ACDP/SEAC/WG/TSE/P95
Appendix 2

Report of CJD Incidents Panel open meeting to discuss the consultation document '*Proposals on the management of possible exposure to CJD through medical procedures*'
17th April 2002, Westminster Central Hall

Contents:

Report of the Question and Answer Session of the Open Meeting of the CJD Incidents Panel to discuss the proposals contained in its consultation document '*Management of possible exposure to CJD through medical procedures*'.

Background

The Panel launched its proposals for the management of incidents involving possible exposure to CJD via medical procedures for consultation in October 2001. The document was mailed to approximately 3,000 people, including health professionals, patient representative groups and lay/ religious groups. The document and response form was also made publicly available on the CJD section of the Department of Health website. The written consultation process closed on 15 January 2002 and the responses were collated and analysed by an independent marketing firm.

The open meeting was an extension to the consultation process and was intended to provide a further opportunity to receive comments and suggestions from interested bodies, the health profession and patient groups. Invitations were sent to all those who had received a copy of the consultation document. The event was also publicised on the website and members of the public were welcome to attend. Just over 300 people attended the event. The papers for the meeting included the interim analysis of the written consultation process.

The open meeting was proceeded by a networking lunch to provide delegates to meet members of the Panel and to informally discuss the consultation document.

The meeting was facilitated by Michael Buerk from the BBC and the following of the CJD Incidents Panel members assisted the Chair in responding to questions raised by the audience:

Professor Michael Banner, Chair of the CJD Incidents Panel
Professor Don Jeffries, Vice Chair of the CJD Incidents Panel
Professor James Ironside, TSE Tissue Infectivity Expert
Mrs Jean Gaffin, Lay representative
Dr Patricia Hewitt, Blood expert
Dr Roland Salmon, Epidemiologist

A biography of the members of the CJD Incidents Panel is provided at Annex 4 and a full list of the delegates who attended the meeting is provided at Annex 5.

Professor Banner opened the meeting with a talk introducing the background to the CJD Incidents Panel and a brief outline of its proposals. This was followed by a talk by Professor Ironside outlining the background to Creutzfeldt-Jakob Disease (CJD) and tissue infectivity. Professor Jeffries then provided a talk on the decontamination of surgical instruments. Information relating to these talks are provided at Annex 2, 3.

Question and Answer Session

Question 1: Some people whom the Panel would include in the 'contactable group' may not want to know of their possible exposure and this may impact on their ability to get life insurance etc.
Response: The Panel accepted that the issue of directly informing patients that they had been placed at a significant risk of developing CJD was a difficult one and had been much discussed and debated when the Panel were drafting the proposals. The Panel had met with patient representative groups to discuss this issue and were informed that patients who may pose a risk to others often wished to be informed, so that they can take precautions to prevent any onward spread. The Panel had also decided that the need to protect the general public health outweighed the individuals right 'not to know'.

The Panel accepted that this proposal might have some implications for insurance and would explore this issue prior to finalising its proposals. This was also an issue of concern for those patients who would not be directly contacted, but placed on a database of possibly exposed patients.

Subsidiary questions
Q. 1. i. Those in the 'contactable' group should be put on the database and given the option to determine if they wish to be informed of their exposure
Response: This was not possible, as the purpose of the database was not to monitor the behaviour of those in the 'contactable' group and it would not be accessible to clinicians. These patients needed to be informed, as precautions would need to be taken if they underwent any further invasive medical procedures and to inform them that they should not donate blood.

Q. 1. ii. What did the Panel propose to tell blood product recipients who would fall into the 'contactable' group?
Response: The risk assessment for blood product recipients had not yet been completed and the Panel were awaiting the results of this work before finalising their advice for this group of patients. It was possible that these patients may not fall into the 'contactable' group. The Panel also accepted that some patients who received blood products, such as haemophilia patients, were a special group and that further thought may be required on how to inform these patients, utilising existing information and support networks.

Q. 1. iii. Would it be possible to include permission for data to be placed on the database as part of the consent form completed by patients prior to surgery?
Response: The Panel agreed that this was a good suggestion and would give it some consideration.

Q. 1. iv. What expert advice had the Panel sought regarding the possible psychological harm that may result in directly contacting patients to inform them of their risk? There is a difference between 'high risk' and 'potential of being exposed'.
Response: The Panel's proposals were made on the basis that secrecy was not an option. Any possible psychological damage that may occur from directly informing patients needs to be balanced by the harm that may be caused if the patient found out at a later date by accident, or may later develop the disease without having been previously told that they were at risk.

Question 2: Everyone potentially exposed should be informed because:

- They have a right to know
- Informed consent must be obtained to enter details on a database

Response: The Panel agreed that everyone has a right to know if they had been exposed to a possible risk of developing CJD and had tried to devise a method that allowed this right, whilst also allowing for the fact that some patients would not wish to have this information and may wish to exercise their right 'not to know'. It was hoped that adequate advertising alerting the public to the existence of the database, and allowing patients to determine if they were on the database, would enable a balance between the right to know and not to know.

The Panel had also consulted legal experts, who advised them that the legal position regarding placing patient's names on a database without their explicit consent is currently unclear. The Panel was seeking further clarification to determine the legal position.

Subsidiary questions:

Q. 2. i. It is important that support systems are in place before anyone is informed of their exposure risk.

Response: The Panel agreed that support mechanisms are needed and its proposals rely on the fact that these will be in place before any patients are informed.

Question 3: No database should be set up because the risks are:

- Too small
- Unknown

Response: The proposed database would contain details of both the 'contactable' group and the wider cohort of patients that the Panel considered to have a very low level of risk of being exposed and who would not be directly contacted and informed of their possible exposure, as the Panel did not believe that they posed a risk of onward transmission.

The database would serve two purposes. The first was in the interests of public health, allowing a mechanism whereby those who have possibly have been exposed to CJD could be alerted in the event that a test/ treatment became available.

The second purpose of the database was for research, which was vital in an area where so many uncertainties surround the disease and where the risks are unknown. It was accepted that the research basis of the database would need ethical approval prior to being established.

Members of the Panel also noted that, in some incidents, it would not be possible to identify those patients who would fall into the 'contactable' group out of the wider cohort of patients who underwent a procedure with the same instruments as those used on the index patient.

Question 4: If instruments are safe after 10 re-uses, should instruments be washed 10 times after every surgery, rendering them safe? This would then prevent the need to discard any instruments and prevent any possible transmission of the disease.

Response: The Panel's proposals that an instrument may be placed back in circulation if it had undergone 10 or more re-uses after being in contact with potentially infectious tissue was a value judgement. The Panel did not think it suitable to subject instruments to a further 10 washes, rather than disposing of them because:

1. This was not a standard process
2. It is not possible to destroy instruments retrospectively. However, if instruments can be identified before they have undergone 10 re-uses then it

is not ethically acceptable to re-wash them and put them back into circulation.

It was stressed that the Panel looks at each incident individually and decides what action needs to be taken on a case by case basis. The proposal regarding the 10 washes is only a guideline and may not be appropriate in every incident. For example, there may be some instruments, such as those that are difficult to effectively decontaminate, which the Panel would advise be disposed of even if they had undergone more than 10 re-uses.

It was also noted that work on the improvement of decontamination and methods of inactivating the infective prion was underway and that hopefully results would soon be available.

Subsidiary questions

Q. 4. i. Lessons from the move to and from disposable tonsillectomy kits to minimise the transmission of CJD should be learned and there should be a move towards using disposable instruments.

Response: The Panel agreed that there may be a case for a greater use of disposable instruments, provided that this could be implemented without compromising patient care. However, this was a policy issue and the Department of Health had the responsibility for taking this work forward. The Panel also agreed that the improvement in decontamination mechanism should be a priority.

Question 5: Should individuals have the right to remove their name from the database?

Response: The Panel had reconsidered and planned to withdraw their proposal that the 'contactable' group should not be able to remove their names from the database. It was stressed again that the purpose of the database was not to monitor individual's behaviour and would not be accessible to clinicians etc. Those in the 'contactable' group would have been directly informed of their risk and told that they should not donate blood and that special precautions should be taken if they underwent any further surgery to prevent the possible onward spread of the disease. Their notes would also be flagged to alert clinicians to their status if they presented for treatment. Therefore, there would be no public health risk if these individuals removed their name from the database. The Panel did not believe that the wider cohort of possibly exposed patients would pose a risk to public health.

The Panel believed that the public would not want to remove their names from the database, as doing so would render it impossible to contact them in the event that a test/ treatment became available.

Subsidiary questions:

Q. 5. i. Had the Panel conducted any consumer research when drafting the proposals regarding the individuals right to remove their name from the database?

Response: The Panel had consulted widely with clinicians, professionals, ethics, religious groups and patient representative groups. The consultation document and response form was also available to the general public on the website. However, it had not commissioned research from any independent consumer groups.

Q. 5. ii. Surgeons who had been exposed to CJD would fall into the 'contactable' group. Would the public be able to determine if a surgeon was at risk?

Response: Surgeons and workers caring for patients suffering from CJD would not be at risk of developing the disease, as CJD was not contagious.

Question 6: Publicity campaigns – openness or causing alarm?
Response: The Panel did not believe that it was acceptable to keep the existence of the database a secret, as the public had a right to know that the information existed and that their names may possibly have been placed on the database. Also, information about incidents involving CJD should be available to the public. The Panel accepted that publicity about such incidents would raise further questions from the public and the proposals relied on the fact that resources would be made available to ensure that the publicity and information campaign would be wide-ranging and effective, with support in place to respond to questions and concerns raised by the public.

Question 7: Blood and plasma derivative recipients should be dealt with differently from surgical instruments
Response: The Panel agreed that patients who regularly receive blood products, such as haemophilia patients, were a special group and that the method of informing such patients and providing counselling should build on existing systems and networks. However, there were some patients who did not fall within this category and who, for example, would only receive one blood transfusion in an emergency situation. The method of informing these patients still needed further consideration, once the risk assessment for such patients was completed.

