



Newsletter

May 2007



Welcome

From the Co-ordinator

It has been a little while since we produced a Folk.us newsletter, but we have been busy and so have our members. We are so pleased that Brian's research, which Folk.us supported, has two publications and the work is continuing. We have a full Programme of events planned including a Folk.us Forum about Participatory Appraisal on the 5th June in Plymouth. There are events in Exeter too.

Dawn the Folk.us Research Assistant is hosting some new Roadshows around Devon with the help of our members. For More information read on!

Rachel

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Brian's Publication

Brian Ruel is a service user and member of the Folk.us Steering Group.

Brian has been part of a research project where he came up with the original question and has been involved throughout the research, which has now been published.

The Question was about the effects on people of taking strong opioid medication over a long time for non-cancerous conditions. Brian started by asking the advice of his GP, Dr David Seamark. It was suggested that some research was needed and a team was formed. Brian says his enquiring mind and trust in his doctor gave him the confidence to go ahead with being involved in the research. He plunged into an intensive 2 weeks training to become familiar with the necessary medical terminology and research methodology.

Brian was involved in refining the research question, developing the interview schedules and helped to run the focus groups. He and the team worked on the coding, analysis and reporting of the study. As well as a publication, the team have presented their study at many conferences.

Brian Ruel. 'Personal profile on pain' *British Journal of General Practice* 2007; **57**;163. and Sue Blake, Brian Ruel, Clare Seamark, David Seamark. 'Experiences of patients requiring strong opioid drugs for chronic non-cancer pain: a patient-initiated study' *British Journal of General Practice* 2007; **57**;101-109.

Research News

HURAdCom

Folk.us is working with the Haematology User's Research Advisory Group who have commissioned a Clinical Psychology Doctorate student to undertake research into psychological impacts following diagnosis of cancer.

With the researcher and Consultant Dr Rudin, they have worked to refine the research question and develop the methodology, patient information sheet and the interview schedule. The researcher will carry out the interviews to benefit from her professional skills and to maintain patient confidentiality. But once the data have been transcribed and anonymised and the analysis phase of the research begins.

Preventing falls in Parkinson's disease: an exploratory study

Back in 2004 Vicki Goodwin, a local physiotherapist, began a pilot study as part of a Clinical Academic Fellowship with the Peninsula Medical School. She attended a lecture by Folk.us on involving users in research and as a result made contact with Andrew Palmer. His input proved invaluable in developing patient information sheets, consent forms and dissemination materials as well as advising on questions for patient qualitative interviews.

As a result of the pilot work, Vicki has been awarded a prestigious Researcher Development Award from the Department of Health to undertake a randomised controlled trial.

Members' news

Peter Buckingham presented to a Littlehampton company that sees the potential enormity of care needed for the brain injured population. The Company saw this as an opportunity benefiting the organisation.

Brain Injury is referred to as "the Silent Epidemic", there are literally hundreds of thousands of cases every year ranging from minor head injuries to brain damage. There are relatively few cases of traumatic brain injury such as Peter's own. A type of recovery is possible provided the person is prepared for all the extremely hard work that it entails. Peter's injury was 13 years ago and he is still improving!

Annie Mitchell is part of 'Tarte Noire' which is a new Women's Playback Theatre Company in Exeter and Totnes. The aim is to create a space where people's stories (big or small, shocking, curious, sad or hopeful) can be expressed and shared. It's a creative way to share experiences and build a sense of community. More information on website for Southwest Playback Company: Mirror Mirror:

www.mirrormirrortheatre.co.uk/index.htm
!

Rachael Carrick & Annie Mitchell presented a paper on "*Service User Perspectives on Ethical Priorities in Psychological Research*" at the UK Community Psychology Conference 2006.

More Members News:



Andrew Palmer is a member of the Folk.us Executive Group and the Steering Group. He also coordinates Devon Young Parkinson Network, is the Health and Social Services Liaison Officer of the Exeter Branch of the Parkinson's Disease Society and sits on Devon Primary Care Trust's Public and Patient Involvement Forum.

Andrew is on the Local Implementation Groups for Devon Strategic Partnership and the Exeter area one, which is leading the Campaign for the Parkinson Disease Nurse specialist. He is the Mid Devon User Rep for Living Options Devon. Andrew is pretty busy and we are very glad he makes time for Folk.us!

What's New for 2007?



Road Shows

As the message about user involvement spreads in the world of research, there is an increasing demand for patients and carers to be involved in projects. But, unless you are receiving treatment and have a GP or consultant who is actively searching for someone to get involved how do you realise that this is an option? and is this the best time for you to find out?

The **Road Shows** are a way of reaching a much wider, more general, audience. A flexible presentation of displays, posters, leaflets and Folk.us presenters that can go to a range of venues. The audience could vary from a WI or U3A

group, to patients in a GP practice, shoppers or a sports club.

We will be furthering the development of a culture of 'research is for anyone' and letting people know of the possibilities that exist to get involved in or initiate research.

Would you like to be involved? We will need volunteers who would be willing to accompany Folk.us staff to **Road Show** events and be willing to talk to interested people. It could involve answering questions about your own experiences of becoming involved in research, or adopting user involvement approaches to research.

Contact : Dawn at the Folk.us office by phone or email to find out more.

Telephone: 01392 403049

Email:

folk.us@exeter.ac.uk



Programme 2007

5th June	Folk.us Forum Participatory Appraisal	Plymouth
12th June	Folk.us Training	Truro
13th June	Folk.us Training	Exeter
18th July	Folk.us Steering Group	Exeter
12th September	Folk.us Forum (Somewhere in Between!)	
7th November	Folk.us Steering Group	Plymouth
12th December	Folk.us Forum	Exeter



Folk.us Address:

***Folk.us
Room 407
Noy Scott House
Royal Exeter & Devon Hospital
Exeter
EX2 5DW***

Telephone 01392 403049

***Email: folk.us@exeter.ac.uk
Website: www.ex.ac.uk/folk.us***

Thanks for reading! Don't forget to get in touch with any comments or contributions for the Newsletter or if you would like to join in with any of our events.