

Personal experiences of health and illness on the web: A resource for patients, carers and health professionals

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People are becoming savvier as health consumers when faced with the need to make decisions. They are turning to the internet for both factual and experiential information. DIPEX, an award-winning, electronic, multi-media resource of personal experiences of health, illness and related issues on the web, addresses this need with evidence-based information alongside video, audio and written interview clips that identify issues that matter to people. The website is freely available 24 hours a day providing support for patients and their families, friends, carers and health professionals from the personal perspective.

People need relevant and reliable information quickly

People have to make decisions about health at various stages throughout life, for example when they or a family member become ill or when they are about to become a parent. At such times most say that they want up-to-date information about the condition and care or treatment options.¹⁻³ They also want to hear what it is like from others who have been through the experience, how to tell family and friends, where to find support and what questions to ask their health professionals.³⁻⁴ In addition, they say that they want their health professionals and others to *really* understand what they are going through. More and more they are turning to the internet for the information and support they need.⁴⁻⁸

DIPEX can help

DIPEX (www.dipex.org), an award-winning, electronic, multimedia resource about people's experiences of health, illness and related issues, helps address these needs by providing up-to-date, evidence-based information (often linked to other sources), answers to questions that the people have raised themselves and information about support groups.^{9,10} It also provides links to other resources such as the Cochrane Collaboration, the UK National Electronic Health Library and Cancerbackup. However, the unique and most powerful part of the DIPEX resource is the video, audio and written accounts of peoples' lived experiences.

DIPEX is available on the internet; some of the modules on the various conditions are also available on DVD. It is of use to patients, carers and health professionals, including researchers, teachers and students. It is completely independent from commercial interests and information. It aims to describe the widest possible range of peoples' health-related experiences and to be an information-rich resource for people faced with health issues and those who care for them.

How DIPEX is built

DIPEX is the result of a series of stand-alone qualitative research studies on a wide and expanding range of health

related topics such as various cancers, cardiovascular disease, mental health, neurological conditions, epilepsy, young people's health experiences, women's health and parenting (see Table 1). The qualitative studies have UK multi-region ethics committee approval.

For each study an Advisory Panel of experts in the field, including academic researchers, health professionals, policy makers and lay representatives, is set up to help recruit participants, to guide the researcher and to review the analysis of the interview data. A maximum variation sample of around 40 people is recruited to capture as wide a variety as possible of experience, age, gender, ethnicity, socioeconomic status, domestic setting, and treatment choice if applicable. Participants are recruited through primary and secondary care, support groups, and informal networks such as internet discussion groups. Interviews are generally conducted in people's homes and recorded on both digital video and audio tapes. After the interview, participants are sent a verbatim transcript and can choose to remove any sections they wish before granting DIPEX permission to use the interview for the website, teaching and research publication purposes. At this point participants also specify in what format(s) their interview may be used (video, audio or written only). The dataset for each study is analysed thematically with the aid of computer-assisted qualitative analysis software. Each theme or topic is written up as a brief summary that captures the range and variation of experience and is illustrated by video, audio or written extracts from the interviews.

How DIPEX can help

Patients, carers, and members of the public who access the DIPEX website can see and listen to other people talking about their experiences. They will find someone with a similar experience with whom they can empathise. They will also gain practical and emotional support for what they are going through and will be able to identify what they need to know and understand, and what questions to ask their health professionals.

In spite of initial opposition to people seeking health information on the internet,

Table 1. List of health related topics on DIPEX website

| Category | Illness or Condition |
|---------------------------------------|--|
| Cancer & screening | Breast cancer Breast screening Cervical cancer Cervical screening Bowel cancer Lung cancer Ovarian cancer Prostate cancer PSA Testing Teenage cancer Testicular cancer |
| Chronic health issues | Chronic pain Rheumatoid arthritis HIV |
| Young people's experiences | Sexual health of young people aged 18-25 Teenage cancer Diabetes Type I in young people |
| Women's health, pregnancy & screening | Pregnancy Antenatal screening Ending a pregnancy for fetal abnormality Screening for sickle cell, beta thalassaemia and other variants |
| Heart disease | Breastfeeding Parents of children with congenital heart disease Heart attack Heart failure High blood pressure |
| Immunisation | Immunisation |
| Intensive care | Intensive care |
| Living with dying | Living with dying |
| Neurological | Epilepsy Carer's of people with dementia |
| Mental health | Depression |

the informed health consumers are now often viewed as desirable¹¹, even if many don't tell their doctor that they have accessed information from the internet.

¹² It has even been suggested that health professionals may give people 'information prescriptions' directing them to appropriate websites such as dipex.org .¹³

Besides directing patients to the website for information, practical and emotional support, health professionals can access DIPEX to gain insight into the non-clinical aspects of what it is like to be faced with a health decision or to live with a health issue or concern. The video clips of personal experiences on the website can be used to enhance shared decision-making between professionals and the people for whom they care. Furthermore, many professions are beginning to use DIPEX for continuing professional development.

The DIPEX website also provides a rich resource for undergraduate and postgraduate

teaching where it has been used in teaching clinical communication and qualitative research methods to a variety of health professional students and health care workers. We intend to develop a range of formal teaching modules from the database.

Other users of the DIPEX site include researchers who have used the data for a variety of secondary analyses, including sociolinguistics, condition-specific analysis of a data set and thematic analysis across several collections.^{14,15} Because the DIPEX website is freely available to all, it provides a means for patients and other representatives on health services committees to access a broad range of experiences and deepen their understanding of a variety of perspectives.

How DIPEX has grown

DIPEX was the brainchild of Ann McPherson and Andrew Herxheimer, both health professionals who had undergone an

illness experience in the mid 1990s. They recognised the value of hearing from others about what it was like to be ill and to be treated. Since those early days, DIPEX has grown until, by summer 2007, 38 conditions will have been completed, with a further 11 studies underway. Collections are planned for over 100 other conditions, but growth will depend upon funding since each module is funded by a mixture of public and private non-commercial sources (for details see website). DIPEX is a registered charity with a research group based in the Department

of Primary Health Care at the University of Oxford. Some projects are done in collaboration with other research groups and there is international interest in setting up DIPEX-like projects in other countries.

How could pharmacists and other health professionals in Malta use DIPEX?

Since in Malta one of the official languages is English, most people could use DIPEX.

If pharmacists know about it and are aware what diseases and problems it

deals with, then they can share that not only with patients and customers, but also with their assistants in the pharmacy and their colleagues in the other health professions. That could lead to many more fruitful conversations between patients and professionals.

We would ourselves also love to know what patients and professionals in Malta think about DIPEX - what seems specially useful in Malta, what they like, what they find difficult, what improvements they suggest.

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Event

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