



**Folk.us Annual Report
July 2006 – July 2007**

Folk.us Index

	Page
Introduction	1
Training	3
Facilitating & Enabling Collaborative Research	5
Networking	9
Clinical Networks and other Networks	11
Access to Resources	14
Cross cutting themes	15
Management and Probity	17
Outcomes	20
Conclusion	24
References	25
Finance Information	26
Appendix 1	
Critical Friend Training Report	i
Appendix 2	
Folk.us - Peninsula Diabetes Local Research Network Report	vii
Appendix 3	
Role of Folk.us	xviii
Appendix 4	
Prioritising Grant Requests	xxiii

Forum for Collaboration with Users in Research (Folk.us) Programme

Annual Report July 2006 – July 2007

Introduction

This Annual Report covers the period of July 2006 to July 2007. This has been a very productive period with the creation of a new Steering Group and its burgeoning membership, development of a set of new training packages, redesign of the leaflet and website and exciting new collaborations being made.

We held a 'Wake up to Folk.us Day' in July 2006 which was open to our existing membership as well as anyone who was interested in hearing a bit more about us! Approximately 40 people attended and there was a wide range of service users, carers and researchers. Having attended the event, ten people signed up to be part of the new Steering Group. Since then, the Steering Group membership has continued to grow and we now have 16 people across Devon who bring very different organisational and personal perspectives which is an invaluable resource for Folk.us

One of the first tasks we asked the group to help us with was in the re-design of the leaflet and 'strap line'. We are delighted with our new leaflet which has been described as 'eye-catching', 'fun' and 'informative'. We have also been working with a website designer to redesign the Folk.us website to make it more user-friendly. A prototype was shown to the Executive Group in July and the website will go live in September 2007.

We have continued to work with three of the South West Clinical Research Networks. This has been very interesting work for Folk.us and has helped us to create a new training package aimed at the steering groups of these networks to help them develop and support meaningful involvement.

Our ongoing work with the Folk.us 'Critical Friend' continues to be very useful and has assisted us produce a training strategy as well as our criteria for being involved in grant applications. Her initial piece of work at the Wake up to Folk.us Day helped us to shape the Steering Group and think in-depth about its role and remit.

We are continuing to work with specific projects in Devon which increases our knowledge and allows new partnerships to form as well as look for new organisations/ people who we could link with. To this end

we are delighted to be working more closely with the Peninsula Technology Assessment Group (PenTAG) to support involvement in their evidence synthesis and cost-effectiveness appraisals.

This report summarises the main strands of our work and we hope it makes enjoyable reading.

Training

Initially our aim for July 2006 – June 2007, was to identify and train other key members to assist in the delivery of the Folk.us training. However, following discussions with the Executive Group, we asked our Critical Friend to review our training with us. As a result of this piece of work (See Appendix 1) we altered the emphasis of our aim. The aim became to redevelop the training content, focussing on designing three different training packages for three specific audiences. Each package is designed to be delivered over half a day.

The first package is for the new and emerging networks and committees. The content is aimed at the governing groups/bodies that are made up of clinicians, researchers, patients, carers and/or service users. This workshop is very much aimed at supporting people working together.

The second package is primarily, although not exclusively, for the research community such as clinicians, researchers in academia and research nurses. This package is an introduction to involving patients, carers and service users in research.

The third package is primarily, although not exclusively, aimed at patients, carers and service users who may be interested in research or who are considering whether to become involved in research.

All three packages outline the principles of good involvement, help to work through the barriers that might exist to involving people and give practical examples of projects where involvement has been successful.

We have now delivered these packages on six occasions. Our audiences have been, academic staff at the University of Plymouth, students undertaking the Doctorate of Clinical Psychology at the University of Exeter, patients, and audiences invited by Peninsula Research and Development Support Unit. Other sessions were for service users and carers in Plymouth and one for service users and carers in Exeter. Approximately 83 people have been to the sessions. The some of the sessions were structured so that over lunch, service users, patients and carers, met with academics and NHS and social care research staff. This structure appeared to work well.

Folk.us was also commissioned by the Peninsula Diabetes Local Research Network to deliver two sessions, one in Exeter and one in Plymouth, for people (patients) with Type 1 and Type 2 Diabetes. Further details are in "Clinical Networks and other Networks" on page 12

and a full report of the Folk.us experience is in Appendix 2. In the afternoon session, people with Type I diabetes were asked to think of areas they thought should be researched.

Overall the training has led to 12 new people from both patient and professional backgrounds joining Folk.us, four of whom have joined the Folk.us Steering Group.

Social Care Training

We have supported and facilitated staff training for the joint Learning and Development Project for the National Health Service and Devon Social Services. These sessions were held over three mornings for trainers whose role it is to deliver training for both Healthcare and Social Services staff in Devon. The Development Officer for the project is supporting the trainers to involve service users and carers in their training to staff. Folk.us helped to design the sessions with one of our service user members and with the Development Officer. The service user and Folk.us Co-ordinator co-facilitated the sessions. We will continue to offer support to this project.

Folk.us Staff Training

The Folk.us Co-ordinator and Research Assistant have undertaken training in Dreamweaver web design in preparation for maintaining the new Folk.us website. They have also undertaken training for using the University of Plymouth system 'Emily'.

The Folk.us Grant holder undertook a brief introduction to Participatory Appraisal research methods.

The Folk.us Research Assistant attended the Understanding Statistics (part II) workshop held by the Peninsula Research and Development Support Unit.

