BLOOD AND ORGAN DONATION ISSUES: FOUR COUNTRIES' MEETING IN EDINBURGH, FRIDAY 7 SEPTEMBER 2007

In attendance:

Scottish Government Health Department of Health, Welsh Assembly and

NI Assembly Health Departments

Dr Aileen Keel (DCMO) Andrew Macleod Sylvia Shearer John Brunton William Connon (DH)
Neil Ebenezer (DH)
Triona Norman (DH) - by telecon

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Dr Elizabeth Mitchell (DCMO) (NIA) - by

teleconference

Karen Simpson (NIA) - by teleconference

Caroline Lewis (WA)
Cathy White (WA)

Scottish Government Solicitors (for item 1)

Joanna Keating Patrick Layden Andrew Mackenzie Gillian Russell

The Archer Independent Inquiry/The Scottish Public Inquiry

- 1. William advised that he had been in touch with the Secretary to the Archer Inquiry about the timescale in producing its report and was told that it would be the end of the year at the earliest. DH had met with the inquiry team but had not offered to give evidence the discussion had not been recorded. There had been no formal approach from the Archer Inquiry asking DH to give evidence. The inquiry team's meeting with DH was considered to be a fact finding exercise.
- 2. NHSBT had now agreed to meet with the inquiry team and William proposed to be in attendance as an observer. However, given that that the Archer inquiry had no legal framework it was not considered appropriate that NHSBT give evidence to the inquiry. It was confirmed that NHSBT had its own lawyers.
- 3. Patrick advised the other administrations of the Scottish Government Cabinet Secretary for Health and Wellbeing's meeting with the Scottish Haemophilia Forum and Haemophilia Society, when she confirmed there would be a Scottish public inquiry a SNP manifesto commitment. He confirmed that the inquiry was likely to be under the terms of the Inquiries Act 2005, which confers powers to hold an inquiry into any matter of public concern, although a purely Scottish inquiry could only look at devolved matters, and there would be a need to consider whether the terms of reference should extend more widely.

- 4. The Cabinet Secretary had indicated that the Scottish inquiry would look at matters not covered by Archer. The premise of holding an inquiry was that questions had not been adequately addressed. Dr Keel agreed that the Scottish inquiry should focus on issues that had not been covered by Archer and there was a question as to how Scottish issues could be disentangled from the rest of the UK in this respect. Welsh Assembly colleagues made the point that their Ministers had not made a commitment to hold an inquiry and took the view that this was a matter for the Ministers of the day, while Dr Mitchell made the point that as the Scottish and NI blood services were associated, a Scottish inquiry would have an influence on NI.
 - 5. William said that it would be difficult to separate the different issues relating to the DA's and expressed the view that a Scotland-only inquiry would need to be presented and handled with sensitivity. He also pointed out that until we know the outcome and recommendations of Archer, it is difficult to plan, as the results of the inquiry will be critical.
- 6. Patrick suggested that the end result from Archer might be more developed than was perceived at this time. There was a question whether the Archer Report would garner public credibility and respect, and whether it would satisfy interest groups. However, Andrew Macleod questioned whether Archer would be able to produce a detailed analysis of what really happened on the basis of the evidence which had been presented. He felt that analysis of the available documents would be important. William suggested that Scottish officials might like to consider approaching the Archer inquiry team to discuss his timescale and the form the final report might take.
- 7. It was agreed that there were a number of issues relating to HCV infection including introduction of testing; quality of products; and how those responsible acted, in eventually drawing up Scottish terms of reference. It was acknowledged that the issues were slightly different in the countries of the UK at the time. Dr Keel mentioned that SNBTS staff had given evidence to Archer, primarily in their professional capacities as a former haemophilia director and a senior scientist, (the latter had been with the organisation for 40 years).
- 8. It was pointed out that there was the possibility that Archer could recommend a pan-UK inquiry. William made the point that it had been the stance of a number of UK Governments over many years that a public inquiry is not justified, not least on the grounds of cost. There is nothing to indicate any wrongdoing or negligence on the part of UK Government. Despite the discovery of certain "missing documents", which have now been published there appears to be no "smoking gun".
- 9. There was a discussion around the documents that had been released to the Scottish Government under the Scotland Act and that there were exceptions under FOI.
- 10. Andrew Macleod suggested that the Remit of the Scottish Inquiry would have to look at:
 - i Blood services: what they did; their knowledge; licensing; blood procurement.
 - ii The patient experience: treatment and information provided.

