Community genetics services in Europe: report on a survey

Abstract
A comprehensive and highly informative account of genetic diseases in Europe and the technologies and services now available for treatment and prevention. Adopting a critical approach, the book uses the results of a European-wide survey to assess the strengths and weaknesses of existing genetics services and map out precise strategies for improvement. Details range from estimated numbers of Europeans suffering from specific genetic diseases to the average annual costs, per patient, of treatment, from advice on the safety and reliability of screening tests to a point-by-point account of deficiencies in most existing services. Throughout, an effort is made to interpret the latest knowledge in clinical genetics in terms of its implications for the design of services, including their preventive and counselling components. The books analysis, which is supported by over 100 references, is presented in four main parts. The first part summarizes and interprets current medical knowledge about the causes, mode of inheritance, prevalence, management, and possibilities for prevention of congenital malformations, chromosomal disorders, and Mendelian (single-gene) disorders. Examples cited include prenatal screening for congenital malformations and chromosomal abnormalities, neonatal screening for phenylketonuria, hypothyroidism and sickle-cell disease, and population screening for carriers of inherited diseases such as the haemoglobin disorders and Tay-Sachs disease. Facts and figures are used to indicate the magnitude of the public health problem posed by these diseases, the costs and outcome of treatment, the future number of people likely to be effected, and the urgent need for rational planning of services based on both projected needs and the development of new screening tools. A review of data on social and ethical issues soundly refutes several common assumptions, including the belief that birth incidence of genetic abnormality increases if people with disabilities reproduce, and the fear that the ability to predict a wide range of genetic characteristics will lead to abortions for minor or even frivolous reasons. The second part evaluates the quality of Europe's existing community genetics services, focusing on the extent to which current tools for primary prevention are being effectively used. Techniques discussed include the use of ultrasound scanning and maternal serum alpha-fetoprotein estimation in screening for congenital malformations, the use of karyotyping to detect chromosomal abnormalities during pregnancy, and DNA methods for carrier diagnosis and prenatal diagnosis. For each method, readers are given advice on safety, effectiveness, advantages, limitations, and the extent to which current services are meeting population needs. To guide the improvement of services, the book sets out six rigorous requirements for quality assessment and technology control that must be met before testing and counselling services are implemented on a large scale. The third part discusses the infrastructure and organization of community genetics services needed to reach the goals of relieving anxiety, increasing the proportion of healthy children born, and allowing families to live normal lives. Detailed advice on cost-benefit analysis is also provided. The final part issues 11 precise recommendations for improvements that could, if adequately implemented, reduce the annual number of births of European children with serious congenital disorders by tens of thousands.

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Science Europe has released on January 14 a Survey Report on 'Strategic Priorities, Funding and Pan-European Co-operation for Research Infrastructures in Europe'.

The 26-page report describes the decision-making landscape when it comes to the planning, funding and collaboration of public scientific research facilities in Europe. It gives insight into the diversity of processes in place to define strategic priorities across the different national research systems. The report highlights the benefits of cross-border collaboration among research organisations and finds that "huge potential still

All the reports of CNNIC have witnessed the whole development process of China's soaring Internet industry. With precise and objective data, the reports provide a significant basis for government departments and companies to master the development of Internet in China and make relevant decisions. Since 1998 CNNIC has been issuing the Statistical Report on Internet Development in China at the beginning and middle of every year by convention. The Internet has growing influence on the overall social stability, economic development and cultural development, and the national strategy of cyber deve Based on the survey results, national and European policy makers, as well as non-governmental organisations, will be able to better target their advocacy strategies and activities to support LGBT communities to live and express themselves freely in a non-discriminatory environment. The survey was completely anonymous (no data on the participants and their sessions were logged in any way). The survey was operated by Gallup, a professional survey and consultancy firm. In order to give weight to the results, the European LGBT Survey counted on the participation of a large and diverse group of les