Next Steps
Professor Banner thanked members for attending and for sharing their concerns and ideas regarding how incidents involving CJD and invasive medical procedures should be managed. The Panel was meeting again in June and would review their proposals in the light of the comments they had received both from the written consultation process and from the open meeting. The Panel hoped to put its final proposals to Ministers in the summer.

Annex 1

Further questions raised following the open meeting

Questions to be addressed by the CJD Incidents Panel

Consultation Issues

- The Community Health councils are, notwithstanding current legislation going through Parliament, the only bodies set up statutorily to represent patients in the NHS. Is the absence of a response from the CHCs our omission or yours?

- The Panel's arguments are sensible.

- I hope after all the lengthy discussions, we will receive concise guidelines of the majority concerns on this complex issue.

- Not at the moment. I felt the Q & A session gave me much more insight into problems faced by hospitals and other organisations. In some ways it is difficult to the problems faced by the haemophilia community, over concerns about contamination or blood products.

- Thank you for a thought – provoking afternoon.

- How long before we get a firm decision on how and when this advice will be implemented.

- What is the opportunity of undertaking this exercise (recording of data, notification, patient support etc)? I suspect they are extremely high. I think the panel was quite dismissive of the need to consult more widely with the general public – will they reconsider this?

- I agree with the Panel's proposals.

Instruments

- An event two months ago in which a patient has a biopsy is verified CJD, instruments are isolated, same patient requires a second biopsy:
  1) Do we use same instruments?
  2) If so, how do we decontaminate them?
  3) Waste a second set of instruments?!

  Where/how should the instruments be best isolated if your CSSD/HSDU is off site?

- I am still not clear (despite two attempts at clarifying this) why we cannot decontaminate instruments 10 times following contamination to make them safe (assuming they fall in the easy to decontaminate category). I am still a bit confused by the prospective/retrospective debate.

- Should a patient in an 'at risk' category that requires haemodialysis have a 'dedicated' machine?

- What do we do with potentially infected instruments? Are 10 washes sufficient?

- More specific guidelines on what to do with endoscopes (flexible heat sensitive).

- Would it be possible for the Panel, if it makes any further recommendations to the DoH, regarding disposable surgical instruments, to suggest that the process should be evolutionary rather than revolutionary, with a proper pilot study and phased introduction rather than a 'big bang' approach?

- Do you use a separate renal haemodialysis machine for the contactable 'at risk' group?

- Plurithms (based on scientific data that should soon be available) for risk of use of instruments in certain surgical procedures will be useful.

- Far too much time spent on need of Database, not enough time spent on decontamination risk factors.

- Can you truly justify prospective/retrospective argument over the 10-cycle recommendation? Either you are confident 10 cycles removes risk or it doesn't, ambiguous?

- An operation on a CJD case could easily result in an entire hospital's supply of instruments being destroyed. The replacement time would be 3-6 months. Does the very small risk of transmission of CJD justify the increased risk from postponed surgery. How will the panel risk manage rather than risk avoids.

- I still fail to understand the disposal of instruments which have had less than 10 decontamination cycles, but keeping in use those that have had more, without the suggestion that the former receive at least 10 process cycles. I don't see a difference between prospective and retrospective decisions.

- Can the panel give advice on non-surgical instruments that are difficult to decontaminate (e.g. portable suction machines without disposable liners, sometimes without filters) that have been used on CJD patients.

Patients

- Very concerned that people may have their name removed from Database as a Public Health issue. Also concerned from a minor's point of view, if the decision to remove is made by parents – and new treatment becomes available.

- Links between Database and Blood Donor database/National Transplants database/Cornea Database.

- Still not sure who will have access to Database.

- If the Database was started now how soon would useful results emerge? For how long is it likely that the Database could be maintained?

- Would the list of 'contacts' be used by Health Care Staff? E.g. a person who is going to be used as an organ donor – could we check they are not on the CJD at risk register?

- Prior to major brain/special surgery should the surgeon check the list because we can't clean the instruments adequately to protect the next patients? And should we quarantine/destroy them? Should all patients for surgery be asked if they are on the list prior to surgery so extra precautions regarding instruments could be taken?

- Will there be dissemination of clear information within & without the NHS re who will be able to access the Database and for what purpose?

- If you are in the contactable group and you remove your name, you can 'pose' a risk e.g. organ donation, blood donation. Will your records be 'tagged' in any case?

- I am concerned that researchers will ensure patients know they are on a database before they are contacted. As Chair of an Ethics Committee, I am aware of several distressing incidents when patients on databases associated with HIV and Cancer have first found that they were on a database when the researcher writes to them. Ethical approval is not enough – researchers must be supervised when using this information.

- As previous concerns have been raised with HIV and the possibility of Health Care staff possibly contracting the disease and continuing to care for patients, has this same concern been discussed with regard to staff who might contract CJD and where they go from there? Will pressure be put on them if a needlestick injury is received, reported and they are then considered to be at risk to other colleagues/patients alike?

- Do you feel you have sufficient clarity in your own mind of the purposes and value of the proposed Database to present these issues clearly to the public?

- Assuming that the Database happens, isn't it too late in view of the incubation period of VCJD to really provide anything meaningful to the Database?

- You have mentioned tracing and identification of instruments but doesn't this provide the Local Trust with the same issues of informing and informed consent?

- On the subject of informed consent of the Database – must bear in mind a degree of reassurance to the patient that any future treatment they may require will not be withheld because they are considered 'at risk'.

- The issue of the Database is very confusing at present. Of the aim of the data is that it provides information for professionals – if so how? If not, for what public use will this be? Otherwise it seems as though this is only to be used for research.

- I understand the document and reasons for the consultation but feel the panel need to realise the implications of the move to publicise and inform. These are acceptable but where does the support come from the Health Professionals dealing with many unanswered questions?

- Advise to take note of survey/majority view. This was a sensible approach to a difficult dilemma. Can't help thinking that all of us in the room are possibly on a whole host of databases that we are not aware of although could possibly find out about if we were determined. I see no difference in terms of personal autonomy between this scenario and the above.

- Why doesn't the Gov. just inform the public – we are all at risk. Some greater than others. Please tick a box if you are at greater risk.

- Has any consideration been given to the possibility of using genetic testing to subdivide the risk groups? Risk could be divided into two components – external and genetic.

- Who/how would databases be accessed by?

- Some members of Macfarlane Trust were advised that they had received clotting factor, which may have been made from blood donated by NV CJD donor, have found that a note has been made on their records and some have been treated as being a greater risk now to dentists/surgeons etc.

- Could the Health Care staff be made aware of the risk of CJD from invasive procedures and be requested to be more selective in choosing patients to reduce the number exposed potentially. 'Prevention is better' than incident management.

- Inform patients before invasive procedures of higher risk so they have informed choice if reusable equipment is planned.

- Database must be confidential except for professionals to know.

- I think the panel need to clarify the purpose and operation of the Database. It did come across as confused. Sounded like policy being made 'on the hoof'.

- Please standardise consent form and ask the question whether the person wishes to know if they've been exposed.

- Database – there is no need for this as the only use is to prevent medical records people trying to hastily draw up a list when a look back is needed. You should be rapidly able to get this info from the new hospital patient admin systems.

- You need to specify an end point for doing look back exercises which are needed to build up knowledge as in Health Care Workers and HIV/HepB. But then you should formally end it as we (in the district) are left with the expectation that look back exercises have to be slavishly carried out.

- If you had a Database there should be two safeguards:
  1) It should be kept very confidential
  2) It should not be used for research without consent

- On the matter of publicity for the Database – a few delegates thought the public would be 'frightened'. Generally speaking I do not think they would. The public I feel would take in varying degrees as everything but the information would be out. It is secrecy in the 80s that did not help.

- In the absence of conclusive evidence regarding blood and blood products, should not the relevant information regarding risk be explained on consent for proven risk procedures (e.g. Neurosurgery). Also registration of exposure/probable exposure should be limited to those who have undergone Neurosurgical LRS procedures where risk of transmission is high/moderate and a relationship to a previous procedure by a CJD patient is likely.

- How big will the Database be and what contact groups?

- I would like you to consider again the idea of consent prior to operation, to be told if during that operation you are exposed to a TSE.

- If Local Authorities have access to this Database, will they then decline the patient healthcare?

- How do you think the information on the Database will be kept from Health Care Providers who need this information to manage risk when undertaking procedures on patients on the Database? If the plan is to keep this information separate, how do you envisage info on patients being made available to Health Care Providers?

- How will you keep the database up to date over 20-30 years, especially if you don't tell people they are on it?

- Why not just establish NHS no. Databases for all procedures and blood transfusions may have a much higher rate?

- I still think that the issues about the data base needs to be given some further thought with regards to ethical and legal issues. The public health implications of holding such a database especially with regards to supporting these included in the database. There are huge implications for primary care and public health professionals.

- CJD, while of course, it's a terrible disease, its not the only one. Patients get bad news everyday, the level of support varies, but we all have the right to know if we are at risk and also responsibility to others.

- Does the panel consider the role of the infection control doctor and team is important in the investigation and management of possible exposure of CJD through medical procedures.

- If so, why is this not discussed in more detail in the consultation paper?

- The Doctor who said having a list of contacts allows these people to be followed up if test/treatment do eventually become available.

- Consent – "If you were to be inadvertently exposed; would you wish to know?" Y/N – to ask this question when informed consent to, say, surgery is being obtained is to ask a delicate question about something having massive uncertainty at a time when they are absorbing potentially serious news about their condition and its treatment. Will they take it in will they understand? How informed can consent in answer to this question be?

- If people are to be contacted about exposure – database (regardless of degree of risk). The patient should solely be told by an expert (from the CJD panel or from central squad) This could be done in connection with GP but the central support is important and essential as there is evidence that if such news is conveyed, will play a large part in the subsequent response; better broken by an expert (team of experts/counsellors) from a central experienced "outreach" team and resources and support.