He believed that it would be difficult to avoid discussions around individual patients and doctors and wondered how this could be prevented.

- 11. Patrick suggested that a retired judge or someone with similar stature might be appointed to produce a report on the published documents and provide an audit trail, which would not be too costly. Dr Keel made the point that this would not meet the commitment to hold a PI although Patrick explained that if we had a preliminary report and hearing, this would at least take us past the historic stage.
- 12. William said that DH had already carried out a similar exercise and that this had made little difference to the calls for an inquiry. Dr Keel suggested that appointing someone independent of the Government would be more acceptable in presentational terms, although William maintained that this would be scrutinizing work that had already been carried out and would be a lengthy exercise. It was nonetheless agreed by the Scottish Government officials that this proposal merited further consideration.
- 13. Patrick mentioned that Archer may endorse the information provided by DH (the Page Report) and Sylvia mentioned that the Scottish Government had submitted the CD-Rom that it had produced from a similar exercise at the end of 2005, to Archer. DQ: I do not know what this comment refers to but I have no recollection of proposing telephoning Lord Archer.
- 14. It was agreed that officials would meet again (without Solicitors) to discuss how best to take forward the commitment to hold a Scottish public inquiry, once DH had taken the views of their Ministers. DN: this is incorrect. I am not planning to seek our ministers' views . I can see no point on approaching them on that at this stage, as there is no real progress to report. I did say at the meeting that I feel Scottish officials could helpfully set out some proposals or options on what the Scottish inquiry may look into, for all of us to consider. This point was, I thought agreed.

Skipton Fund

15. Colleagues from the Welsh Assembly had placed this item on the agenda. There was a short discussion about the Skipton Fund and communication between the four administrations with regard to funding/payments and changes to the Scheme. Caroline and Cathy had some concerns in this regard, although Karen was unsighted to any problems having only just taken up post. Notwithstanding this was not an area that William covered, he agreed to take this back to DH colleagues, closer to the scheme. DN: not sure this is exactly what I said but once the minutes are agreed I am happy to copy them to colleagues and ask them to respond directly to colleagues in the Welsh Assembly.

Establishment of Advisory Committee on the Safety of Blood, Tissues and Organs (ACSBTO)

- 16. Neil reported that there had been a good response to the advert for the various positions, with 7 applications for the Chair and 77 applications for membership. The only specialist position that had attracted no applications was Health Economist. A sift for the Chair would be carried out the following week, with all posts being sifted by the end of the month.
- 17. William explained that the UK Blood Forum had decided that the Secretariat could be partly resourced by NHSBT identifying individuals and costs would be shared across the four Administrations. DH is not looking for specific funding, but rather people to provide support such as minute meetings and maintain its website with short summary papers. He explained

that the Committee might want to undertake research and it would be helpful to have a pool of people to call upon from the four Administrations. Dr Keel endorsed this idea in principle, although she felt that there was little spare capacity in the system. Health Directorates would, however, consider the matter further.

Cathy had doubts about identifying somebody within the Welsh Health Department, although someone from the Welsh blood service might be a possibility, and Dr Mitchell said that Northern Ireland also had very limited resources and to explore with the NI blood service was probably the only option for them.

18. William confirmed that he was not necessarily looking for civil servants and that the blood services were always very responsive to these approaches and have provided similar support in other areas. Academic institutions are also interested in these sorts of arrangements and we have found that they can be made to work very well in England. He suggested that a note could be put round colleagues. **Dr Keel thought that it would be helpful if bullet points or a job specification of what would be required was drawn up.** Sylvia mentioned that DH taking charge of the Secretariat provided continuity. She suggested that a fund could be established specifically to service the Committee and make payments to contributors to that function as necessary, but the meeting agreed this approach would not be pursued. However, Dr Keel said that the type of people they were looking for would support ACSTBO for prestige rather than remuneration.

Regulatory Authority for Tissues and Embryos (RATE)

19. William confirmed that following the proposal not to proceed with the establishment of RATE within the Human Tissues and Embryos Bill. The new body is now unlikely to be established, although this is still subject to ministerial announcement. In the event of this being so then, the MHRA would be asked to continue its regulatory role as Competent Authority on a permanent basis.

