that time:

Although some of the animal disorders may in the end turn out to be communicable, I would not myself have classed most cases of Creutzfeldt-Jakob Disease this way. We have spent much time with expert advice considering how to monitor cases of CJD and concluded it would not be appropriate for CDSC to be involved at this stage. In general, I would not encourage PHLS/CDSC to become involved in monitoring diseases unless they are known to be communicable. For the moment, that includes CJD.106

3.27 In February 1990, Dr Pickles wrote to the Director of the PHLS, Dr (now Sir) Joseph Smith, to update him with the work funded by DH being carried out on spongiform encephalopathies.107 The letter was produced following discussions between Dr Pickles and Dr Smith about possible involvement of the PHLS and CDSC. In evidence to the Inquiry, Dr Pickles said that she wrote the letter at Dr Smith’s request to assist him in persuading doubting colleagues that PHLS involvement was unnecessary.108

3.28 In her letter, Dr Pickles detailed the reasons why DH was reluctant for PHLS to become involved. These included:

i. The role of the PHLS was limited in practice to the study of the human health aspects of infections that were known to transmit from animals to man. This had not been shown for BSE.

ii. The Tyrrell Committee had concluded that the most effective way to monitor CJD was to embark on a study similar to that conducted by Professor Matthews in the late 1970s and early 1980s. Experiences in the early study suggested that direct verification of cases would be essential and therefore that clinical neurologists/neuropathologists

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103 S115 Pickles para. 26
104 YB99/6/00/4.1
105 S251 Acheson para. 40; S115 Pickles para. 29.4
106 YB99/12.8/2.8
107 YB99/2.1/5.1–5.3
108 S115C Pickles para. 26; YB99/4.24/7.2
would be indispensable. The PHLS and CDSC did not have this expertise available.

iii. It was generally accepted that CJD was not communicable in the normal sense (ie, transmission had only been shown iatrogenically and experimentally). It did not therefore seem necessary to involve the CDSC in monitoring, not least because it might have given the impression that CJD could spread from person to person. Moreover, CDSC involvement could have been misinterpreted to suggest that a rival study had been set up. Similarly it was not desirable for local groups to report on CJD cases without consideration of the complete and accurate set of data collected by Dr Will.

iv. It was not considered part of the mainstream business of the PHLS to be involved in laboratory studies of CJD, investigating the neuropathology or nature of the agent. In addition, it was considered desirable from a health and safety aspect to keep this type of work confined to as few laboratories as possible.

3.29 Dr Pickles’s letter was submitted by Dr Smith to the PHLS Board for their consideration in April 1990. Dr Smith provided the Board with background information on CJD surveillance and noted that the PHLS was not undertaking significant microbiological or epidemiological work on slow viruses, something for which it might later be criticised. However, he also stated that:

On the other hand, comprehensive surveillance and research is in progress in the UK and unnecessary duplication of research effort is to be avoided. The PHLS has to prioritise the use of its resources and currently savings in the order of £1.0 million have to be found.

3.30 The PHLS Board concluded that there was not a need to undertake studies in view of the extensive work in hand by DH which it would not be cost-effective to duplicate. Indeed, the memorandum submitted by the PHLS on 11 June 1990, in response to an invitation from the Agriculture Select Committee for its inquiry into BSE, reflected the conclusions of the PHLS Board:

... the service has no body of data to justify a memorandum to the Agriculture Committee, but we are of course keeping a close watching brief on the situation. If appropriate areas of work were to be identified which were not thoroughly covered by other groups, or for which a duplication of effort by PHLS staff appeared to be justified, this work would be seriously considered. As yet, however, such needs have not been identified and it is believed that the necessary areas of investigation are already being very adequately addressed by various expert groups.