- Further careful consideration is needed for the medical legal aspects of the database and the notes and responsibilities of the health practitioners.

- Reassurances have to be sought to ensure that? ? ? will not become professionally vulnerable when they are potentially asked and breach GMC guidelines on consent and also use of research data without the full knowledge of the patient.

- Not giving wide publicity to incidents is not ? to secrecy. Current service provision is not adequate to deal with health service costs this will determine what kind of expenditure did panel recommend for covering these?

  That the database is not there to influence public behavioural is reasonable; the subject's right to remove their names from it compromises research value or it?

- As an ? I would like to know more about the likely population exposure by CJD. If great deal of emphasis and discussion time was taken up with the exposed – person (contact) database. But if the population exposure has been as large or some studies suggest, then does this not overwhelm the worry about trying to identify contacts through surgery or other terms of exposure?

  In other words, if the mass exposure on population basis, really is mass exposure, then why bother constructing database, since the vast majority of the population named need to be on it.

- Database should include the contactable group for public health reasons.

  i) Why does the non-contactable group have to be on a database
  ii) Surely these people can be identified later in a look-back exercise from operations registers if it becomes useful to contact them.
  iii) This gets around putting people on a database without informed consent.

- I very much liked the idea that before any procedure or treatment that a consent form to be placed on a database or to be informed of any future risks, be signed. This could be done at the GP's surgery or first point of contact with the medical profession and could be updated at various times of life and at further points of contact with the medical profession.

- My question (oral) was not answered. In what circumstances would someone initially on the database but "non-contactable" become contactable? If no such circumstances exist, what public health (as opposed to research) purpose is served by the database?

  If they were to become "contactable" would they have any option over this?

- The right not to know is just as great as the right to know. I am concerned about the compulsory contactable group. There is a need to explore all other ways of achieving public health aims regarding this group without forcing this knowledge on them.

- I don't see a contradiction in allowing those in the contactable group to remove themselves from the CDSC database. If they are determined to, e.g. donate blood despite advice not to do so, they could easily give a false name, i.e. the database cannot ensure that those who seek to inflict harm on others, do not do so.

  I agree that individual autonomy here is paramount. If you wish to find out, fine. If not, you should not have this information inflicted on you. The need for a contactable group would be easier to accept, if it were a real lead, if the argument were set in context of the background, e.g of meat eaters!

- Would the database be annonymised as in the case of the HIV database? If not, why not.

- In order to comply with informed consent, healthcare workers need to know what the databases consist of, in order to help the patient and informed decisions. Have the panel decided what information is to be on the database.

- How will healthcare workers know if patients are on the database. In order to process instruments.

- Will the panel be informing trusts which operations are higher risk than others.

- I felt my question on surgeons etc being in the contactable group was not adequately answered – I know they are at no greater risk of getting CJD but they may get it through a transfusion etc. If they come into the contactable group (especially neurosurgeons) can they still practice? With increased public awareness patients may ask their surgeons etc if they are on the "contactable" group database, surgeons will need professional advice to deal with this.

- The means by which incidents are investigated locally needs clarification. Clear note for infection control doctors within hospitals needs to be defined.

- If database is not vehicle for managing public health issue, how exactly is infection control to be achieved.

- If risk of eating beef as great as risk from surgery, surely an universal precaution approach in management of surgery is the way forward not having "special treatment" for an "at risk" group.

- With regard to telling "contactable patients will there be an age guide line and check that support is in place e.g. university students.

- Publicity – although a telephone number will be given for advice GP's will be inundated with questions. Will each surgery be supplied with suitable information.

- You are sitting on the same risk as John Gummer is not telling people now there is a risk.

- Will your advice change if numbers increase and public awareness grows.

- Who can access the database apart from the patient and those who are involved in any research at a later date?

- Can Insurers ask patients if they have accessed the database?

- 2 Purposes of database: public safety & research.

- What if informed consent were required? Would it reduce the value of the database to nil?

- Mentioned that database "not a means of monitoring behaviour" this can be made clearer if access to database is defined, if these blood and organ donation agencies can access, then it is a means of monitoring behaviour.

- Perhaps the premises stated of a no risk situation is unrealistic. You should ask:-

  i) How will you be able to regain public confidence by setting up a database?
  ii) Will there be responses to online that decontamination is safe? Or verifiable.
  iii) If informed ? Is the option to go for it, would it be feasible to give consent only under patient detailed conditions? E.g. only previously unused instruments will be ?

- There must be informed consent prior to a procedure that people will be contacted/go on a database prior to a procedure if you are going to do anything.

- I am concerned that notifications/publicity etc. may lead to morbidity – mortality from suicide in which case the overall public health benefit is negative so the exercise fails on a utilitarian perspective.

- It was reported this week that the Panel would put as much into the public domain as possible (a laudable sentiment) but areas of "commercial confidentiality" would be held back. Bearing in mind that "commercial confidentiality" is perceived to be "the last ? of the scoundrel" wouldn't this undermine the appearance of openness/ interest should not be reported; how do we know in face of this secrecy that the panel is putting the public interest first.

- How can the database/register be established without some form of informed consent and avoid the inevitability of undesirable negative publicity in the future.

- Much emphasis on openness – very funny notion of openness which has at its centre a "secret" list. As a doctor I would not be able to contribute patients names to this list.

- It was said several times that patients could withdraw from the database if they don't want to be included. My question is how will they know that they are on a database for them to withdraw from the database?

- Historically, was any other disease given so much importance? Are we getting value for money when resources are spent identifying an unquantifiable risk.

Blood

- Regarding advice to recipients of blood and blood based products – we have been waiting for "new" advice for over 2 years.

Miscellaneous

- How should Trustees or more particularly Neurosurgeons & ENT surgeons go forward with local policies in view of the varied and 'muddled' national view?

- In the era of evidence based medicine what is the hard evidence that there is more than a theoretical risk posed? Is there not a danger of a very expensive pile drive being created to crack a theoretical peanut? Why not wait for more definitive research answers?

- Concentration of Neurosurgery mainly Spinal Surgery is performed frequently in Orthopaedic Surgery. Has this been considered? Is it an issue regarding instrumentation decontamination? Should this be treated the same as Neurosurgery?

- I agree with the philosophy of openness regarding informing individuals. I think many of the problems of the past in the UK have been caused by 'secrecy' climate.

- Has the Panel been aware of any evidence or chance of spread of vCJD from vaccinations? – to put into context the surgical risk? What is being done about this risk?

- Generally is there a lack of quantification of risk factors (even if extreme risk) here – even though there are plenty of techniques for doing this? There are also governance and risk control issues, which are not being handled as well as could be the case.

- The panel takes an absolutist view of risk. No other potential infection is dealt with using the precautionary principle to some degree.

- Surely it is "possible" that anyone died from CJD via instruments.

Questions to be addressed by the Department of Health

Patients

- Need to train medical practitioners who will speak to patients. Not just those directly involved but general Infection Control & Public Health Specialist.
- What resources, counselling support sessions will be in place for people who end up on the database & find out that they are on it? This is not acute counselling but long term.

- What arrangements might be considered to advise/support people on the database/contact list who have a mental illness or learning disability?

- There must be an agreed package of information & support offered to all people on the Database/contact group list. This info. must be consistently available regardless of geography.

- How is the publicity programme for CJD to be rolled out? Awareness at a lower level should precede a full publicity campaign. NHS Direct, web sites, leaflets giving information before more 'mass media' for example newspaper, tv advertising. The NHS is good at raising 'alarm' and not having the answers rehearsed.

- Point of clarification/correction:
  The Consumer Association would support the Panel's recommendation for a broad-based publicity/communication/education campaign. Our question would be what strategies are being considered by the Panel to ensure that the public (especially hard to reach groups) are made aware of the database? Furthermore, what counselling & advice structures will be put in place to help support those people who find they are on the database? Will this be ongoing?

- Creation of a database on the basis of right to know will increase number of litigations enormously and the cost of compensation payment will go through the roof. Has the Panel considered this?

- When you indulge in publicity please remember the impact that this will have on Primary Care. Do not put 'If you have any other questions please ask your GP' on the bottom.

Instruments

- Given the fact that more emphasis is being placed on washing & disinfecting of surgical instrumentation, when are funds for 2002/3 going to be released & what is there to back this up?

- Is there a requirement to trace individual instruments to patients and if so will this be funded?

- Mouth gags that are disposable but not 'safe'. Why are we not investigating improvement of disposable instrumentation?

- There is currently no robust system in many areas of primary and acute care for the traceability of instruments. There was much debate about the database but traceability issues need to be resolved to maintain it. There are substantial costs to employ robust traceability methods – who will pay for them and when will they be put in place?

- Disposable instruments are not of the same quality as re-useable so this does present another risk.

- Should reusable tonometer heads be reused after chemical disinfection?

- Should diamond knives (the blade) used for cataract surgery be reused after decontamination (autoclavable) or single use always be used given patients are usually elderly and single use diamond knives are of a lower quality.

- When disposable tonsillectomy sets were introduced/mandatory the Trust next door decided to treat all biopsies as potential CJD. Our Trust did the same, now that they are no longer mandatory should we treat tonsil biopsies as normal i.e. not potential CJD. What are the Panel's views?

- More clarification about surgical instruments and tracking systems. Is there funding going to be available for this?

- In a case well known to me, the 'possibly exposed' group totalled 7000. This was because instruments could not be individually traced. Should not the introduction of instrument tracking systems nation-wide (? cost) accompany the introduction of the proposed databases?

- Will compensation be paid to departments who need to replace surgical trays – otherwise there will be a severe temptation to put instruments through a couple more cycles if that is all that is required to get to 10 cycles.

- Please could the Panel come out with a clear statement about contamination and decontamination of surgical instruments so that communities that cannot afford 'private' health care may feel confident in the NHS care provision.

- Effective methods of sterilisation/deactivation of the prion: Some methods of sterilisation were only referred to. Was Gamma Radiation of instruments explored? Would this be a viable method of deactivation for use with instruments known to have been contaminated with the prion? Also, what about other methods?

