Clinical genetics in practice

A survey of the current clinical facilities for the management of familial cancer in Europe

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Referrals to genetics departments for evaluation of genetic cancer susceptibility are increasing rapidly in all countries, particularly those with higher socioeconomic levels, and efficient and effective management of these referrals is paramount. Evaluation of the cost effectiveness of such services is vital, both for the geneticists developing them, and for the wider Health Service planners and Departments of Health. Thus, service development requires a partnership between clinicians, service providers and purchasers, and health planners. The drive behind the increase in demand for services is a combination of increase in scientific knowledge about cancer genetics, and the rapidly increasing public appreciation of this, and its potential impact on cancer prevention. Such developments are likely to be greatest in countries with a high general standard of living and health care. In less well developed countries, such a cancer genetics service, whose benefits have not yet been clearly shown, may be considered a barely affordable luxury. In the current situation, where the service has been developed more in some countries than others, it seems prudent for the experience of the countries where services are further advanced to be passed on to countries just initiating them. The identification of factors impeding their development may be helpful, and observing how different countries approach the problem and overcome obstacles may be instructive. To this end, we have documented the current cancer genetics service provision in different European countries and related this to their economic, political, and general health care backgrounds. The development of services within Europe is occurring in parallel with those in the United States and Australia.

In the United States, a national network of cancer genetics services was proposed by the National Institutes of Health in 1996. Five years funding was provided in 1997 to support collaborative investigation into inherited cancer susceptibility, explore how this knowledge could be integrated into medical practice, and identify means of addressing the associated psychosocial, ethical, legal, and public health issues.¹ However, this is difficult to administer

effectively in the absence of a well established collaborative health service network in a very large country. Common guidelines have been drafted for the management of people with inherited susceptibility to breast/ovarian cancer and colorectal cancer, based on the deliberations of a task force from the National Human Genome Research Institute Consortium, organised by the National Human Genome Research Institute.^{2,3} In the United States, the role of genetic nurses and counsellors has been accepted as part of service delivery.⁴

In Australia, despite the geographical problems posed by a large, relatively underpopulated country, attempts are being made to standardise the management of susceptible people throughout the country, according to agreed guidelines.⁵

We have set out to evaluate the current status of services for inherited breast cancer in different European countries, with the following specific aims.

(1) To determine the provision of clinical services for inherited breast cancer in relation to the population served, in different European countries.

(2) To evaluate the progress of service development in these countries, with particular emphasis on the use of genetic counsellors for the delivery of such services.

(3) To assess the provision of educational and career structures for such nurses and counsellors for each country in relation to their perceived roles.

(4) To determine the provision of educational materials on cancer genetics in European countries, in the context of general public education and awareness.

(5) To identify factors which have an impact on the development of such services.

A questionnaire about cancer genetics services was devised and sent out to all BIOMED participating centres (see Annexe on Web) and to selected professionals in all European countries. A second questionnaire and reminder were sent out about one year later, requesting broader information about such services in these countries, and replies were analysed. Personal contacts were made at international con-

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Table 1 Survey of cancer genetics services in 89 centres from 34 European countries

