Confidential Draft

Draft Minutes of the Meeting of the CJD Incidents Panel

Thursday 17th October 2002, Bloomsbury Suite, Kenilworth Hotel, London.

Chairman	
Professor Michael Banner	Ethics
Members	
Professor Don Jeffries (Vice Chair)	Virology
Dr Tim Wyatt	Microbiology
Dr Mike Painter	Public Health
Dr Roland Salmon	Epidemiology
Dr Noel Gill	Epidemiology
Dr Hester Ward	Epidemiology
Dr Geoff Craig	Dental Surgery
Ms Gillian Turner	Lay Representative
Professor John O'Neill	Ethics
Mr John Barker	Sterile Service Management
Professor Mike Bramble	Gastroenterology
Professor John Lumley	General Surgery
Dr Pat Hewitt	Blood Safety
Dr Geoff Ridgway	Microbiology
Professor Dame Lesley Southgate (am only)	General Practice
Ms Diana Kloss	Law
Non-member :Dr Peter Simpson (am only)	*Representing Prof Smith Anaesthesia*
Observers	
Dr Glenda Mock	Department of Health, Social Services & Public Safety, Northern Ireland
Dr Mike Simmons	National Assembly of Wales
Dr Peter Christie	Scottish Executive Health Department
Dr Peter Horby	Communicable Disease Surveillance Centre
Secretariat	
Dr Pip Edwards	CJD Policy Unit, DH
Mr S Norton	CJD Policy Unit, DH
Ms Katie Oakley	Communicable Disease Surveillance Centre
DH Officials	
Ms Mary Holt	CJD Policy Unit, DH
Dr Rowena Jecock (am only)	CJD Policy Unit DH
Apologies	
Professor James Ironside	TSE Infectivity, Neuropathology
Dr David Taylor	TSE Infectivity, Decontamination
Professor Peter Hutton	Anaesthesia
Professor Graham Smith	Anaesthesia
Ms Susan MacQueen	Infection Control
Ms Carole Fry	Nursing Policy Unit, DH

Ms Jean Gaffin	Lay Representative
Mr Luke Gormally	Ethics
Professor Ian Cooke	Obstetrics and Gynaecology
Mr Andrew Tullo	Ophthalmology
Ms Kate Woodhead	Theatre Nursing
Prof Bob Will	Neurology

1. Welcome and apologies

The Chair thanked members for attending and announced the apologies above. The Chair announced that Prof Bob Will had joined as a new Panel member but was unable to attend today. The Chair welcomed Dr Peter Christie replacing Dr Martin Donaghy as the observer from Scotland and Mr Steve Norton replacing Miss Claire Mills (DH Secretariat). The Chair said that he will be writing to Professor Len Doyal who has resigned from the Panel thanking him for his work as Panel member.

The Chair welcomed Dr Peter Horby of the Communicable Disease Surveillance Centre (CDSC) as an observer to today's meeting and informed the Panel that Dr Gerry Bryant and Mr Simon Gregor (both of CDSC) would be attending to make a presentation on the CJD Communications Strategy. Dr Peter Simpson informed the Chair that he was attending in lieu of Professor Graham Smith.

2. Ratification of the minutes of the last meeting (CJDIP 7/01)

The minutes were agreed subject to the following changes to para 35. A query was raised regarding the requirements for the retention of blood transfusion laboratory records. There was discussion as to whether the requirement to retain records of potential occupational exposure pertained to the COSHH or the RIDDOR regulations. The correct information will be inserted in para 35.

ACTION: Dr Hewitt/Ms Kloss/Secretariat

3. Matters arising (oral update)

3.1. Membership:

A list of names of possible experts on 'giving bad news' has been drawn up but members were asked to contact the Secretariat with further suggestions so that an expert could be appointed to the Panel.