- Their ENT Theatre Sister should have approved the tonsil instruments in question. I personally checked each supplier (of which there were several of varying qualities) and the results were excellent.

- What measures will be put in place to ensure the adequacy of record keeping of the use of medical instruments so that if a case of CJD is diagnosed late, the instruments can be traced efficiently? The adequacy of batch-tracing systems is particularly important. If surgical instruments are used in batches, for example, can the other instruments from the batch be traced if it is spilt up in subsequent operations?

- It is important to understand the level of risk from surgical instruments. I feel this however does not square with the fight most NHS Trusts have to secure the funding for a computer based tracking system for both endoscopes and instruments. You may have a state of the art SDU but have no way of tracking instruments. Such systems should now be mandatory with appropriate funding centrally.

- Too much time on database issues compared to those from instruments/inspection control problems.

- Question on decontamination and dental services has already been sent in from Chichester CHC. We hope for a reply.

- How should contaminated equipment be disposed of?

- Is there any intention to ensure that our Trusts have, sooner rather than later, robust systems for tracking surgical instruments to enable the database to work efficiently and effectively? Surely this needs to be addressed across the UK.

- In terms of decontamination – has an approach been made to the Association of British Healthcare Industries (ABHI) with a view to re-engineering/designing reusable instruments, so that critical difficult to clean components may be replaced with disposable equivalents.

- There was little time to discuss practical issues related to identification and disposal of contaminated instruments.

- How are recommendations going to be made in the light of current status of decontamination services, and traceability of surgical instruments in many UK hospitals

- Staff in NHS would welcome the practical help in ensuring that instruments are traceable e.g. by more pressure placed on manufacturers to make it easier for making instruments etc.

- What about making all surgical instruments with serial numbers of entries made in the patient notes? Surgical packs must have overall specific set numbers and individual instruments numbered to the same sets otherwise traceability is impossible.

- Would the panel make recommendations around future introductions of e.g. disposable instruments by the DOH to prevent a recurrence of the difficulties around T & A instruments, and ensure patients were not at greater risk from DOH intervention from unknown and unaccountable sources?

- Has the panel liased with the Environment Agency? Some incinerators refuse to take large metal instruments e.g. drills. We've had equipment in quarantine for over 2 years now and can't get it incinerated.

- Acknowledging the issue of resources (availability of funding) no mention was made on the implementation of tracking systems in the NHS which needs urgent attention. (Significant manual cleaning and how this can link with tracability issues)

- Since many pieces of equipment are not autoclavable ventilator equipment and accessories are theatre instruments for specialist ops (neuro, ENT, Opthathic)) are there going to be clear guidelines on the appropriate methods of decontamination (whether reuse or disposable)? This would help facilitate better standardisation throughout the UK as opposed to localised guidelines, which may be inconsistent.

- I know that the Panel had nothing to do with disposable instruments, but the Panel needs to address the support that is needed to be given to health staff that have had to live through the chaos of last year.

- I very nearly left my job as a Senior ENT Theatre Sister due to the stress of trying to source, order chase up, pacify surgeons etc. I know it was the government's knee jerk reaction.

- We thank god are using our old instruments, which I stored with the view to reusing when everyone saw sense. There have only been 100 patients so far how many staff has been sent into despair over the last year.

Blood

- I know it's not a direct remit, but could you recommend minimising exposure by responsible use of blood/products. Well done.

- Will the DoH revise its existing instruction to the NHS not to inform patients when vCJD implicated plasma products have been used?

Miscellaneous

- What steps will the Government take to minimise the incidence of CJD through the consumption of infective beef?

- The resources required cannot be 'skirted over'. No resources were provided to help us deal with retained organs and this has so far cost our Trust hundreds of thousands of pounds.

- SEAC considered the potential use of pentosan polysulphate as a prophylactic agent against vCJD in January 1999. Further research was recommended as a high priority. In the absence of further data on efficacy and safety, SEAC did not consider it was justified to recommend the wide spread use of Pentosan as a possible prophylactic against vCJD. In the absence of any other prophylactic agent the Panel is asked if those individuals with a history of prior exposure should be given the facts and allowed to make up their own mind. Would the Panel then help them to obtain pentosan if they wish for it.

- When will the risk assessment of dental issues become available?

- I have a lot of sympathy with one member of the public who suggested that much more effort should be placed on preventing risk of transmission in neuro-surgery.

- There are so far two major risks that need to be identified.

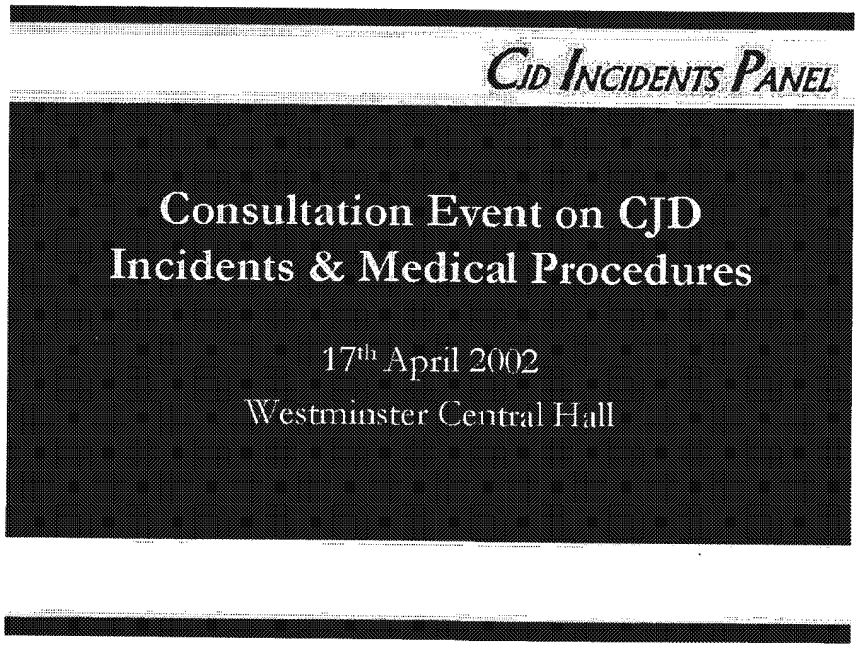
  i) Iatrogenic i.e. from surgery or organ/tissue donations. This is a high risk.
  ii) Naturally occurring disease (risk) still needs thorough research and monitoring. This is the unknown risk so far.
  iii) Emphasis should now (as it is) be focused on prevention/decontamination of surgical instruments/food industry.

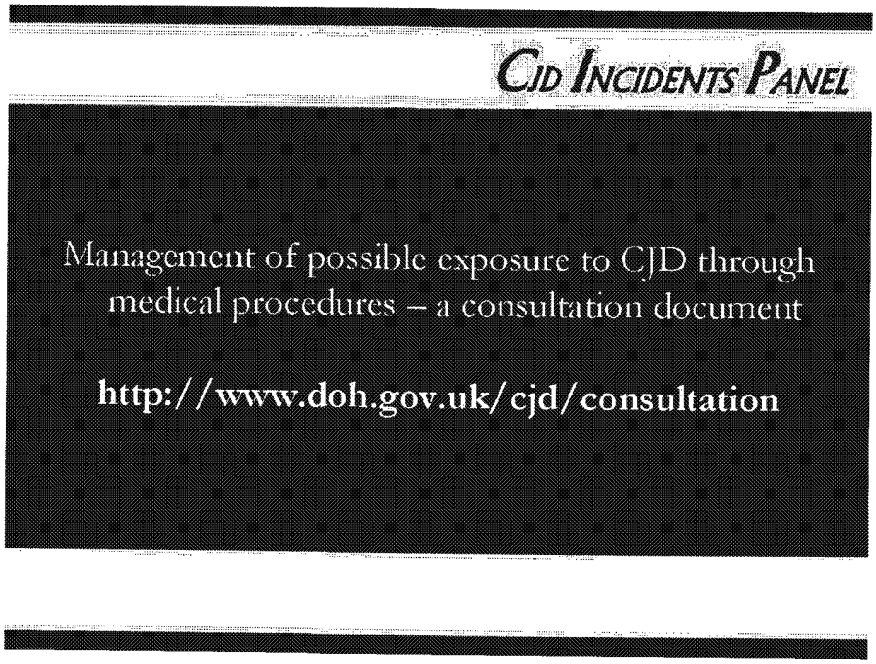
<u>Panel/ Department of Health British Medical Association queries</u>

- I should like more information on:

1) vCJD spread by transfusion of blood products/blood
2) vCJD spread by burning and burying carcasses during foot & mouth epidemic.
3) The extent of the vCJD epidemic.
4) The costs of the proposed publicity and database exercise.

Presentation by Professor Michael Banner, Chair of the CJD Incidents Panel





CJD Incidents Panel

Actions

- Removing the instruments/blood products from use
- Setting up a confidential database of all possibly exposed people
- Informing some individuals about their exposure to CJD
- Providing publicity

CJD Incidents Panel

Principles

- To protect patients from the risk of acquiring CJD in healthcare settings
- To provide high quality and appropriate information to people who may have been put at risk while respecting where possible the wishes of those who do not want to be informed

CJD INCIDENTS PANEL

Principles

- To be open about the risk of acquiring CJD in healthcare settings and the scientific uncertainties surrounding the risk
- To increase our knowledge about the risk of spreading CJD through medical procedures
- To protect patient confidentiality and quality of care of patients exposed to a risk of acquiring CJD

CJD INCIDENTS PANEL

Consultation Event on CJD Incidents & Medical Procedures

17th April 2002

Westminster Central Hall

Presentation by Professor Don Jeffries, Virologist, St Bartholomew's Hospital

Global cases of iatrogenic transmission of CJD (up to July 2000)

Mode of infection	Number of patients infected
Tissues/Organs	
Growth Hormone	139
Dura mater graft	114*
Corneal transplant	3#
Gonadotropin	4
Surgery/invasive procedures	
Neurosurgery	5±
Stereotactic EEG	2

*In two cases, dura was used to embolise vessels of non-CNS tissues, rather than as intracranial grafts.

