

23rd June 2009

## Launch of Clinical Trials

a new section on [www.healthtalkonline.org](http://www.healthtalkonline.org)

Jon Snow, patron of DIPEX, today chaired the launch of a new section of the award-winning website Healthtalkonline on people's experiences of clinical trials. Speakers included Professor Dame Sally Davies, Director General for Research and Development, Department of Health, Sir Iain Chalmers, Editor of the James Lind Library, Sir David Weatherall, Emeritus Regius Professor of Medicine, University of Oxford and Lester Firkins, Chair of the James Lind Alliance. Based on research led by the DIPEX Health Experiences Research Group at the University of Oxford, the new section presents video and audio interviews with over 40 people talking about why they took part – or chose not to take part – in a clinical trial, what information they needed and what it was like for them.

At the launch, Dame Sally spoke of the vital importance of clinical trials to improving health and quality of care and of the great reliance on people being willing to volunteer. Sir Iain stressed the importance of up-to-date published information on what trials are taking place and how people can volunteer; whilst Sir David emphasised the need for training of professional staff who run the trials so that they have a greater understanding of what it's like to take part and how best to provide information and care, both during and after the trial. Lester Firkins, who chaired a trial testing treatment for Creutzfeldt-Jakob Disease after his son died from the condition, talked about the difference the new website section can make to people thinking whether to take part in clinical research.

Louise Locock, Deputy Research Director, who headed up the project, said: *“Clinical trials are a vital part of improving healthcare through the development of new treatments. This research provides much-needed information on how people react to participation in trials, what their experiences of trials have been and how they view the management of such trials, including after-care. The project also provides an online resource at Healthtalkonline for people considering participation in clinical trials to share in the experiences of others”*.

The new clinical trials section of Healthtalkonline includes summaries of what interviewees said on a number of topics, including how they were approached about taking part in a trial, their reasons for taking part or saying no, their feelings about being randomised, practical issues such as appointments, tests and monitoring, and their feelings when a trial ends. We have illustrated these summaries with video and audio clips from the interviews.

The project has been funded by the National Institute for Health Research. The NIHR has also generously supported the launch. The new section appears under the new Group heading of 'Medical Research' at [www.healthtalkonline.org/medical\\_research/clinical\\_trials](http://www.healthtalkonline.org/medical_research/clinical_trials).

## About DIPEX/Healthtalkonline

DIPEX has created two websites – [www.healthtalkonline.org](http://www.healthtalkonline.org) and [www.youthhealthtalk.org](http://www.youthhealthtalk.org) – of people's experiences of almost 50 different illnesses and health conditions. The websites are aimed patients, their carers, family and friends, doctors, nurses and other health professionals and are based on in-depth qualitative research carried out by the DIPEX Health Experiences Research Group at the University of Oxford.

Users of our websites will find accounts – presented through video, audio and written material – which resonate with their own perspectives and experiences of issues such as reaction to diagnosis, consultation with their doctor, effect on work, social life and relationships, decisions on treatment options and side-effects. The questions that patients want answered are identified in their interviews and summarised on our websites.

To date, we have covered illnesses including cancer, heart disease, neurological conditions (Parkinson's, epilepsy and autism) chronic health issues (HIV, diabetes, rheumatoid arthritis) and mental health. We also provide experiences of women's health (pregnancy, breastfeeding, antenatal screening) and publish young people's experiences (including epilepsy, sexual health, teenage cancer) on our dedicated website – [youthhealthtalk.org](http://youthhealthtalk.org).

Our supporters include Jon Snow, Dawn French, John Humphrys, Ian McEwan, Dr Jonathan Miller, Jenni Murray, Michael Palin, Philip Pullman, Libby Purves, Claire Rayner, Thom Yorke and many others. DIPEX, a registered charity no. 1087019, is funded by the Department of Health and charitable trusts. Full details are on our websites.

For more information contact:

Graham Shaw, Chief Executive  
Phone: 07799 664371  
Email: [graham.shaw99@btinternet.com](mailto:graham.shaw99@btinternet.com)

Francie Smee  
Phone: 01865 289328  
Email: [dipexadmin@dphpc.ox.ac.uk](mailto:dipexadmin@dphpc.ox.ac.uk)

DIPEX Charity  
PO Box 428  
Witney, Oxfordshire OX28 9EU  
Phone: 01865 744209  
Fax: 01865 289287  
Email: [info@dipex.org.uk](mailto:info@dipex.org.uk)

DIPEX Research Group  
Department of Primary Care  
University of Oxford  
Old Rd, Headington

Oxford OX3 7LF

Email: [dipexadmin@dphpc.ox.ac.uk](mailto:dipexadmin@dphpc.ox.ac.uk)