

Profile

DIPEX: A Database of Individual Patient's Experiences of Illness

Background

From the outset of the Cochrane Collaboration, designed to identify a basis for evidence-based medicine in the best of the world's controlled clinical investigations, the question has been debated as to whether better use cannot be made of individual patient experiences. They are uncontrolled and their reliability varies greatly, yet they provide an input in how the individual experienced both illness and the way in which health care is practised. The facts and views which they convey rarely penetrate beyond the consulting room, yet many believe that they could provide an additional tool to help medicine in its further development and to aid patients in understanding and facing ill-health. DIPEX is a novel step in mobilizing the patient's own experiences for that purpose. As its initiators write, ". . .to be diagnosed with an illness can be bewildering and frightening, especially if there is no-one around to tell you the things you really want to know. How is this illness going to change my life? How will it affect my relationship with my family, friends and colleagues? What will it be like having this operation or taking these drugs? Will I still be able to do the things I used to do?"

Description

Established in the United Kingdom but accessible worldwide, DIPEX is an internet-based multimedia resource derived from primary qualitative research set in its scientific context. It will answer questions like those cited above by providing access to the experiences of others who have faced the same dilemmas. On the DIPEX internet site one can see videoclips, listen to the voices or read the accounts of people relating their experiences of illness and the impact it had on their lives. One can also obtain information on an illness and the treatments for it which are available, and find links to support groups and other reliable sources of medical information.

DIPEX aims to promote more balanced encounters between patients and health care professionals by providing detailed access to the patient perspective. It is, at the same time, a 24-hour support group for anyone whose life is touched by an illness, and a valuable resource for the training of doctors, nurses and other health professionals and health workers.

Finances and organization

Access to the DIPEX website is free. There are also plans to make it available through CD ROM at public libraries in the United Kingdom, support groups, general practice surgeries and hospital out-

patient departments. DIPEX is a registered charity which has received support from the UK Department of Health, the Citrina Foundation, Macmillan Cancer Relief, the Lord Ashdown Trust, the Consumers' Association and individual donations. The operation is based at the Department of Primary Health Care of the University of Oxford.

Current and planned activities

In May 2002, the data base covered the experiences of patients with hypertension, breast cancer, prostate cancer and bowel cancer. Other areas to be covered in the course of 2002, will include Cervical Cancer, Cervical Screening, Carers of People with Dementia, and Testicular Cancer. Many other fields will follow. DIPEX collections in other languages and cultures are envisaged for the future.

Contact

The website is available to all at <http://www.dipex.org>.
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