±Contaminated neurosurgical instruments

Chemicals & processes RECOMMENDED for use against TSE agents

Chemical disinfectants	Gaseous disinfectants	Physical processes
20,000ppm available chlorine of sodium hypochlorite for 1 hour 2M sodium hydroxide for 1 hour* For histological samples only, 96% formic acid for 1 hour	None	Porous load steam steriliser 134-137°C for a single cycle of 18 minutes, or 6 successive cycles of 3 minutes each*.

* But not known to be **completely** effective.

Chemicals & processes INEFFECTIVE against TSE agents

Chemical disinfectants	Gaseous disinfectants	Physical processes
Alcohols Ammonia B-propiolactone Chlorine dioxide Formalin Glutaraldehyde Hydrochloric acid Hydrogen peroxide Iodophors Peracetic acid Phenolics sodium dichloroisocyanurate (e.g. 'Presept")** 10,000ppm sodium hypochlorite	ethylene oxide formaldehyde	dry heat ionising, UV or microwave radiation moist heat at 121°C for 15 minutes

** the rate of release of chlorine from this product is insufficient to ensure complete inactivation of the agent.

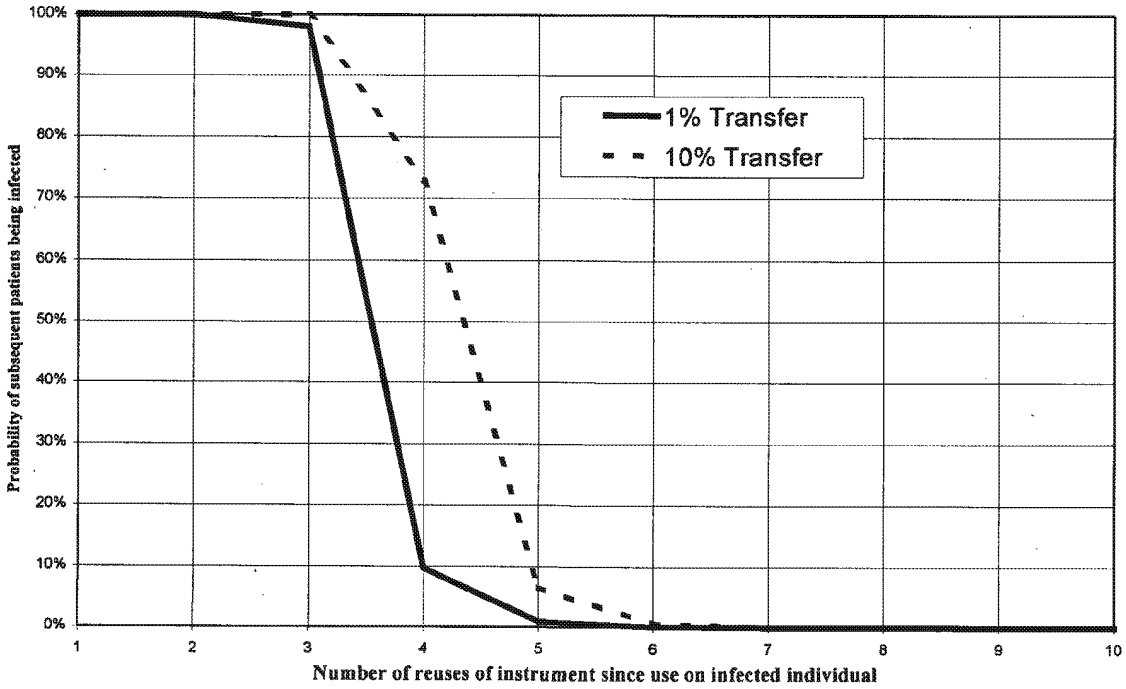
Potential infectivity in variant CJD, by source tissue and site of exposure

Source tissues and tissues exposed during surgery	**Disease stage**	**Infectivity** [ID_{50} / g]
CNS to CNS (or retina or optic nerve)	First 60% of incubation period	$0 - 10^4$
	Last 40% of incubation period and during clinical disease	10^8 (this could increase to 10^9 in the final year and to 10^{10} after the onset of symptoms)
Other parts of eye to other parts of eye	First 60% of incubation period	$0 - 10^4$
	Last 40% of incubation period and during clinical disease	$10^5 - 10^6$
LRS to LRS	All of the incubation period and during clinical disease	$10^5 - 10^6$
Remaining tissues, including blood	All of the incubation period and during clinical disease	$0 - 10^4$

Effectiveness of instrument decontamination

Variable	Value /range
Initial amount of material on instruments (mean, per instrument)	10 milligrams
Cleaning (washing / disinfecting)	
Reduction in amount of material after first cleaning	$10^2 - 10^3$ fold reduction
Reduction in amount of material after subsequent cleanings	$0 - 10^2$ fold reduction
Deactivation (sterilising / autoclaving)	
Reduction in infectivity after first autoclaving	$10^3 - 10^6$ fold reduction
Reduction in infectivity after subsequent autoclaving	$0 - 10^3$ fold reduction

Scenario modelling probability of infecting subsequent patients.
Tissue Infectivity 10^{10} ID_{50}/g (e.g. CNS in patient with symptoms of CJD)



Patients to be included in 'contactable' group

Clinical procedure in index patient[1]	'Contactable' group
High risk procedures CNS, retina, optic nerve procedures in patient with symptoms or within one year of developing symptoms of any type of CJD	First 6 patients
CNS, retina, optic nerve procedures in patient who subsequently develop any type of CJD (in last 40% of incubation period*).	First 4 patients
Medium risk procedures Other eye tissue procedures in patients who have, or subsequently develop any type of CJD (in last 40% of incubation period*).	First 2 patients
LRS procedures in patients who have, or subsequently develop variant CJD (at any stage in incubation period).	First 2 patients

* In sporadic CJD the mean incubation period is assumed to be 20 years. In variant CJD the incubation period is assumed to start in 1980.

[1] See Box 2 for detailed categorisation of clinical procedures

Annex 4

Biography of CJD Incidents Panel Members

Name	Biography
Professor Michael Banner	Chairman of the CJD Incidents Panel and Animal Procedures Committee with an interest in bioethics. Professor of Moral and Social Theology at King's College, University of London.
Professor Donald J. Jeffries BSc, MB BS, FRCP, FRCPath	Deputy Chair of CJD Incidents Panel. Professor of Virology and Head of Dept of Medical Microbiology, St Bartholomew's and the Royal London School of Medicine and Dentistry. Chairman of ACDP/SEAC Joint Working Group on Transmissible Spongiform Encephalopathies. Member of Expert Advisory Group on AIDS and Committee for Safety of Medicines.
Members	
Mr John Barker	Past Chair and currently a member of the Institute of Sterile Service Management. SDU manager, Derriford Hospital, Plymouth.
Professor Mike Bramble	Represents the British Society of Gastroentereology and chairs the Endoscope Committee of that society having been elected Vice-president (Endoscopy) in 2000. He works at the James Cook University Hospital in Middlesborough and in the Centre for Integrated Health care research at the university of Durham (Stockton Campus). He has been an NHS consultant Gastroenterologist for 20 years.
Professor Ian Cooke	Emeritus Professor of Obstetrics and Gynaecology, University of Sheffield, President of the British Fertility Society, representing the Royal College of Obstetricians and Gynaecologists.
Dr Geoff Craig	Reader and Hon. Consultant in Oral Pathology at the University of Sheffield, School of Clinical Dentistry. Until recently, Chairman of the British Dental Association's Health & Science Committee for almost ten years and member of the BDAs Executive Board.
Professor Len Doyal	Professor of Medical Ethics, Queen Mary, University of London and an Honorary Consultant, Barts. and The London NHS Trust. He has published on most areas of bioethics and is particularly interested in its philosophical and legal foundations. His latest book (edited with J. Tobias) is Informed Consent in Medical Research (BMJ Books).
Ms Jean Gaffin OBE	Taught social policy and then managed health related voluntary organisations; she retired in 1998. She remains involved in the voluntary sector as Trustee or Committee member and is a member of the Financial Services Consumer Panel. Since 1st April she has chaired Brent Primary Care Trust
Dr Noel Gill	Medical epidemiologist at the National Communicable Disease Surveillance Centre

Name	Biography
Mr Luke Gormally	Senior Research Fellow of The Linacre Centre for Healthcare Ethics, of which he was Director from 1981 to 2000. He is also a Research Professor of Ave Maria School of Law, Ann Arbor, Michigan, USA
Dr Pat Hewitt	Lead Consultant in Transfusion Microbiology, National Blood Service. Interest in transfusion transmitted infection. Responsible for counselling of infected blood donors and investigation of cases of possible transfusion transmitted infection.
Professor Peter Hutton	President of the Royal College of Anaesthetics. Professor of Anaesthesia and Head Department of Anaesthesia and Intensive Care, University of Birmingham and Hon. Consultant Anaesthetist, University Hospital Birmingham NHS Trust since 1986.
Professor James Ironside	Director of the National CJD Surveillance Unit, Member of SEAC and the ACDP/SEAC Joint Working Group with an interest in neuropathology and human prion diseases. Professor of Clinical Neuropathology in the University of Edinburgh and Honorary Consultant Neuropathologist in Lothian University Hospitals NHS Trust.
Ms Diana Kloss	Barrister, Senior Lecturer in Law in the University of Manchester, Honorary Fellow of the Faculty of Occupational Medicine of the Royal College of Physicians, has a special interest in occupational health law and is a member of the Expert Advisory Group on AIDS as well as the CJD Incidents Committee
Professor John Lumley	Member of the Council of the Royal College of Surgeons. Professor of vascular surgery and Hon. Consultant surgeon at Saint Bartholomew's Hospital, London.
Ms Susan MacQueen	Lead Clinician and Clinical Nurse Specialist in Infection Control at Great Ormond Street Hospital for Children NHS Trust, London with an interest in Medical Anthropology. Past Chairperson of the Infection Control Nurses Association.
Mr Henry Marsh, FRCS	Senior Consultant Neurosurgeon at Atkinson Morley's Hospital, representing the Society of British Neurological Surgeons.
Professor John O'Neill	Professor of Philosophy, Institute for Environment, Philosophy and Public Policy, Lancaster University. Research interests in ethics, political theory and public policy.
Dr Mike Painter	Public health physician from Manchester. Member of SEAC from 1996 - 2000. Member of ACDP/SEAC Joint Working Group on Transmissible Spongiform Encephalopathies from 1997 to date.