3.31 Dr Pickles has pointed out in evidence to the Inquiry that these comments suggest Sir Joseph was not supportive of PHLS involvement.
3.32 However, in his evidence to the Inquiry, Sir Joseph said that he felt at the time that the PHLS should have played a role in the investigations, given the expertise and experience within the organisation. He said:

From, I believe, early in 1990, however, it was made increasingly clear to me that DoH and Ministers did not wish the PHLS to work upon BSE/CJD, nor to be seen to work or comment upon the subject, and especially that CDSC should not be involved. This caused me much concern. I thought that the PHLS should be involved in the critically necessary human epidemiological studies of BSE/CJD, and that the PHLS could make a valuable contribution to their planning and operation.113

3.33 Sir Joseph felt that their involvement would have had a positive effect in reassuring the public,114 and that the public was not sufficiently aware of the work of the PHLS to associate their involvement with the possibility that BSE might be communicable to humans.115

3.34 Similar views were held by Professor Stephen Palmer and Dr Roland Salmon, consultant epidemiologists from the Welsh Unit of the CDSC. They felt that there was insufficient evidence to support the pronouncement by the CMO that beef could safely be eaten by everyone.116 Indeed, Dr Salmon felt that a number of features of the biology of BSE and CJD suggested that a small risk of transmission to humans could not be excluded.117 In addition, both were surprised that it appeared that SEAC had not considered certain scientific publications which reported associations between CJD, food consumption and animal contact. Moreover, they felt that SEAC was not completely on top of the epidemiology and that there was a preoccupation with biological rather than statistical issues.118

3.35 Both Professor Palmer and Dr Salmon were therefore concerned about the lack of PHLS involvement. They had reservations about the CJDSU epidemiology study and considered that ‘such an important and long term study (20 years +) might be better directed by either MRC or PHLS or both’.119 The contribution that members of the PHLS felt could have been made by the PHLS/CDSC is discussed later in this chapter.120

Second request for PHLS involvement in CJD surveillance

3.36 In January 1993, Dr Diana Walford was appointed Director of the PHLS. Dr Walford reopened the question of PHLS involvement in BSE/CJD. She believed that the argument that BSE was not a human pathogen could not be sustained, because this was not known at the time. Her opinion was that the PHLS should have been engaged in work in order to ascertain whether or not it was a human pathogen.121

3.37 Furthermore, Dr Walford also believed that the PHLS’s unique expertise in communicable disease epidemiology, coupled with its experience in the

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113 S181 Smith para. 19
114 T67 p. 35
115 T67 p. 44
116 YB90/7.18/5.1–5.2
117 YB90/5.22/7.1–7.2
118 S286 Salmon para. 20; S286A Salmon paras 2–4
119 YB90/7.18/5.1–5.2
120 S67 Smith Walford para. 30
121 S182A Walford para. 6
investigation and handling of major national incidents, should have been fully utilised.\textsuperscript{122}

\textbf{3.38} However, in evidence to the Inquiry, Professor Will has stated that the work of the CJDSU was supervised by the MRC Allen Committee, whose membership included epidemiologists.\textsuperscript{123} Further, he has pointed out that the CJDSU received expert epidemiological and statistical advice from the London School of Hygiene and Tropical Medicine (LSHTM).\textsuperscript{124}

\textbf{3.39} Dr Walford with the support of other PHLS staff,\textsuperscript{125} discussed this topic with Sir Kenneth Calman (CMO) several times between March and September 1994.\textsuperscript{126} Sir Kenneth continued to express the view that the PHLS should not be involved in this area of work.\textsuperscript{127} He believed that there was no gap in surveillance that the PHLS could readily fill and that there was no room for PHLS involvement while a diagnostic test was still unavailable.\textsuperscript{128}

\textbf{3.40} In November 1995, when the report of a small number of cases of CJD in young people became known, Dr Walford again became concerned that the PHLS was not involved in human TSE work. She took the initiative of contacting Dr Will directly to ask him if he would welcome any epidemiological assistance from the PHLS.\textsuperscript{129} Dr Will asked to see several of the PHLS surveillance databases to try to identify possible misdiagnosed cases of CJD and suggested that Dr Walford should contact Professor Smith (LSHTM), who had been providing statistical input to the CJDSU.\textsuperscript{130}