Country	Population ($\times 10^6$)	GNP/cap ($\times 10^3$)	Recognised specialty	Genetic counsellors	Integrated service	Cancer genetics services	Genetic registers	Recognised training in cancer genetics	Audit and evaluation	Discussion fora?	State funding?	Cancer charities?
Austria	8.0	20.9	1994	Few	Yes	Comprehensive	No data	No data	No data	Soc Hum Genet	Yes	Yes
Belarus	No data	No data	No	Yes	No data	No data	Yes	Developing	No data	No data	Yes	Yes
Belgium	10.1	20.8	No	Some	Yes	Comprehensive	Yes	Developing	Yes	Yes & website	Yes	Yes
Bulgaria	8.4	4.6	1985	Yes	No data	Limited	No data	Developing	Yes	Yes	Yes	Yes
Croatia	4.8	3.9	No	Some	No data	Limited	Yes	Developing	Some	Some	Yes	No data
Cyprus	0.7	11.6	No	Some	No data	No	Yes	Outside Cyprus	Yes	Yes	Some	Yes
Czech Republic	10.3	21.5	1980	Yes	Yes	Limited	Yes	Developing	No	Yes	Yes	Yes
Denmark	5.2	26.0	1996	Yes	Yes	Comprehensive	Yes	Yes	Yes	Yes	Yes	Yes
Estonia	No data	No data	No data	No data	No data	No data	Yes, cancer	International only	Yes	Yes	Yes	Yes
Finland	5.1	17.1	1981	Yes	Yes	Comprehensive	Yes	Developing	Yes	Yes	Yes	Yes
France	58.1	20.0	1995	Few	Yes	Comprehensive	Yes	Yes	Yes	Yes	Yes	Yes
Germany	81.6	20.4	1992	No	Yes	Comprehensive	Not integrated	Yes	Yes	Yes	Yes	Yes
Greece	10.6	11.7	No	Some	No data	Limited	No data	No data	No data	Little	Yes	Yes
Hungary	10.2	6.6	1978	Few	Yes	Limited	Yes, cancer	No data	Some	Yes	Yes	No data
Iceland	No data	No data	No data	Developing	Developing	Developing	Yes	Yes (in Sweden)	No data	Yes	No data	No data
Irish Republic	3.58	16.43	No	Yes	Yes	Developing	Yes	Developing	Yes	Developing	Yes	No data
Israel	5.5	15.7	1986	Yes	Yes	Comprehensive	Yes	Yes (including MSc)	Yes	Yes	Yes	Yes
Italy	57.3	19.5	1940	No	Developing	Developing	No data	Developing	Yes	Yes	Yes	Yes
Latvia	2.5	3.3	No data	No	Developing	Limited	Yes	Developing	(Yes)	Developing	Yes	Yes
Lithuania	3.7	4.0	1991	Yes	Only 1 centre	Limited	No data	Developing	Yes	No data	Yes	No data
Netherlands	15.5	19.3	1987	Yes	Yes	Comprehensive	Yes	Yes	Yes	Yes	Yes	Yes
Norway	4.4	23.2	1971	Yes	Yes	Comprehensive	Yes	Yes	Yes	Yes	Yes	Yes
Poland	38.6	5.5	1998	Few	Yes	Developing	Yes	Yes	Yes	Yes	Yes	No data
Portugal	9.9	12.8	Yes	Few	Developing	Developing	Yes	Yes	Yes	Yes	Partly	No data
Romania	22.7	4.3	1997	No data	No	Limited	Some	Developing	No	(Yes)	Yes	No data
Russia	148.1	4.4	1988	Few	Not integrated	Limited	Local only	Developing	Developing	Yes	Yes	No data
Serbia	10.5	0.4	No	Yes	Yes	Limited	No data	Yes	No data	Developing	Yes	Yes
Slovenia	2.0	10.7	No	Few	Yes	Developing	Yes	Developing	Yes	Yes	Yes	No data
Spain	39.2	14.2	No	No	Partly integrated	Limited	Yes, cancer	No	Developing	Yes	Yes	Yes
Sweden	8.8	18.2	1991	Developing	Yes	Comprehensive	Yes	Developing	No	Yes	Yes	Yes
Switzerland	7.0	24.4	No data	No	Yes	Comprehensive	Developing	No	No	Yes	Partly	Yes
Turkey	62.5	5.6	1990	No	Partly integrated	Limited	Developing	No	Developing	Yes	Yes	Yes
Ukraine	51.5	2.4	1993	Yes	Yes	Comprehensive	Yes	Developing	Yes	Yes	Yes	Yes
United Kingdom	58.3	18.4	1970	Yes	Yes	Comprehensive	Yes	Yes	Yes	Yes	Yes	Yes

ferences such as the European Society of Human Genetics meeting in Portugal in 1998 and posters were presented and discussed at the European Society of Human Genetics meeting in Geneva in 1999, and the American Society of Human Genetics meeting in Denver, Colorado in 1998.

The information received was drawn into a comprehensive report. Detailed data are shown in table 1 incorporating some data from reference 6..

Information received indicates that important factors influencing the development of these services are:

(1) The Gross National Product of the country.

(2) Health service structure and its relationship to any private health care systems.

(3) General financing structures for health care.

(4) The tradition and network structure of primary care, and its relationship to other health care services.

(5) The recognition of genetics as an official speciality.

(6) Established networks of genetic services.

(7) Established networks of cancer services and how they relate to genetics services.

(8) Systems of service audit and evaluation already in place.

(9) The existence of established cancer registries.

(10) The existence of genetic screening programmes for other genetic conditions, for example, thalassaemia.

(11) Education provision for genetics and cancer genetics for health care professionals at all levels.

(12) The acceptance of the role of genetic nurses and associates, their status, role, and career pathways. Such associates have an important role in cancer genetic service provision, particularly in view of the large potential volume of referrals, and the need for effective "triage" of referrals.

(13) Level of public awareness and education provision in cancer genetics, and information and support provided.

(14) Patient support networks, including cancer charities.

We hope that the overview of the current status of cancer genetic services provided in the www site will provide an insight into the relative importance of the above factors and a baseline upon which to evaluate the development of such services in the future.

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**website
extra**

*The complete survey
of cancer genetics
services can be found
on the JMG website*

www.jmedgenet.com

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- 1 Senior K. New US cancer genetics network announced. *Mol Med Today* 1998;4:459-60.
- 2 Burke W, Petersen G, Lynch P, Botkin J, Daly M, Garber J, Kahn MJ, McTiernan A, Offit K, Thomson E, Varricchio C. Recommendations for follow-up care of individuals with an inherited predisposition to cancer. I. Hereditary nonpolyposis colon cancer. *JAMA* 1997;277:915-19.
- 3 Burke W, Daly M, Garber J, Botkin J, Kahn MJ, Lynch P, McTiernan A, Offit K, Perlman J, Petersen G, Thomson E, Varricchio C. Recommendations for follow-up care of individuals with an inherited predisposition to cancer. II. BRCA1 and BRCA2. *JAMA* 1997;277:997-1003.
- 4 Peters JA, Stopfer JE. Role of the genetic counsellor in familial cancer. *Oncology* 1999;10:159-66.
- 5 Hopper JL. Some public health issues in the current state of genetic testing for breast cancer in Australia. *Aust NZ J Public Health* 1996;20:467-72.
- 6 Harris R, ed. Genetic services in Europe. A comparative study of 31 countries by the Concerted Action on Genetic Services in Europe. *Eur J Hum Genet* 1997;5(suppl 2):1-220.