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Mr Angus Evans
Penrose Inquiry
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Dear Angus

I am now replying to the questions raised in your letter to me of 6th January 2012. I have already explained the reason for the delay in responding. Nevertheless I apologise for being so slow. I am numbering the paragraphs for ease.

1. I would like Lord Penrose to know that I did my best when giving evidence in June 2011, to recall as accurately as I could events that happened in the late 1980' s.

2. Unfortunately I personally have very few papers from the study. Confidential notes that I had, have long since been shredded. I did make some comments in the patient notes kept in the Haemophilia Unit. I do not know whether these still exist. Other progress reports, notes of meetings of the research teams, etc were held in the Psychology Department, Stirling University and by Professor Ivana Markova. Again I do not know whether or not these still exist. I used to have hard back diaries that kept details of my movements. Again these have long since been destroyed. So I have had to rely on my recollection of the studies, of published material and on some very incomplete personal papers detailing my movements and activities in this period.

3. I think it is important for the Inquiry to understand that I was involved in three studies at GRI in the period in question. The first, and my reason for being in GRI, was working with patients with adult polycystic kidney disease, studying the social, psychological and ethical implications of that disease. I had a room in the Renal Unit. This study was funded by the British Kidney Patients Association. When Charles Forbes asked for help and when we, Charles, Ivana and I decided to apply for a grant (at that time one had to have a permanent post to be a grant holder) I was thus able to do some preliminary work in the haemophilia unit although I was not paid for that work at that time. I was already working in the hospital. This was not an uncommon situation for researchers at that time.

The second study was that funded by the SHHD to investigate how patients with haemophilia cope with information about HIV and AIDS. The grant was awarded in **July 1985** and the project formally started in **October 1985** i.e. when I would have received my first pay cheque!! Early in that study it became very clear that there was a need to clarify what counselling was needed, what specialist information was required in counselling and who should give the counselling. It seemed important to investigate these issues so that the best possible service could be offered to haemophilia patients and their families.

In **November 1986** an application for a grant in support of this work, the third study, was made to the Haemophilia Society and awarded. A report of this study was submitted to the Haemophilia Society in **December 1987**. The two studies were conducted in parallel. At different stages of the SHHD study there were two additional members of staff, Simon Naji responsible for the statistical analysis and mainly based in Stirling and Mrs Judy Watson who carried out some of the interviews in GRI.

4. To the best of my knowledge it was in December 1984 that Charles Forbes contacted me deeply concerned that he had tested, I recollect that he said 2, of the severely affected patients and found them to be positive. I had come from working in genetic counselling which was evolving and developing. By then in the early 1980's it was considered good practice in **genetic units** in the UK that, when it was possible to test for a genetic disorder (this was before the human genome project) the permission of the patient should first be given. But in 1984 it was **not** considered necessary to seek the permission of the patient before doing a blood test and testing for different illnesses. This also applied to frozen samples held by different departments and laboratories. Charles Forbes and Ivana Markova had worked together for many years on studies on different aspects of haemophilia. Ivana and I worked together on the Polycystic Study and both Charles and Ivana had followed and been interested in my previous work on testing the acceptability of having a national genetic register when I first became involved in the ethical, social and psychological implications of genetic disease. So in December 1984 Charles was aware of testing for a condition with potentially serious and life threatening implications for the patient. Thus his phone call to me.

5. Shortly after the phone call informing me of the situation, Ivana and I met at Charles' house in Glasgow and spent a day discussing whether we should develop a study and if so what kind of study. I am afraid I no longer have the relevant diary, personal or work, to confirm the precise date, but it was a Saturday and I think in December 1984 or very early January 1985.

6. The SHHD research proposal does not state that HIV positive patients would be targeted but that the majority of patients with haemophilia would be sent information about the study and invited to participate. This was so that we could explore the effect of HIV/AIDS on the lives of all haemophilia patients regardless of their risk factor and their families. In addition I did not know the HIV status in advance of the interview. This was because the counselling approach was to ascertain what the patient knew about HIV and whether they wished to be tested. It also protected the confidentiality of the patient, an issue beginning to be raised particularly by the gay community.

