

**Dr. Stephen C. Jordan. Statement to the Bristol Royal Infirmary Inquiry regarding the Bristol Congenital Heart Register and database.**

This Statement has been produced in response to a request for a formal Statement on this particular issue and includes replies to queries raised in Annex A to a letter from Mr. P.F.O. Whitehurst dated 14th May 1999.

**(i) South West Congenital Heart Register.**

Before dealing with the specific queries, I think I need to describe something of the history of the Register, since the nature of the queries suggests that those posing them have a rather too great expectation of the extent of the system and of the impact that any data obtained from the Register will have on the evidence given to the Inquiry:

There had been a congenital heart register in Bristol before 1966 when I arrived back as a senior registrar, but it had been lost and the only information available for patients investigated up until then was in a book in which patients who had had cardiac catheters who were listed under their respective diagnosis (eg ventricular septal defect) and a book containing the notes of discussions about patients seen in the congenital heart register meetings. Both these books were still in existence at the time of my retirement and were kept in the cardiac catheter laboratory at the Children's hospital.

I was anxious to keep records of all children seen with any kind of heart condition, including then acquired heart disease such as rheumatic fever, although these were becoming few, and also adults with congenital heart disease. In the order in which the developments occurred, the main ones were:

- I. Each patient's basic data was entered on a pro forma. These are still all in existence. Initially it ran to about 8 pages and included about 65 items, each with a code, apart from date of birth and hospital number
- II. This data was transferred to 80-column (Holerith) cards, by punching and verifying initially by staff at the University Department of Public Health and then on machines kept at the BRI and subsequently at the Children's Hospital and used primarily by medical records.
- III. This data could then be sorted using a mechanical sorter. The BRI did not possess one and I used one in Canynge Hall, in the University Department of Public Health. This allowed for example, all patients with a certain diagnosis or who had had a particular operation to be identified.
- IV. In about 1973 I obtained limited access via the Department of Public Health to the University Computer, to allow more detailed sorting of patients, for example, patients with a given diagnosis who had had one of two operations. It also allowed a limited amount of additional verification, for example by checking that the dates of any operation were not before the date of birth.
- V. In about 1975 the BRI obtained its own computer. This was capable of intaking information from a card reader and I used this for a few years, although the basic programs were being constantly changed, which meant that (with those used by the University) I had to learn new programming languages (Algol, Fortran, Cobol, Pascal and Basic, as I recall).