Acta Genet Med Gemellol 28:381-382 (1979) The Mendel Institute/Alan R. Liss, Inc.



## Session V

## **Data Collection**

## Discussion following papers presented by Dr. Keith\* and Dr. Thompson

Dr. Cetrulo asked how long it took to fill out the data sheet and who filled it out.

Professor MacGillivray, along with Dr. Hall and Dr. Thompson, described how the maternity hospital case sheets in Aberdeen were filled out by the medical staff, and how trained clerical staff extracted the data, with additional checking by medical staff when required.

Professor MacGillivray further added that it was now possible to look at the total pregnancies of each woman, including gynaecological events such as spontaneous abortions as well as successful pregnancies.

Professor Leroy added that a similar type of exercise was carried out in several centres in Belgium and that one of the major problems was that the definition of criteria changed as the years passed, and he wondered if this was a problem also in Aberdeen.

Professor MacGillivray highlighted this problem by quoting the vexed question of the definition of preeclampsia, and said that they tried to keep this constant, and strict criteria were laid for the definition of any particular condition.

Dr. Hall added that, with computerization of data, there was no limit to the amount of information that could be recorded and it was therefore preferable to record basic data rather than anyone's interpretation of that data.

Dr. Thompson then gave, as an example, the definition of perinatal death which has changed over the years, but pointed out that it was known exactly when the changes occurred and also that the new classification could be accommodated to the old one and vice versa.

Dr. Schneider asked whether these records were separate from the case notes and was informed that they were.

Dr. Thompson pointed out that the coding document was derived from the case sheet.

Dr. Hall cited the neonatal case sheet as being a self-coding case sheet.

Dr. Keith pointed out that the difficulty of following a system like the one that was in operation in Aberdeen is the difficulty of financing it in different parts of the world, particularly where there was much private medicine carried out.

Dr. Hall pointed out that private patients were included in the Aberdeen record system.

Professor Nylander then said that what the group should decide would be not what specific questions to ask but what data would the group like to have collected on all twin pregnancies and would it be worth setting up a twin register.

Dr. Keith agreed with this.

Professor MacGillivray also pointed out that twin registers were being set up for the continuing followup of twins, as well as the development of congenital abnormalities, which was a question which interested Dr. Vlietinck.

Dr. Keith felt that it would be reasonable to ask all those who now have data sheets and systems of coding to send these to one central point for distribution to all members of the workshop who could come to the next meeting in a year's time having studied this, and knowing what information they could supply for the study of twin pregnancies in different centres.

\*The paper by L. Keith, "International Study on obstetric management and outcome of twin pregnancies", is not published in this issue.

## 382 Session V Discussion

Professor MacGillivray pointed out that one of the difficulties in the study of twin pregnancies was that he wondered how many centres were determining the zygosity.

Professor MacGillivray further suggested that it would be reasonable to write to all the people interested in the workshop and all centres, asking whether they would be willing to participate in a study, for example, of fetal abnormality in twin pregnancies, asking whether or not they determine zygosity accurately. Dr. Keith agreed with this.