Name	Biography
Dr Geoff Ridgway	ACDP/JWG working party on TSE, Committee for Safety of Devices, and Chair of Microbiology Advisory Committee to D of H. Consultant Microbiologist, Honorary Senior Lecturer, University College London Hospital NHS Trust and University College London.
Dr Roland Salmon	Epidemiologist with the Public Health Laboratory Service, based at their Communicable Disease Surveillance Centre (Wales). This involves monitoring trends in infectious disease (surveillance), investigating outbreaks and advising on prevention and control. After qualifying from St Bartholomew's Hospital, London, he worked in hospital and general practice before training in public health. His interests include zoonoses (diseases you get from animals) and food and waterborne disease.
Professor Graham Smith	Vice-president of the Royal College of Anaesthetists with an interest in anaesthetic equipment. Professor of Anaesthesia, University of Leicester
Professor Dame Lesley Southgate	Professor of Primary Care and Medical Education. She was made a Dame Commander of the British Empire in the June 1999 Birthday Honours List for services to standards of practice and primary care. She was recently elected President of Royal College of General Practitioners and began her 3-year term in November 2000. She also leads the President's programme to develop and implement the assessment methods for the GMC performance procedures for the medical profession. She is also Chair of the DOH Refugee Health Professionals Steering Group. Clinical research interests have been in Chlamydial Infections, and she is the author, with three others, of a book on Infection published by Oxford University Press in July, 1997.
Dr David M Taylor PhD MBE	A private consultant who previously worked at the Neuropathogenesis Unit in Edinburgh. His particular area of expertise is with regard to the inactivation of CJD-like agents.
Ms Gillian Turner	Gillian Turner has worked in the voluntary and private sectors for the last sixteen years, working with patients, carers and service providers. Her posts have included those with Red Cross and Age Concern. She is currently the National CJD Case Co-ordinator for the CJD Support Network, part of the Alzheimer's Society.
Mr Andrew Tullo	Consultant Ophthalmologist at Manchester Royal Eye Hospital and spokesman for the Royal College of Ophthalmologists on prions and the eye.
Dr Hester Ward	Consultant Epidemiologist National CJD Surveillance Unit, Consultant in Public Health Medicine and Honorary Consultant at the Scottish Centre for Infection & Environmental Health.

Name	Biography
Ms Kate Woodhead	Independent Operating Theatre Consultant and former Chairman of the National Association of Theatre Nurses. Worked in NHS and Independent Sector Operating Theatres for 23 years in clinical and managerial positions.
Dr Tim Wyatt	Consultant Clinical Microbiologist at the Mater Hospital Trust Belfast. Wide interest in Microbiology. Member of ACDP/SEAC TSE Joint Working Group; Advisory Committee on the Microbiological Safety of Blood and Tissues for Transplantation [MSBT]; Advisory Committee on the Microbiological Safety of Food [ACMSF]; HSAC on Safe Working in Clinical Laboratories and Post-Mortem Rooms.
Observers	
Dr Martin Donaghy	Consultant in Public Health Medicine currently seconded to the Scottish Executive Health Department. He has responsibility for the development of the public health function in Scotland especially as it relates to communicable disease control, including vCJD.
Dr Glenda Mock	Principal Medical Officer with the Department of Health, Social Services and Public Safety in Northern Ireland. After gaining experience in several hospital specialities, she worked as a Principal in General Practice for six years before joining the Department in 1988.
Dr Mike Simmons	Senior Medical Officer (Communicable Diseases) for the Welsh Assembly Government. Dr Simmons has a medical microbiology background and acts as an observer on behalf of the Chief Medical Officer for Wales.
Secretariat	
Dr Nicky Connor	Communicable Disease Surveillance Centre,
Dr Pip Edwards	Department of Health, CJD and BSE Policy Unit
Miss Claire Mills	Department of Health, CJD and BSE Policy Unit
DH Officials	
Ms Carole Fry	Department of Health, Public Health and Clinical Quality Directorate
Dr Rowena Jecock	Department of Health, Head of CJD and BSE Policy Unit
Dr Mary O'Mahony	Department of Health, Head of Communicable Disease Unit

Attendees at open meeting

Attendance Statistics

Expected on site = 396

Cancelled on 17th April = 12

No shows = 94

Registered on site = 18

Actual number on site = 308

Title	Surname	Job Title	Organisation
Dr	Ahmad	Consultant Microbiologist	Ealing Hospital NHS Trust
Dr	Alshafi	Lead Clinician for Infection Control and	Gwent Healthcare NHS Trust
		Chairman of Infection Control	
Dr	Anderson	Consultnt Microbiologist	York Health Services NHS Trust
Mr	Andrews	Statistian	Public Health Laboratory Service
Dr	Ashton	Medical Director	BMI Healthcare
Ms	Askwith	Chair of Infection Control Committee	Parkside NHS Trust
Dr	Bain	Consultant Microbiologist Trust Infection Control Doctor	Southend Hospital NHS Trust
Dr	Bakhshi	Consultant In Communicable Diseases	Birmingham Health Authority
Prof	Banner		CJD Incidents Panel
Dr	Bardhan	Consultant In Communicable Diseases	Coventry Health Authority
Mr	Barker		CJD Incidents Panel
Dr	Barker	Consultant In Communicable Diseases	Southampton & South West Hampshire Health Authority
Ms	Barkess-Jones	Infection Control Nurse	Wigan & Leigh Health Services NHS Trust
Dr	Barnes	CC DC	Calderdale & Kirklees Health Authority
Mr	Bascombe		Black Country Mental Health NHS Trust
Dr	Bates	Consultant Microbiologist	Central Sheffield University Hospitals NHS Trust
Ms	Baxter	Divisional Support Manager	Northern Lincolnshire & Goole Hospitals NHS Trust
Mr	Beasley	COMMS-MD	Department of Health
Dr	Bendall	Consultant in Forensic Psychiatry	Rampton Hospital
Dr	Bennett		EOR4
Mr	Beyless	Honorary Treasurer	CJD Support Network
Mr	Bibby		Human BSE Foundation
	Binji		Department of Health
Miss	Binns	Acting Clinical Risk Co-ordinator	Northamptonshire General Hospital NHS Trust
Ms	Bolton	CML Manager Critical Care	Kingston Hospital NHS Trust
Dr	Booth	CCDC	North & Mid Hampshire Health Authority
Mrs	Bowden	IC Sister	United Bristol Healthcare NHS Trust

Title	Surname	Job Title	Organisation
Dr	Bowler	Chair of Infection Control Committee	John Radcliffe Hospital
Prof	Bramble		CJD Incidents Panel
Mr	Broome	Sterile Services & Decontamination Manager	Barnsley District General Hospital NHS Trust
Dr	Bryant	Specialist Registrar Public Health	CDSC
Prof	Buckley		Royal College of Ophthalmologists
Mr	Byron	Senior Nurse Infection Control	Heatherwood & Wexham Park Hospitals NHS Trust
Ms	Campbell		Scottish Health Executive
Mr	Carey	Senior Nurse Adviser Infection Control	Brent, Kensington, Chelsea & Westminster Mental Health Trust
Ms	Carey	Quality Assurance and Clinical Governance Manager	Papworth Hospital NHS Trust
Ms	Carey	Clinical Manager	Ashford & St Peters Hospitals NHS Trust
Mrs	Carroll	IC Support Nurse	United Bristol Healthcare NHS Trust
Ms	Carroll		Tonbridge Cottage Hospital
Mr	Carver	Chief Executive	George Eliot Hospital NHS Trust
Ms	Cattini	Infection Control Nurse	Kingston Hospital NHS Trust
Ms	Chadwick	Senior Nurse Infection Control	Christie Hospital NHS Trust
Dr	Chambers	Consultant Microbiologist	West Park Hospital
Dr	Chandrakumar	Clinical Director Kent CDC	West Kent Health Authority
Dr	Chapman	Chair of Infection Control Committee	Isle of Wight Healthcare NHS Trust
Dr	Chattopadhyay	Consultant Medical Microbiologist	BUPA Roding Hospital
Mr	Clough	Medical Director	King's Healthcare NHS Trust
Dr	Colville	Consultant Microbiologist	Royal Devon & Exeter Healthcare NHS Trust
Dr	Connor		CJD Incidents Panel Secretariat
Prof	Contreras	National Director of Diagnostics - Development & Research	National Blood Service
Prof	Cooke		CJD Incidents Panel
Ms	Coombs	Senior Staff Nurse - Theatres	Taunton & Somerset NHS Trust
Ms	Cornall		Institute of Actuaries
Dr	Cowan	Medico Legal Adviser	Medical Protection Society
Dr	Craig		CJD Incidents Panel