ACTION: Members/Secretariat

3.2. Dental Risk Assessment:

Members were informed that the Department of Health dental risk assessment seen by the Panel in April 2002, together with an additional assessment of the risks from files and reamers used in root canal treatment, will be discussed at the meeting of the ACDP/SEAC TSE Joint Working Group on 23rd October 2002. These risk assessments plus the opinion of the JWG will be provided for the next Panel meeting. Members agreed with the Secretariat's proposal for convening a reconstituted Panel Dental Risk Assessment Drafting Group. The Group will be chaired by Dr Ridgway and will include Dr Craig. The remit will be to draft the dentistry section of the Framework Document. The Panel is waiting for expert dental pathology opinion on how to increase the number of cases currently available to inform the dental risk assessment.

ACTION: Secretariat/GR/GC

3.3. Brain Biopsies:

Two incidents involving brain biopsy have been reported to the Panel. Members were informed that there was much common ground at a recent meeting held on 10th October 2002 between the Department of Health and neurosurgeons to discuss the redesign of neurosurgical instruments in order to reduce cross-infection risk. Consideration was given to the use of single use instruments where CJD is a possible diagnosis and to the redesign of some neurosurgical instruments to make them easier to clean. The Panel agreed that when brain biopsy is performed on patients where CJD is a possibility, the instruments must not be reused until CJD is excluded.

ACTION: Mr Marsh is contacting SBNS/Secretariat

3.4. Hospital Record Keeping:

The Chair said he will write to the Department of Health expressing the concerns of the Panel about the length of time hospital records are retained and requesting that hospital patient records should be kept for a minimum of 20 years. **ACTION: Secretariat**

4. Public Summary April 2002 Meeting (CJDIP 7/02a)

The Panel agreed the public summary of the closed morning meeting and a report of the open meeting. The Joint Working Group has agreed the publication and the Secretariat is arranging for it to be placed on the Panel page of the DH website.

ACTION : Secretariat

5. Draft Public Summary June 2002 Meeting (CJDIP 7/02b)

Members reiterated the comments made above (point 3.4) on the retention of hospital records.

ACTION: Secretariat

6. Framework Document Submission to CMOs (CJDIP 7/03a,03b, 03c,03d)

The Chair thanked the Secretariat for their hard work over the summer on this document. Members were reminded that although this has been submitted to the CMOs (with a Key Issues paper), it will remain a working document. One member commented that the tone of the document was paternalistic and in particular on page 8 para 2 that the starting point should be 'everyone has a right' rather than 'it is proposed'. Another member suggested that sentence 1 of page 8 para 2 sentence one should be moved to the beginning of the previous para. **ACTION: Secretariat**

Members noted that Prof Doyal had resigned from the Panel. The Chair stated that he felt sure Members would like to thank Prof Doyal for all his input. The Chair stated that, in his opinion, the difference between the views of Professor Doyal and those of the Panel was small.

A discussion ensued on the mechanism for informing people and ensuring that people in the 'contactable' group do not pose a risk to public health. It was agreed that the proposed strategy should not specify that the health professional informing the 'contactable' individuals is necessarily the General Practitioner. The concern was raised that a person in the 'contactable' group may be worried about stigmatisation and consequently not inform clinicians treating them. Members agreed that other issues raised, such as the communication between doctors and dentists and private hospitals were to be addressed elsewhere and were not the remit of this Panel. The Chair agreed that an infallible mechanism of communication has not been found. Members agreed that the wording is the best we can get and that the framework allows flexibility. Members wanted hard copy loose-leaf versions of the document to be made available in addition to a website version. The Chair will write to CMOs' seeking a response if he has not heard by late November 2002. Department of Health officials indicted that such a response is likely to be interim and will not be definitive, as it may need ministerial approval.

ACTION: Secretariat

7. Database Group (CJDIP 7/04)

The Framework document has been altered so that the text agrees with the algorithm at Annex 5. This means that it is anticipated that database entry will only be considered in incidents involving medium and high risk procedures. The Panel was asked to consider whether this is the approach intended. It was suggested that the word 'normally' should be added to the statement on the coversheet in the Panel papers i.e. 'database entry will only normally be considered in incidents involving medium and high risk procedures.'