7. To the best of my knowledge I alone interviewed all the "severe" patients. Mrs Judy Watson referred to in paragraph 3 above, carried out some of the interviews. Mrs Watson was employed as a part time research associate and started work in early 1986. She was **not** a replacement counsellor as appears in the HSRC report. Interviews for Mrs Watson and Simon Naji were carried out in the autumn of 1985 once the funding had gone through.

8. As I explained in 6 above, I did not know the antibody status of patients before I interviewed them. To the best of my knowledge there was one exception where the family had gone to the press and everyone knew the status of the patients. I did **not** say in my evidence that I had interviewed 20 HIV positive patients. I emphasised that I had interviewed patients with severe haemophilia.

9. By the time that interviewing for the Haemophilia Society funded project on the counselling needs of haemophilia patients and their families in the light of HIV started, all HIV positive patients already knew their HIV status. All the patients were by then known to me.

10. I do not have the precise date when I started interviewing patients in the SHHD study. Some were carried out in the late summer and-autumn of 1985 and the remainder in 1986 by both me and Judy Watson. As I have already mentioned in 7 above I interviewed all the patients with severe haemophilia.

11. The process adopted was to elicit from patients what they knew about HIV /AIDS and the transmission. Then to find out what they thought their own status might be and whether they wished to be tested. It was important that patients knew what the implications of a positive result could be. We discussed general health implications of HIV /AIDS, treatments available responsibility for sexual partners, insurance although there were already considerable difficulties for people with haemophilia, who might want to know the status, and attitudes of society. (Please see Patricia Wilkie 1992 *People with Haemophilia and HIV In: Reflective Helping in HIV and AIDS*. Editors Charles Anderson and Patricia Wilkie. OUP where all the issues are discussed fully) If they said that they wished to find out because they "suspected" that they must be positive because of the amount of Factor they had had and where the batches came from I said that I would inform Dr Forbes. My memory is that most of these patients were very clued up about where their Factor had come from. Only one patient did not wish to find out their status. I suspect that underneath he knew quite well what the situation was. He simply did not wish it stated and put in black and white.

12. I recollect that when I started seeing patients with severe haemophilia sometime in the late summer and early autumn of 1985, patients did not appear to have been formally informed of their status. While this does not mean that no one had formally told them, to the best of my recall, no patients remembered having been informed of their HIV status. There are several possible explanations for this. These include:

One of the findings of the SHHD study was that the greater the problems a person with severe haemophilia experiences the less important it may seem to him to acquire knowledge about HIV. The patients may simply not have taken in the information or the patients may never have been told.

13. Testing for HIV involved testing for antibodies in an individual's serum. When antibodies were found the person was described as being HIV antibody positive indicating that the person has been exposed to HIV infection and could potentially infect others. The test could not predict whether or at what rate an individual may develop AIDS. This was complex information to give to patients in 1985 when limited medical and epidemiological information about HIV and AIDS was changing quite rapidly. Most consultants at that time did not have training in communication skills or in how to give complex information to patients.

14. There was increasing discussion about informed consent amongst the medical profession, amongst knowledgeable lay people and in the counselling world in the mid 1980's. In the Sidaway case reported in 1985, Lord Scarman said that until the courts found differently, the decision must rest with the patient and not their medical practitioner. I was very familiar with this concept having worked with the principle of informed consent in the genetic studies. My views were that patients should not be tested for HIV unless they fully understood the implications of the test.

14. I am sorry that I have no records that show when patients were told of their test results. This information would have been recorded in the patient notes kept in the Haemophilia Unit. It would have been any time from the late summer of 1985 onwards.

15. I am sorry but I do not have a copy of the letter sent to patients. Somehow I thought it might have been attached along with questionnaires in reports to the SHHD.

16. I did give the information to some patients that they were HIV positive. This was usually because the patient indicated that they would like me to do so and it was always always with the knowledge of Dr Forbes. I am afraid I do not know whether these were the "original 20 patients with severe haemophilia".

I have wanted to help the Inquiry and find it infuriating that official records no longer appear to exist and that I shredded most of my notes from the studies some years ago. I would also like to emphasise that Charles Forbes had great vision in involving Ivana Markova and me in this work. I think he showed an understanding of where different skills were needed! And to the best of my knowledge GRI was the first Haemophilia Unit to involve an independent counsellor and researchers investigating problems of HIV in patients with haemophilia.

I hope that the enclosed information is helpful.

With best wishes

Yours sincerely

Patricia Wilkie