Title	Surname	Job Title	Organisation
Dr	Crawshaw	Regional Consultant Epidemiologist	University Hospital
Mr	Crowe		Human BSE Foundation
Dr	Cummins	Consultant In Communicable Disease Control	South Essex Health Authority
Ms	Dailly	Infection Control Nurse	Winchester & Eastleigh Healthcare NHS Trust
Dr	Dasan		
Dr	Davies	Consultant Microbiologist	North Bristol NHS Trust
Dr	De Silva	Consultant Neurologist	Romford Hospital
Dr	Dealler	Chair of Infection Control Committee	Burnley Health Care NHS Trust
Ms	Dempster	Infection Control Advisor	The William Harvey Hospital
Ms	Dolan	Infection Control Nurse	Manchester Childrens University Hospital NHS Trust
Dr	Donald	Consultant Microbiologist	University Hospital
Mr	Donohoe		MDA
Ms	Dooley	Senior Theatre Sister	East Cheshire NHS Trust
Dr	Double	Consultant in Communicable Diseases	Barking & Havering Health Authority
Prof	Doyal		CJD Incidents Panel
Mrs	Drabwell	Trustee	Primary Immunodeficiency Association
Mrs	Dye	Deputy Chief Officer	East Hertfordshire Community Health Council
Ms	Edgar	Haemophilia Nurse	Avon Haemophilia Unit
Mr	Edge	Member ESCHC	East Surrey Community Health Council
Dr	Edwards		CJD Incidents Panel Secretariat
Mrs	Edwards	Senior Nurse,Infection Control	Royal Brompton & Harefield Hospital
Rev	Edwards	Assembly Liaison Officer	CNAC
Ms	Egan	Clinical Specialist - Infection Control	Mid Cheshire NHS Trust
Dr	Ejidokun	Consultant In Communicable Disease Control	Gloucestershire Health Authority
Ms	Elliott	Directorate Manager Neurosciences	Oxford Radcliffe Hospital Trust
Dr	Ely	Member	Chichester Community Health Council
Ms	English	Medical Ethics Committee	British Medical Association
Dr	English	Consultant In Communicable Disease Control	East Surrey Health Authority

Title	Surname	Job Title	Organisation
Ms	Evans	Infection Control Nurse Adviser	Community & Mental Health Services NHS Trust
Miss	Evans		City Hospital NHS Trust
Ms	Fairbank		Macfarlane Trust
Mr	Fanning	Chief Nurse	The Oxford Radcliffe Hospitals NHS Trust
Dr	Faris	Consultant Microbiologist	Salford Royal Hospitals NHS Trust
Dr	Farrag	Consultant Microbiologist Chair Of Infection Control	St George's Healthcare NHS Trust
Ms	Fennell	Senior SR Training/Education	Birmingham Children's Hospital NHS Trust
Mrs	Firkins		Human BSE Foundation
Mr	Firkins	Chair	Human BSE Foundation
Mrs	Fisher	Divisional Manager/Assist Director of Nursing	South Tees Hospitals NHS Trust
Ms	Fitzgibbon	CNS Infection Control	Addenbrookes NHS Trust
Mr	Flood	Theatre Manager	Birmingham Children's Hospital NHS Trust
Dr	Franklin	National Medical & Scientific Director	Scottish National Blood Transfusion Service
Ms	Fraser	Infection Control Nurse	Kettering General Hospital
Ms	Fuller	Clinical Nurse Advisor, Infection Control	Bradford Health Authority
Ms	Gaffin		CJD Incidents Panel
Mr	Gair	Chief Executive	Ealing Hammersmith & Hounslow Health Authority
Mrs	Gauci	Nursing Officer Communicable Diseases	Princess of Wales Hospital
Dr	Ghose	Consultant Microbiologist	Warwickshire Health Authority
Mr	Gibson		Newcastle Upon Tyne Hospitals NHS Trust
Dr	Gill		CJD Incidents Panel
Ms	Goddard	Infection Control Nurse	Oxford Radcliffe NHS Trust
Dr	Goodbourn	Consultant Microbiologist	Whipps Cross University Hospital NHS Trust
Dr	Gosden	Consultant Medical Microbiologist	Weston Area Health NHS Trust
Dr	Gransden	Consultant Microbiologist	Royal Bornemouth Hospital
Ms	Grove	Community Infection Control Nurse	Harrow & Hillingdon Healthcare NHS Trust
Ms	Grummitt	Senior Nurse: Infection Control	Ealing Hospital NHS Trust
Mr	Hale	Clinical Director of Community Dental Services	Eastbourne & County Healthcare NHS Trust

Title	Surname	Job Title	Organisation
Mrs	Hall	Secretary	Human BSE Foundation
Mr	Hambley		Aberdeen and North East Scotland Blood Transfusion Service
Ms	Hammond	Theatre & Allied Services Manager	United Lincolnshire Hospitals NHS Trust
Dr	Handslip	Medical Director	George Eliot Hospital NHS Trust
Mrs	Hardwick	Senior Infection Control Nurse	Hammersmith Hospitals NHS Trust
Mr	Haricharan	Senior Dental Officer	Tower Hamlets Primary Care Trust
Mrs	Harmon	Infection Control Advisor	Riverside Community Health Care NHS Trust
Mr	Harris	Regional Adviser Pharmacy & Prescribing	NHS Executive Trent Regional Office
Mrs	Harrison		Barts Guild & Barts Campaign
Mr	Harrison	Manager TSSU, Theatres	North Hampshire Hospital
Ms	Hart	Clinical Nurse Specialist Infection Control	Royal Marsden Hospital NHS Trust
Mr	Hart		Royal Liverpool Hospital
Dr	Hewitt		CJD Incidents Panel
Ms	Hill	Nurse Consultant Infection Control	North Bristol NHS Trust
Mr	Hill	Member	Hillingdon Community Health Council
Ms	Hithersay	Centre Director	Medical Trustee Macfarlane Trust
Mr	Hodgeson	Chairman	Haemophilia Society
Mr	Holland	Sterile Services Manager	Kingston Hospital NHS Trust
Mrs	Hollis		Barking, Havering and Redbridge NHS Trust
Ms	Holt		Department of Health
Ms	Home	Directorate Manager, Theatres & Anaesthetics	Radcliffe Infirmary
Dr	Hosein	Chair of Infection Control Committee	Cardiff & Vale NHS Trust
Dr	Howie	CPHM (CD/EH)	Grampian Health Board
Mrs	Hughes	Assistant General Manager, Surgery	Gloucestershire Hospitals NHS Trust
Mrs	Hughes	Divisional Nursing Manager	Moorfields Eye Hospital NHS Trust
Mr	Hunt	CSSD Manager	Gloucestershire Hospitals NHS Trust
Mrs	Huyton	Infection Control Nurse	Mid-Cheshire Hospital NHS Trust
Ms	Inman	Acting Assistant Clinical Director (Dentla Services)	South Warwickshire Combined Care NHS Trust

Title	Surname	Job Title	Organisation
Prof	Ironside		CJD Incidents Panel
Dr	Iversen	Consultant in Communicable Disease Control	East Sussex, Brighton & Hove Health Authority
Dr	Jacobson	Chair of Infection Control Committee	Royal United Hospital NHS Trust
Mr	Jago		Royal Surrey Hospital
Ms	Jameson	Assistant Director - Clinical Operations	Epsom & St Helier NHS Trust
Dr	Jayshree	Consultant Microbiologist	Leeds General Infirmary
Ms	Jeanes	Infection Control Nurse	Lewisham Hospital NHS Trust
Dr	Jecock		Department of Health
Dr	Jeevananthan	Medical Director	Milton Keynes General Hospital NHS Trust
Prof	Jeffries	Head of Service	CJD Incidents Panel
Dr	Jenkins	Lead Infection Control Officer	University Hospitals of Leicester NHS Trust
Dr	Jepson	Chair of Infection Control Committee	St Mary's Hospital NHS Trust
Ms	Jokinen	Practical Development Adviser	Royal College Of Midwives
Mrs	Jones	Theatre Nurse Manager	North East Wales NHS Trust
Dr	Jones	Consultant Haematologist	Welsh Blood Service
Dr	Jordan	Lecturer	University of Wales
Dr	Judkins	Medical Director	Pinderfields & Pontefract Hospitals NHS Trust
Dr	Kangesu		Redbridge and Waltham Forest HA
Dr	Karcher	Consultant Microbiologist	Homerton University Hospital NHS Trust
Mr	Kaur Reeve	Public Health/Infection Control Nurse	Camden & Islington Health Authority
Dr	Keyworth	Chair of Infection Control Committee	Winchester & Eastleigh Healthcare NHS Trust
Mrs	King		Royal United Hospital NHS Trust
Mrs	King	Chief Officer	Portsmouth & South East Hants CHC
Mrs	Kleban-Stanczak	SSD Manager	St George's Healthcare NHS Trust
Miss	Kloss		CJD Incidents Panel
Mr	Knight	Nurse Adviser	Hull & East Yorkshire Hospitals NHS Trust
Dr	Kumar	Consultant in Communicable Disease Control	Ealing, Hammersmith & Hounslow Health Authority
Dr	Lacey	Consultant Microbiologist	King George Hospital

Title	Surname	Job Title	Organisation
Dr	Lanham	Consultant Anaesthetist & Lead Clinician For	Poole Hospital NHS Trust
		Poole Hospital Trust	
Dr	Lau	Consultant In Communicable Disease Control	Kensington Chelsea & Westminster Health Authority
Ms	Law	Senior Nurse Infection Control	St. George's Hospital
Mr	Layhe	Community Liaison Officer	Sussex Ambulance Service NHS Trust
Dr	Leach	Consultant Microbiologist	Kingston Hospital NHS Trust
Dr	Lessing	Consultant Microbiologist	Heatherwood & Wexham Park Hospitals NHS Trust
Ms	Lewis	Community Infection Control Nurse	Nottingham City Primary Care Trust
Dr	Lewis	Consultant Epidemiologist	Communicable Disease Surveillance Centre
Dr	Lighton	Consultant in Communicable Disease Control	West Pennine Health Authority
Mrs	Liles	Chief Officer	Basildon & Thurrock Community Health Council
Mr	Lister		Department of Health
Miss	Logan	Directorate Manager - Anaesthetic Services Directorate	Swindon & Marlborough NHS Trust
Prof	Lumley		CJD Incidents Panel
Ms	Lusardi	Acting Senior Nurse for Infection Control	Bro Morgannwg NHS Trust
Dr	Lyons	Consultant in Communicable Disease Control	Bro Taf Health Authority
Major	MacDonald	S O 2 Communicable Desease Control	Surgeon General's Department
Ms	MacQueen	Past Chair, Infection Control Nurses Association	CJD Incidents Panel
Mr	Mahon	Health Policy Adviser	Association of British Insurers
Dr	Manek	Director of Clinical Education	George Eliot Hospital NHS Trust
Dr	Mawson	Independent Dental Adviser	GDS Unit
Ms	Mayland		East Kent NHS Trust
Ms	McDougal	Infection Control Nurse	St Mary's Hospital NHS Trust
Ms	McNeil	Theatre/TSSU Development Manager	East Kent Hospitals NHS Trust
Dr	Millar	Consultant Microbiologist	Barts & The London NHS Trust
Ms	Mills	Infection Control Nurse	Nuffield Orthopaedic Centre NHS Trust
Miss	Mills		CJD Incidents Panel Secretariat
Dr	Mock		Department of Health, Social Services & Public Safety, Northern Ireland