The Panel were also asked whether 'no further action' in the algorithm in annex 5 should imply that standard decontamination procedures are followed with any instruments used. In a number of incidents

involving sporadic CJD and endoscopes e.g. PI 154 and PI 142, more stringent decontamination procedures have been advised.

There was a prolonged discussion on the instruments. The draft revision of the 1998 ACDP/SEAC Joint Working Group Document 'Transmissible spongiform encephalopathy agents: safe working and the prevention of infection' is based on the assumption that infectivity in sporadic CJD is limited to the brain and back of the eye. This draft revision will go to SEAC for approval. It was agreed that letters advising stringent decontamination of endoscopes would stand for now, but would not set a precedent and the response of SEAC to the revised draft JWG guidance would be awaited.

8.Panel Secretariat (oral update)

The Panel were informed that the Health Protection Agency (HPA) will be established on 1st April 2003 following a consultation process. Part of the remit of the HPA will be operational work on communicable diseases including provision of support at local level. It has thus been decided that the CJD Incident Panel Secretariat will transfer from the DH to the Public Health Laboratory Service (PHLS) which will become part of the HPA. There will be a transition period until 1st January 2003 when PHLS will take over full responsibility for the Secretariat.

Policy work such as the redrafting of the Framework Document and the Risk Assessments for Blood and Dentistry will continue to be the responsibility of the CJD Policy Unit at the Department of Health. Recognising the link between Panel work and policy issues, representatives from the Department of Health CJD Policy Unit will continue to attend Panel meetings as observers. Panel members were assured that the high quality, confidential service currently provided by the Secretariat will continue to be maintained. The DH CJD Policy Unit confirmed that they will ensure that lines of accountability are clear and supported and that the work of the Panel will not be compromised. Observers from the devolved administrations asked for clarification about the role of the HPA in their countries. Members were reminded that the CJD Incidents Panel is a national Panel appointed by the Chief Medical Officer of England, with agreement from the other UK Chief Medical Officers and that it is the Secretariat

function that is being transferred, not the Panel itself. Members were informed that they would receive a letter outlining the arrangements.

ACTION: Secretariat

9. Discussion of Incidents

PI 76 (CJDIP 7/05a) Members were informed that this is the first incident involving familial CJD and that experts in this field had been consulted. The experts had advised that the information available would indicate that peripheral tissues would not contain significant infectivity in this case. The letter of advice has been sent and the Panel agreed that epidemiological follow-up was not necessary. The members agreed with the expert advice given, but stressed that this applied only in this case as each individual case of familial CJD is different.

PI 143 (CJDIP 7/05b) Members were informed that a group of Panel members had met prior to this meeting to consider this case. The members agreed that additional information on instruments is not needed other than on the 'black max' drill. The members agreed that all instruments should be permanently removed from use with the possible exception of the drill (pending further information). All the patients, apart from patients 12,15, 34 and one patient who had died, might potentially be in a 'contactable' group but a further refinement of the risk was necessary. Members requested that a field visit is undertaken by PHLS to confirm the final list of 'contactable' patients and to find out more about the black max drill; how it was used and what happened to all the attachments. A letter would be sent to the local CCDC to this effect.

Members expressed concern at the suboptimal cleaning procedures reported in this case and the lack of traceability of instruments, which had resulted in a current list of 29 'contactable' people. Mr Marsh said he will write to SBNS on the matter of brain biopsies. The Chair will write to the CMOs. The Secretariat will contact NHS Estates regarding inspections.

ACTION: Secretariat/Mr Marsh/CDSC

PI 154 (CJDIP 7/05c)

Members considered this case where the patient has a diagnosis of possible CJD. There is no suspicion of variant CJD. The patient has undergone endoscopic procedures (about which a draft letter has already been agreed by some Panel members) and cataract surgery.

A number of questions were put to members regarding the cataract surgery but they required further information and the opinion of the ophthalmology Panel expert, Mr Tullo. The Chair said that a decision on the eye surgery would not be possible at this meeting.