NHS Blood Transfusion Service (NHSBT)

- 20. William outlined the following issues:
 - The NHSBT Service Strategy is currently being reviewed. This will include consideration of the number of Blood Processing Centres required which has attracted considerable public reaction.
 - The future shape of the current strategy will be looked at and the review, will report in January 2008.
 - The CEO Martin Gorham has taken early retirement, and the post had been advertised. In the meantime Barry Slavery is acting CEO.
 - The post of Medical Director had been advertised.
 - A full-time Communications person was required.
 - A number of senior management posts need to be filled.
 - The Director of Research had also retired.
- 21. There is a need for proper succession planning, as the mechanisms had not been put in place. However, William thought that the current Chairman, who had come from the

pharmaceutical industry, was dealing with this. NHSBT's Annual Review would be held on 14 September and Chaired by Lindsay Davis, senior DH Sponsor to NHSBT. Cathy said that she was disappointed that the Welsh Health Department had not been kept informed of the changes underway at NHSBT, and that her Minister had expressed an interest in the changes and had requested briefing. William took her point but pointed out that Wales received papers for the Annual Review in July, at which these issues were discussed. He also pointed out that whilst he will continue to try to ensure DA's are kept fully informed it is equally important that each DA establishes its own lines of communications with the blood service.

22. William then went on to mention that NHSBT are looking at ways to attract and retain a wider donor base including more people from ethnic backgrounds. As part of the overall strategy NHSBT are looking at options such as increasing appointments; on-line booking and a greater variety if collection sites.

Post Elections/Changes in Governments

23. Andrew Macleod advised that Scotland now had a new minority administration with a smaller cabinet. They were in the process of developing their health policies and had produced a discussion document Better Health: Better Care. An action plan was to be produced by the end of 2007. Dr Keel added that there had been no major change in policy direction to-date. Andrew also mentioned that the Scottish National Blood Transfusion Service had been developing its future strategy to widen its donor base. William suggested it would be helpful to circulate details of Better Health: Better Care and any other changes which have been or are about to be announced.

Organ Donation Task Force

- 24. Triona advised that the UK Organ Donation Task Force had been set up at the end of 2006 and was due to report, with final recommendations, following its final meeting at the end of September. She informed the group that the UK is at the bottom end of the table for organ donation and that Spain (?) was well ahead of us. She hoped the proposals would go to Ministers in October and, if agreed, would cost up to £50 million over 5 years. It was confirmed that the Task Force's report was UK wide and the report should go to Ministers in all four UK Administrations, and that there would be financial implications and changes to current practices for all four countries if the recommendations were implemented.
- 25. At this point Dr Keel mentioned that the Cabinet Secretary for Health and Wellbeing was aware that the report was imminent, although the financial aspects had not been discussed in detail. Triona went on to say that there would be an impact on NHSBT and the wider NHS and that some thought had been given to the preparation of Impact Assessments. She confirmed that Will Scott (SG Health) was working within the same parameters and was fully engaged she would stay closely in touch with the other administrations. It was anticipated that the Task Force would write to all four Administrations in the later part of October and William said that there were various ways that this could be handled. It was agreed that a direct approach from the Chair of the Task Force to the relevant Ministers in all four Administrations would most appropriate.

Presumed Consent

- 26. Caroline advised the group that there had been discussions on using new Welsh powers. Welsh Ministers were looking for a public debate on presumed consent, although it was acknowledged that the proposal ran counter to current legislation, the Human Tissues Act. It was suggested that the UK Organ Donation Task Force was the best placed to take this matter forward, although Dr Keel flagged up that there was not a lot of time before it reported. It was mentioned that there had been a public debate in 2005, when the BMA came out in favour of presumed consent. The Cabinet Secretary for Health and Wellbeing was fully signed up to a four country approach, and it was acknowledged that it would be very difficult to present if only one or two counties signed up to presumed consent. Dr Keel agreed that the Task Force was the best vehicle to look at this issue as it already had the expertise.
- 27. Dr Keel made reference to the work in the area of consent for organ donation that Scotland had carried out in preparing for the Human Tissues Act. Triona then said that she was aware that the Welsh Minister wanted a public debate and public consultation and Dr Keel added that the Welsh Minister proposed writing to Scotland and Northern Ireland Ministers, setting out her proposals and seeking their support.
- 28. The point was made that presumed consent was not legal at present and that further legal advice was required. William mentioned "directed donation" although naming family members as donation recipients was a very narrow field, and the legal implications were considerable.

Next Meeting

29. It was agreed that the meeting had been very useful and that the next meeting would take place in Northern Ireland in Six months time.