Title	Surname	Job Title	Organisation
Dr	Modha		Leicestershire Health Authority
Dr	Mohanraj	Consultant Microbiologist	Dewsbury Healthcare NHS Trust
Dr	Monk		Leicester Royal Infirmary NHS Trust
Dr	Morris	Acting Medical Director	Oxford Radcliffe Hospitals NHS Trust
Ms	Murphy	Infection Control Nurse	Harrow & Hillingdon Healthcare NHS Trust
Dr	Nadarajah		Camden and Islington
Dr	Nazareth	CC DC	Cambridgeshire Health Authority
Ms	Ndokera	Directorate Manager, Specialist Surgery	Radcliffe Infirmary
Dr	Nehaul		Gwent Health Authority
Dr	Newton	Consultant In Communicable Disease Control	East Riding & Hull Health Authority
Mrs	Nichols	Member	North West Surrey Community Health Care
Mr	Nisbett	Chairman	Hospital Dental Services Sub-Committee
Ms	Nnoruka		Newham Healthcare Trust
Prof	Noah		London School of Hygiene
Ms	O'Brien	Project Co-ordinator Decontamination	NHS Estates
Ms	O'Donovan		Nottingham Healthcare NHS Trust
Dr	O'Driscoll	Microbiologist	Microbiology Department
Mrs	O'Hara	Chief Officer	Mid Essex Community Health Council
Mr	O'Kwei-Noay		Redbridge CHC
Ms	O'Mahony	Infection Control Adviser	Barking, Havering and Redbridge Hospitals NHS Trust
Prof	O'Neill		CJD Incidents Panel
Mr	Okwei-Nortey	CHC Member	Redbridge Community Health Council
Mr	Oldroyd		Scarborough WHS
Dr	Osman	Chair of Infection Control Committee	Barnsley District General Hospital NHS Trust
Mr	Pallett		Southampton University Hospitals NHS Trust
Mr	Pappenheim	Chief Executive	Haemophilia Society
Mr	Parker	President	British Association for Tissue Banking
Mr	Parkes	Director of Facilities and Estates Dept.	Kettering General Hospital NHS Trust

Title	Surname	Job Title	Organisation
Ms	Parkin		York NHS Trust
Mrs	Parkinson-Stacey	Team Leader in ENT Theatres	Bradford Hospitals NHS Trust
Dr	Partridge	Consultant Microbiologist	Morecambe Bay Hospitals NHS Trust
Prof	Pfeffer	Professor	Consumers for Ethics in Research
Dr	Phillips	Consultant In Communicable Disease Control	North Derbyshire Health Authority
Dr	Pitman		Medical Research Council
Prof	Preece		Institute of Child Health
Mrs	Qua	Chief Nursing Officer	Department of Health & Social Services
Dr	Quoroishi		Llandough Hospital
Dr	Radford	Director of Public Health	Doncaster Health Authority
Dr	Rahman	Consultant Microbiologist	Sherwood Forest Hospitals NHS Trust
Ms	Ratcliff	Senior Policy Adviser	Consumers' Association
Dr	Rawaf	Director of Clinical Standards	Merton, Sutton & Wandsworth Health Authority
Mrs	Reed	Infection Control Nurse	Barnet & Chase Farm Trust
Ms	Remington	Chief Pharmacist	Adden Brookes Hospital
Mr	Renfree	Assistant Theatre Manager	Royal Cornwall Hospitals NHS Trust
Mr	Ribeiro	Consultant General Surgeon	Royal College of Surgeons
Ms	Richards	Infection Control Nurse	Royal West Sussex NHS Trust
Dr	Ridgway		CJD Incidents Panel
Mr	Roberts	Policy Adviser	General Medical Council
Mr	Roberts		Department of Health
Ms	Roberts	Consultant Microbiologist	Bromley Hospitals NHS Trust
Ms	Roberts		Queen Elizabeth The Queen Mother Hospital
Dr	Robinson	Medical Director	National Blood Authority
Ms	Rosbottom	Infection Control Nurse	Warrington Community Health Care NHS Trust
Mr	Rothstein		Centre for Analysis of Risk and Regulation
Mr	Roy	Chair	Wandsworth Community Health Council
Mr	Russell	Vice Chairman	Community Health Council

Title	Surname	Job Title	Organisation
Ms	Ryan	Infection Control Sister	Harefield Hospital
Dr	Salmon		CJD Incidents Panel
Ms	Samaroo	Decontamination Co-ordinator	Hammersmith Hospitals NHS Trust
Dr	Sarangi	Consultant In Communicable Disease Control	Avon Health Authority
Dr	Schweiger	CCDC/MOGH	Leeds Health Authority
Dr	Seehra	Senior Registrar in Public	Bexley, Bromley & Greenwich Health Authority
Dr	Seng	Consultant In Communicable Disease Control	Brent & Harrow Health Authority
Ms	Serne	Theatre Manager	Mayday Healthcare
Ms	Shadick	Senior Sister	Mayday Healthcare NHS Trust
Mr	Simmons	Senior Medical Officer	National Assembly for Wales
Mrs	Simpson	Infection Control Nurse	Chesterfield & North Derbyshire Royal Hospitals NHS Trust
Mrs	Slater	Team Leader ENT & Oral Theatre (Theatre Sister)	Heatherwood & Wexham Park Hospitals NHS Trust
Dr	Sloss	Consultant Microbiologist	South Durham Healthcare NHS Trust
Mrs	Small	Clinical Risk Manager	Rotherham General Hospitals NHS Trust
Mrs	Smith	Senior Nurse, Infection Control	Royal Bournemouth & Christchurch NHS Trust
Mr	Smith		SEAC
Prof	Southgate		CJD Incidents Panel
Mr	Stacey	Lead Manager - Theatres Anaesthetics & Sterile Services	St George's Healthcare NHS Trust
Mrs	Stephens	Theatre Services Manager	Royal Free Hampstead NHS Trust
Ms	Stevens	Infection Control Adviser	West London Mental Health NHS Trust
Ms	Stokle	Senior Nurse	Institute of Pathology
Mr	Strang	General Manager - Surgical Services	Newham Healthcare NHS Trust
Miss	Strong	Deputy Exec Director Surgery	Southport & Ormskirk Hospital NHS Trust
Dr	Struthers	Consultant Microbiologist	Coventry & Warwickshire Hospital
Mrs	Swain	CNS Infection Control	East Cheshire NHS Trust
Dr	Tahir	Regional Epidemiologist	CDSC (West Midlands)
Dr	Taylor	Clinical Scientist	Newcastle Public Health Laboratory
Dr	Taylor		CJD Incidents Panel

Title	Surname	Job Title	Organisation
Dr	Thomas	Consultant In Communicable Disease Control	Croydon Health Authority
Mr	Thompson	Consultant Vascular Surgeon	Royal Devon & Exeter Healthcare NHS Trust
Dr	Thould	MFPHM	South & West Devon Health Authority
Ms	Treasure		Department of Health
Ms	Trundle	Senior Nurse Infection Control	Addenbrookes NHS Trust
Dr	Turner	Consultant Microbiologist/Infection Control Doctor	South Devon Healthcare Trust
Ms	Turner	National CJD Case Co-ordinator	CJD Support Network
Prof	Van Dellen	Consultant Neurosurgeon, Associate Medical Director	Hammersmith Hospitals NHS Trust
Dr	Van Den Bosch	Clinical Director	Berkshire Health Authority
Mrs	Van Limborgh	Decontamination Lead	Chelsea & Westminster Healthcare NHS Trust
Mrs	Vidler	Chair	Haemophilia Nurses Association
Dr	Walapu	Consultant in Communicable Disease Control	Dyfed Powys Health Authority
Dr	Walker	Chair of Infection Control Committee	Ysbyty Gwynedd
Mr	Waller		Institute of Sterile Service Management
Dr	Walsh	CC DC	Kingston & Richmond Health Authority
Ms	Ward	Infection Control Technical Adviser	Hammersmith Hospitals NHS Trust
Mr	Watson	Consultant Otolaryngologist, Head & Neck Surgeon	Doncaster & Bassetlaw Hospitals NHS Trust
Mr	Watters		Primary Immunodeficiency Association
Mr	Webber	Dental Representative	Vale Local Health Group
Dr	Westmoreland	Consultant Virologist/Deputy Director	Public Health Laboratory
Dr	White	Consultant Microbiologist	Pontypridd & Rhondda NHS Trust
Dr	White	The Chair	North Wales Local Medical Committee
Dr	White	Group Director	PHLS East
Dr	Wight	Deputy Chairman Medical Ethics Committee	British Medical Association
Dr	Williams	Consultant Microbiologist	Castle Hill Hospital
Dr	Williamson	Consultant In Primary Care Development	East Riding & Hull Health Authority
Dr	Wilson	Consultant Microbiologist	University College Hospital
Ms	Wiseman	Infection Control Nurse Adviser	West Dorset General Hospitals NHS Trust

Title	Surname	Job Title	Organisation
Dr	Wyatt	Consultant Clinical Scientist	CJD Incidents Panel