



The future of the ERA-EDTA Registry

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The ERA-EDTA Registry began in 1964 and the office was initially in Amsterdam. In 1984 the office was moved to St Thomas' Hospital in London where it has remained for the past fifteen years. The Registry and its constituent population grew steadily over the 30 years from the time of its establishment so that by 1996 it covered 43 countries, 3690 renal units and a population of 716 million. The number of new patients entering dialysis per million population by that year had risen to 72 with of course a very wide variation between the constituent countries from less than 5 per million population at one end of the scale to more than 150 per million population at the other end.

The function of the Registry up to the present time has been threefold. Firstly it has provided information on request to its constituent renal units, National registries and numerous other organisations including Governmental bodies and health authorities. Secondly analyses of the demographic and individual patient data have been carried out mainly by members of the Scientific Advisory Board. These analyses have been presented to the ERA Congress each year and published in the Congress proceedings and more recently in *Nephrology Dialysis and Transplantation*.

After a highly successful period of operation which lasted for about 25 years the ERA Registry began to experience difficulties at the beginning of the 1990's. These difficulties were along two lines. Firstly the Registry had failed to keep up to date with its computerised database and attempts to introduce new computer systems ran into technical difficulties. Secondly increasing difficulty was being experienced in obtaining comprehensive data returns from some of the constituent countries in particular those countries which have not developed their own national registry. Over the past few years there has been an increasing realisation that radical revision of the operation of the Registry was necessary. At this point the problems being experienced by the Registry were

compounded by notification that the accommodation previously provided by St Thomas' Hospital would cease to be available towards the end of 1999. By fortunate coincidence this adverse event was followed shortly thereafter by an invitation from the Academic Medical Centre in the University of Amsterdam to take over the running of the Registry and house it in the Departments of Epidemiology and Informatics in the Academic Medical Centre. This offer was debated by the Council of the ERA and at a meeting of registry representatives in Madrid in September 1999 and it was decided to accept the offer.

It is planned that the new Registry office will open in Amsterdam at the beginning of November 1999. The day to day running of the Registry will be under the supervision of a senior member of the Department of Epidemiology and a senior member of the Department of Informatics. Under their direction the Registry will be supervised by a full time epidemiologist who also has a nephrology background and by full time database manager who has experience in the operation of a renal registry gained from a post held in the USA. Also the Department of Epidemiology in Amsterdam has in the recent past been involved in the supervision of several national registries in the Netherlands. Thus the members of staff who will be involved in the supervision of the ERA Registry in the Amsterdam office are all experienced in nephrology, the supervision of registries and data transmission, storage and analysis. There is therefore optimism that the problems of supervision which have hampered the operation of the Registry during the past few years will be resolved under its new management.

As indicated, above, the other major problem which the ERA Registry has experienced in recent years has been the incomplete returns of data from some of its constituent countries. The Registry has the inherent disadvantage which is not shared by some other registries such as USRDS in that it is a voluntary registry and this makes it difficult to achieve returns of data from close to 100% of its constituent renal centres. The proposal was therefore made by the ERA Council and agreed by representatives from the countries within the ERA that in future individual patient data would only be obtained from national registries or the larger regional re-

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gistries. The number of national registries within the ERA countries has grown from three in 1987 to 17 ten years later. Also most of the other countries who are members of the ERA are either in the process of establishing their own national registry or hope to set one up within the next few years. Thus by the beginning of the new millennium the ERA Registry will be collecting data from around 17 national registries and in addition from a number of regional registries. It is hoped that over the next few years the number of national and regional registries which are able to contribute data to the ERA Registry will rise considerably. Thus in the short term the population base of the ERA Registry will fall but should then rise steadily as more national registries are established.

The philosophy of the ERA Registry with regard to the type of data collected and the method of carrying out analyses is also changing. In future only core data will be requested from the national and larger regional registries i.e. less detailed data will be requested than at present. This core data should enable the ERA Registry to provide demographic information on dialysis and transplant patients within its constituent countries. In addition the Registry will pursue studies which will require more detailed in-

formation by obtaining this from the databases of the national registries at the time of each individual study rather than conducting studies by an analysis of its own database as has been the case in the past.

Another change in the philosophy of the ERA Registry will be that in the future it will be much more a collaborative effort between national registries and the ERA Registry than has been the case in the past. In order to further this aim a new advisory committee will be established which will be composed of members proposed by national registries and by the ERA Council. The members of this new committee will have three roles. Firstly they will represent the interests of the national registries, secondly they will advise the Registry office on technical matters such as disease codes, data transmission and confidentiality of data and thirdly they will recommend studies and analyses to the staff of the Registry office. Thus one of the roles of the new committee will be to take over the work previously carried out by the scientific advisory board of the Registry.

The proposals which have been outlined above will radically change the structure and function of the ERA Registry and hopefully they will lead to a return to the pre-eminent role which the Registry enjoyed in the past among the world renal registries.