ACTION: Secretariat to discuss with Mr Tullo

So far as the endoscopy was concerned it was agreed that the letter should include the wording 'however as a precautionary measure in the light of present knowledge' at the beginning of para 3 in the draft letter to the CCDC. The letter for case PI 154 could be used as a guide for similar cases although the Panel should consider each case individually.

In future, where the diagnosis cannot be established due to a family declining permission for a post mortem, the Panel expressed the view that it might be helpful to consider approaching the family for consent to do a burr hole brain biopsy on the deceased patient.

ACTION: Secretariat to discuss with Prof Ironside

10. Endorsement of advice provided since 20th June 2002 (CJDIP 7/06)

One Panel member was concerned about the advice given in the letter for PI 142 regarding the retention of patient records in case the risk assessment changes in the future, and whether this advice would be given for all future incidents. A decision was not reached on whether the Panel would always recommend that records are retained by the hospital.

11. Blood Risk Assessment (CJDIP 7/07)

Members noted that difficulties remain with the assessment of the risks from plasma derivatives. After consideration of the assessment by three expert scientific committees, two different assessments of the risk, obtained by making different assumptions, exist. It was agreed that the Panel needed to issue advice inspite of this uncertainty.

One member said that the list of patients to be possibly contacted (with support mechanisms in place) is growing. There is concern about the delay due to the support mechanisms not being in place. Members were reminded that a response is awaited from the CMOs on the Framework Document. The Panel is waiting for the CMO to accept the Framework Document and support the strategy.

One member felt that in the spirit of openness patients should be given information now and told about the uncertainties involved but others felt this could cause unnecessary distress. The Panel would not seek to prevent clinicians from telling a patient if that is what they want to do, but at the moment the Panel is unable to advise on the level of risk and felt that the information could cause unnecessary distress to patients. The Secretariat pointed out that the Panel is giving advice to individual clinicians regarding recipients of contaminated products who need invasive procedures but that there is no blanket advice. One member said that the situation should be communicated to all clinicians as they feel there is an unexplained delay. All agreed that the Blood Risk Assessment is needed as soon as possible.

12.Correspondence from Scotland and NI Haemophilia Directors to CMO Scotland (CJDIP 7/07a).

Members considered the letter and the Chair said he would write to CMO (Scotland) commenting on the letter and explaining the current position regarding the blood risk assessments.

ACTION: Secretariat

13 CJD Communication Toolkit (CJDIP 7/08)

The Panel welcomed the strategy. Members asked for time to absorb the tabled documents and it was agreed that a small subgroup chaired by Prof Dame Southgate would give feedback on the toolkit. There was discussion on the inconsistency about who will give the news and a concern that consistency is important. The new term 'precautions group was welcomed by the Panel. They felt the proposed term 'research group' needed further consideration.

ACTION: Secretariat/some members

14. Annual Report (CJDIP 7/10)

The Panel were invited to comment on the draft 2nd Annual Report of the CJD Incidents Panel. The Report was accepted provided the following amendments are made:

- p.19. the Panel would like the list of instruments removed
- p.19 the dental records reference should be qualified by adding 'for non-regular attenders' as most dentists keep records for 7 years at least and Dr Craig would like to comment on the amended para.
- p.20. the advice on ventilators is out of date: 'use of filters' section to be changed to the new advice as per the Association of Anaesthetists Guidelines
- p.15. incorporate the point made in Prof Ironside's letter.

The Chair said that once the Report has been agreed by ACDP/SEAC TSE JWG it will be published on the Panel's page of the DH website. **ACTION: Secretariat**

15 Consultation Paper

The Members were informed that the Panel's response to the consultation document *Human Bodies, Human Choices* has been submitted. Members agreed that the same letter would be sent as the Panel's response to the consultation document on coroner services. This consultation closes on 22nd November

2002 and members were reminded that they could have further input either as a Panel member or individually. **ACTION: Secretariat**

16. AOB : None

17. Date of next meeting: January/February 2003