\textbf{3.41} Dr Walford kept Sir Kenneth fully informed of her discussions with both Dr Will and Professor Smith.\textsuperscript{131} But when she informed him, on 22 December 1995, of a proposed meeting between CJDSU and PHLS, he made it clear that he did not wish the meeting to go ahead. Sir Kenneth felt it might compromise the position that SEAC, whose epidemiological expertise had been strengthened by recent appointments,\textsuperscript{132} should be the single source of scientific expertise on prion disease.\textsuperscript{133} The proposed meeting was cancelled.\textsuperscript{134}

\textbf{3.42} Since the announcement on 20 March 1996 of the possible link between vCJD and BSE, the PHLS has been involved in a number of aspects of work on CJD, including:

\begin{itemize}
  \item[i.] a project to detect, retrospectively, under-ascertainment of vCJD in Wales;
  \item[ii.] establishing active surveillance, through the British Paediatric Surveillance Unit, of progressive intellectual and neurological deterioration in children under 16 years of age in the UK, to determine whether cases of CJD were occurring in that population;
\end{itemize}

\begin{thebibliography}{99}
\bibitem{122} S182A Walford para. 6
\bibitem{123} S61 Will para. 9
\bibitem{124} S61 Will para. 5
\bibitem{125} YB94/2.23/5.3
\bibitem{126} YB94/3.10/4.1; YB94/04.11/5.1; YB94/07.20/7.1; YB94/09.01/2.1
\bibitem{127} YB94/03.24/3.8
\bibitem{128} YB94/4.05/4.1; YB94/4.22/5.1
\bibitem{129} YB95/11.29/15.1
\bibitem{130} YB95/12.05/9.1; YB95/12.15/6.1
\bibitem{131} YB95/12.15/6.1
\bibitem{132} Professor Smith (LSHTM), Dr Mike Painter (a consultant in communicable disease control) and Professor John Collinge
\bibitem{133} YB96/1.12.8.1–8.2, S182A Walford para. 18
\bibitem{134} YB96/1.19/10.1, YB96/1.22/9.1
\end{thebibliography}
iii. a project to set up a panel of clinical samples from patients with neurological disorders, for the evaluation of candidate tests for CJD;

iv. a project to develop a diagnostic test for CJD;

v. regular monitoring of the trend in incidence of vCJD, in collaboration with the CJD Surveillance Unit; and

vi. various reviews of the methodology and work of the CJDSU.

Furthermore, a PHLS statistician was appointed as a member of SEAC’s Epidemiology Subcommittee and Dr Walford was herself appointed a member of the CMO’s Committee on the Human Aspects of Spongiform Encephalopathies. 135

What could the PHLS have contributed to CJD surveillance?

3.43 In evidence to the Inquiry, Sir Joseph Smith and Dr Walford identified several areas in which they felt that PHLS could have contributed to CJD surveillance. These include paediatric surveillance, development and administration of the questionnaire and field work, dissemination of information to health professionals and facilitating links with clinicians other than neurologists. In the following sections we describe these points and the contrary arguments put forward, especially by Dr Pickles. In the discussion section at the end of Chapter 5 we return to the role of the PHLS in CJD surveillance.

Paediatric surveillance and access to medical registers

3.44 A close link existed between the British Paediatric Surveillance Unit (BPSU) and the PHLS, who supplied a consultant epidemiologist as an advisor to the BPSU. The association between the two organisations established a system of ‘active case searching’ whereby paediatricians reported monthly on cases of specific diseases. Where these specific diseases were not reported, a system of ‘follow-up’ checks ensured that no cases were missed. 136 Sir Joseph noted that this surveillance had been very successful in the surveillance of Reye’s syndrome 137 and SSPE. 138 139

3.45 Dr Walford also felt that the paediatric surveillance was a good model for how the PHLS might have approached surveillance of a rare condition like CJD. The PHLS could have worked with partners such as BPSU, British Paediatric Association, British Neurological Surveillance Unit and with neurologists to cover both the UK as a whole and all age groups.

