

## 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.<sup>1</sup> 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.<sup>2,3</sup> In the United States, the role of genetic nurses and counsellors has been accepted as part of service delivery.<sup>4</sup>

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.<sup>5</sup>

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 speciality | 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               | No data                                | 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                             | Developing           | 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               | Developing                             | Yes                  | Yes              | Partly         | Yes               |
| 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                             | Developing           | Yes              | Yes            | Yes               |
| Switzerland    | 7.0                          | 24.4                      | No data               | No                  | Yes                | Developing               | 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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*The complete survey of cancer genetics services can be found on the JMG website*

[www.jmedgenet.com](http://www.jmedgenet.com)

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