

**W**e are delighted that the Institute of Health and Community Studies (and the WOMen, Babies and their families research group- WOMB- in particular) are collaborating with the award winning DIPEX team<sup>1</sup> on the production of a web-based module concerning experiences of breastfeeding.

In order to explain what DIPEX is, it is impossible to improve on what they've written about themselves:

"DIPEX - Personal Experiences of Health & Illness

DIPEX is an Oxford based charity which produces a unique, award winning website [www.dipex.org](http://www.dipex.org) giving personal accounts of health and illness. These accounts are in written, audio and video format and aim to give information and support so that people are better informed about the life choices they might need to make when encountering a new health experience, serious illness or health problem. DIPEX is also able to tell health professionals, from the health consumers' perspective, what it is really like to have the health experience or illness, enabling its use within teaching and training settings.

The interviews on the site discuss different aspects of peoples' individual experiences including initial diagnosis (where relevant), symptoms, treatments and treatment choices and the side effects of the particular disease or condition, talking openly about issues such as living with the condition, the effects on relationships, sex life, telling family and friends and even the most difficult decisions about end of life choices.

On the DIPEX site people's frequently asked questions are answered; these are often very different from the questions that health professionals think people want to ask. The site also provides reliable medical information about each experience/condition or illness, links to other organisations, support groups and other useful resource materials and has a key word index that covers all the

interviews.

Each health experience/disease has its own site or 'module' on the DIPEX website. At the moment the website has published 20 modules and there are 13 in progress including: cancers, heart disease, mental health, screening programmes, chronic pain, pregnancy and maternity issues and rheumatoid arthritis amongst others.

DIPEX are also planning a new site just for young people, which will cover teenage cancers, chronic illnesses, sexual health and issues such as bereavement and dealing with a parent who has cancer or another terminal condition. The site will also provide general information such as young people's rights when speaking to a doctor, how to deal with bullying, have links to the teenage pregnancy unit and other good quality young people's websites.

Each module is based on detailed, qualitative academic research carried out by a DIPEX funded research post at the DIPEX Research Group based in the Department of Primary Health Care at Oxford University or in collaboration with DIPEX. The researcher conducts interviews with a purposive sample (approximately 40-50) of people from a variety of ages, backgrounds and ethnic groups. The participants are recruited through support groups, hospital out-patients clinics and GPs as well as direct volunteers and an advisory panel of experts, clinicians and consumers is formed to help and advise the researcher. The interviews are analysed and prepared by the researcher before being passed to the DIPEX charity for the website team to prepare and format them for inclusion into the website.

DIPEX is being used in a number of ways including, use as a pilot teaching tool within the RCN e-learning programme, as a training aide by GP tutors, a teaching tool in communication skills for non-British nurses, information and support in UK wide Cancer Information Centres and has been integrated into numerous PALS groups as an online



*Jo Alexander*

'expert patient' resource for patient representatives.

DIPEX aims to publish the 100 main illnesses and experiences/conditions on the site within the next 10 years and to be the UK's primary health information resource. The topics covered will include not only specific illnesses such as cancers, heart conditions, mental health and rare disorders, but issues such as treatment choices for surgery, immunisation, HRT, pregnancy and smoking cessation, in addition to the area for young people mentioned earlier.

The site, which can now be made available on DVD as well as via the internet, is a unique resource in the field of consumer and healthcare information and is aimed at several audiences. Our aim is to have the DIPEX DVDs available in all GP surgeries, out-patient clinics, PALS groups and in public libraries to ensure access to all. We are working hard to increase participation and access within BME (Black and Minority Ethnic) groups and our recent presentation to community leaders, project workers and other charities and organisations working in this field, has led to the formation of a Working Party to take this project forward.