3.46 However, in evidence to the Inquiry, Dr Pickles pointed out that at the time the CJD monitoring study was initiated, only one case of CJD in a person under the age of 16 had been reported worldwide. It did therefore not seem appropriate to involve the BPSU at the time. About access to medical registers, the CJDSU could have had access to the registers of neurological disease held by the PHLS (eg, SSPE,

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135 S182A Walford para. 23
136 T67 p. 60
137 Reye’s syndrome – a sudden, sometimes fatal, encephalopathy occurring in children after chicken-pox or influenza related illnesses. Paediatric surveillance identified the use of aspirin as a risk factor for the condition and led to guidelines on the use of aspirin in children
138 Subacute sclerosing pan encephalitis – a rare encephalitis arising as a complication of measles. Surveillance showed that vaccination was not a risk factor as feared, but rather protected against the condition
139 T67 p. 60
hospital discharge statistics, death certificates) on an informal basis as envisaged by
the PHLS Board in their April 1990 meeting. Dr Will had in fact examined the
PHLS’s SSPE register in 1995, since it was possible that CJD cases had been
misdiagnosed as SSPE (he did not, however, find any evidence of misdiagnosis).

Development and administration of the questionnaire

3.47 Dr Walford noted in her evidence to the Inquiry that food questionnaires, such
as the CJDSU questionnaire, entail a high possibility of ascertainment bias and that
the design and administration of such questionnaires is a skilled job. She
considered that however skilled the research neurology registrars available to the
CJDSU may have been, they did not have the required training in the field, nor the
skills of PHLS epidemiologists, to ensure sufficient accuracy in data collection. A
partnership between the PHLS and the CJDSU would have allowed a PHLS
epidemiologist to accompany the neurologist to interview the relatives of CJD
victims.

3.48 In her evidence to the Inquiry, Dr Pickles recognised the experience and
expertise of the PHLS epidemiologists, but questioned whether their experience of
relatively acute events such as food poisoning was pertinent to the investigation of
causative factors which were widely used and where no information on the
necessary dose for exposure or duration of exposure was available. She also
doubted whether anyone, regardless of experience, would be able to obtain reliable
or accurate dietary history in CJD cases, where information had to be obtained from
family members. Dr Pickles noted the methodological advantages of having a single
interviewer who needed to be a neurologist.

Dissemination of information

3.49 The PHLS had and has a variety of mechanisms for disseminating
information. A weekly publication, Communicable Diseases Report, provides
information about infectious diseases to public health doctors, microbiologists and
the Environmental Health Departments on current infection statistics and issues.
The consultant in communicable disease control in each district would also receive
the publication and disseminate the information to those who needed it. Electronic
means for the dissemination of information also existed. The PHLS ‘Epinet’ was
used to alert all public health professionals, departments of public health and district
directors of public health to specific matters of concern. Latterly, the internet has
provided an opportunity for more widespread dissemination in the form of the
PHLS website, on which the Communicable Diseases Report is also available.

3.50 Both Sir Joseph and Dr Walford felt that these vehicles could have been used
to alert general practitioners and psychiatrists to CJD through public health
professionals, though they appreciated that direct information to relevant
professional associations needed to be supplied by DH. However, DH had its own
networks for disseminating information and advice to the medical profession
through letters from the CMO and the publication Health Trends. With regard to
CJD, Dr Will arranged for the inclusion of relevant enclosures circulated by the

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140 S115C Pickles p. 14
141 T67 pp. 51–52
142 T67 pp. 76–77
143 S179A Calman para. 9
Association of British Neurologists to its members, communications were relayed directly to neurologists and relevant information was provided directly to professionals in public health if required or requested.¹⁴⁴

**Facilitating links with clinicians other than neurologists**

3.51 It has been suggested that the PHLS might have been able to facilitate links with clinicians other than neurologists, eg, psychiatric geriatricians, to whom CJD might present.¹⁴⁵ However, DH expected that given the neurological nature of CJD, patients would be referred to a neurologist even if they had been seen by other specialists first.¹⁴⁶ It was considered in this case that Dr Will would have had closer links to neurologists than the CDSC could have developed.

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¹⁴⁴ S115C Pickles, para. 14
¹⁴⁵ T67 p. 72
¹⁴⁶ S115C Pickles p. 14