### **Modules available on the site:**

- prostate cancer
- lung cancer
- colorectal (bowel) cancer
- breast cancer

- testicular cancer
- cervical cancer
- cervical screening
- epilepsy
- heart failure
- high blood pressure
- parents of children with congenital heart disease
- heart attack
- living with dying
- depression
- ovarian cancer
- antenatal screening
- sexual health of young persons
- chronic pain
- carers of people with dementia
- breast screening

### Modules in progress:

- complex regional pain syndrome
- intensive care
- teenage cancer
- young people's diabetes
- rheumatoid arthritis
- sickle cell and thalassemia
- experiences of pregnancy
- childhood immunisation
- PSA testing
- stroke
- Aids and HIV
- lymphoma
- ending a pregnancy due to foetal abnormality

### Website statistics:

The number of 'hits' received on the DIPEX website has increased steadily. We now receive approximately a million hits a month on the site and there are now over 300 organisations that have links to the DIPEX website including NHS Direct Online, Macmillan Cancer Relief, CRUK, British Heart Foundation, Cancer BACUP. The site has over 120 hours of video interviews and over 1200 pages of reliable health information.

DIPEX has been awarded the BUPA Foundation prize for communication, 2004."

### The breastfeeding module:

I am very pleased to have had the opportunity to develop this collaboration with DIPEX, have been on the advisory panels for the antenatal screening and pregnancy modules and written the outline for this new module.

The Healthiest Start for babies is breastfeeding<sup>ii iii</sup> but those least likely to start are the very mothers whose babies would benefit most; mothers from lower occupational groups, with less education and of a younger age<sup>iv</sup>. The 40-50 video interviews that will form the core of this module will be accessible to those with lower levels of literacy. Our previous Department of Health funded research<sup>v</sup> has shown the value women place on other women's experiences of infant feeding. The module will aid the National Service Framework target of increasing the breastfeeding initiation rate by 2% a year, especially among women from disadvantaged groups and of increasing duration<sup>vi</sup>. The module:

- will be a continuously (24/7) available free resource for women who are deciding how to feed their baby and those who are breastfeeding but may need support to continue
- will include interviews with people from disadvantaged and minority ethnic groups
- will include the experiences of those who have overcome difficulties with breastfeeding and provide the related evidence-based information
- will improve understanding of people's experiences of breastfeeding and weaning
- will answer frequently asked questions about breastfeeding and weaning
- will inform people about the many different sources of support that are available, such as support groups, resource materials and links to other websites
- will be a resource for healthcare professionals when giving nutritional advice during pregnancy, breastfeeding and weaning<sup>vii</sup>
- will link to the DIPEX modules on pregnancy choices and antenatal screening
- will be accessible to those without

internet access as a DVD (e.g. via Community Centres, Sure Start outreach venues, peer support groups, antenatal clinics and GP surgeries)

- could be considered a pilot for possible extension into other areas of public health.

Dr Kath Ryan will be coming from her post at the University of Otago (New Zealand) to take up post at Bournemouth University as Senior Research Fellow responsible for developing the module on 19.9.05.

If you would like to know more about the breastfeeding module (or even to help us to recruit participants!) I would be delighted to hear from you.

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<sup>i</sup>*Herxheimer A, Ziebland S. (Editorial) DIPEX: fresh insights for medical practice. Journal of the Royal Society of Medicine 2003; 96: 209-210*

<sup>ii</sup>*Department of Health. Choosing Health - making healthy choices easier. www.dh.gov.uk/publicationsandstatistics Accessed 19.11.04*

<sup>iii</sup>*American Academy of Pediatrics. Breastfeeding and the use of human milk - work group on breastfeeding. Pediatrics 1997; 100: 6: 1035-1039*

<sup>iv</sup>*Hamlyn B, Brooker S, Oleinikova K, Wands S. Infant Feeding 2000. London: TSO, 2002*

<sup>v</sup>*Alexander J, Anderson T, Grant M, Sanghera J, Jackson D. An evaluation of a support group for breast-feeding women in Salisbury, UK. Midwifery 2003; 19: 215-20*

<sup>vi</sup>*Department of Health (England). Getting the right start: National Service Framework for Children. www.doh.gov.uk/nsf/children/gettingtherightstart.htm 2003* <sup>vii</sup>*Department of Health. Healthy Start: Government response to the consultation exercise. London: DoH, 2004*