Training Activities related to Folk.us and its people

In addition, the Folk.us Co-ordinator has designed one of the first Nationally Accredited Disability Equality/Awareness Qualifications for an organisation called Education Development International (EDI). EDI is an accredited Awarding Body and leading international education company. Services include: accredited vocational and professional qualifications to training providers, pupil and school online performance measures for schools and assessment solutions for awarding bodies and companies. This was conducted by the Folk.us Co-ordinator as an external piece of work.

Facilitating & Enabling Collaborative Research

Our aims for July 2006 to 2007

- Identify and work with a limited number of research projects across Devon
- Initiate discussions about the funding of collaborative or service user or carer led research projects with Health and Social Care Organisations

RfPB (Research for Patient Benefit)

With Involve, RfPB have been developing patient involvement in this programme. The South West Committee and Involve approached Folk.us to assist in the recruitment of service users and carers to the Committee. Folk.us advised on the wording for the initial advert for service user and carer recruitment in the South West and promoted the opportunity for patients, service users and carers to be involved on the commissioning committees. Folk.us has been asked to be a collaborator on two local proposals and has provided advice on service user and carer involvement on two others.

Informal discussions with academic committee members and lay members suggest that additional support for lay members in reviewing proposals would be helpful and that the majority of applications (particularly those outside of Devon) do not have patient involvement either in the design or in the proposed delivery of the project.

Haematology User Research Advisory Committee (HURAdCom) at the Royal Devon and Exeter NHS Foundation Trust:

We have supported this committee for four years. The committee is made up of five former patients who have used the Haematology Unit, Dr Claudius Rudin Consultant Haematologist, the unit nurse, unit counsellor and the Folk.us Research Assistant. The committee have had great success in designing patient information sheets for complex treatment trials as well as helping to produce information sheets for patients about their diagnoses. However, the former patients have also initiated an idea for a project which is concerned with the psychological impact of receiving a diagnosis of cancer. Folk.us suggested that Dr Rudin approach the University of Exeter's Doctorate in Clinical Psychology Programme to see if any students would be interested in taking up this research idea for their research project. We are delighted to report that the research idea has been taken up by a student. Folk.us is supporting the committee and student in practicing good involvement. The committee have been involved in the design of the research question as

well as the questionnaires for collecting the data and the Patient Information Sheet. The project has now received ethical approval from both the Local Research Ethics Committee and the University of Exeter and has met all the Research Governance requirements at the Royal Devon and Exeter NHS Foundation Trust. The project is about to start recruiting patients to participate in the study. The project title is: "Barriers to accessing psychological support for patients with haematological cancers". We are very pleased to be supporting this Committee and this project.

RiPfA (Research into Practice for Adults)

Folk.us was asked to present at the "Promoting User Engagement in Research" seminar in Bristol. We outlined our experience of involvement in research. We also invited a researcher and a service user to present on their experience of involvement and of working with Folk.us.

Practice Learning Manager Project - Social Work Degree Programme University of Plymouth

Folk.us was asked to assist with the initial stages of a research project looking into the role of the Practice Learning Manager within the new Social Work Degree programme at the University of Plymouth. The group undertaking the research is made up of service users from Social Care and staff from the Degree Programme at Plymouth. The Folk.us co-ordinator attended the initial meetings and with the support of the Folk.us Grant holder designed a draft proposal for the research for further discussion by the group. We understand that the project has now been developed and taken on by a researcher under the guidance of the group.

T.R.I.A.D.S Project (Torbay Representatives In Action for Drug Services)

T.R.I.A.D.S is a group of people who have experience of using drug services in the Torbay area. A worker from one of the services and a representative from TRIADS attended a Folk.us led workshop about involvement in research. The representative and worker asked for our support to design a project to collect data about the usage of crack cocaine in the South Devon area. Initial work on designing a protocol has taken place in partnership with the Exeter Research and Development Support Unit and Folk.us. Folk.us has also sought information on a similar project undertaken in partnership with former drug service users by MORI through their Participation Unit. In this project the service users undertook the collection of data and other research activities.

Due to changes in staffing the Devon project has not progressed much further but Folk.us is continuing to offer support and feels that this project

offers an opportunity to work with people that up to now Folk.us has not had much contact with.

A qualitative study of haemodialysis patients' perspectives on psychosocial support

This project has now finished and the findings have proved very useful to the Haemodialysis Unit at the Royal Devon and Exeter NHS Foundation Trust. The project involved the interviewing of ten patients who used the Haemodialysis Unit and the gathering of their views on what they felt was helpful to them.

The final analysis was undertaken by a Clinical Psychologist and was presented to the Unit's staff. A publication will be produced in due course.

The Peninsula Technology Assessment Group (PenTAG)

PenTAG is under contract to the NHS R&D Health Technology Assessment Programme to assess the effectiveness and cost effectiveness of health technologies. This involves synthesizing existing and new research through systematic reviews and decision analytic modelling in order to address major policy questions about the adoption of new drugs, devices, procedures and screening programmes in England and Wales. PenTAG currently produces two multiple technology assessments and six single technology assessments per year for high profile national policy making bodies. The major consumer is the National Institute for Health and Clinical Excellence (NICE).

PenTAG hosts the Value for Health Panel, a Department of Health funded evaluation of a new method to bring lay people's values to the forefront in modelling the cost utility of interventions. When the initial ideas for the project were being developed Folk.us advised and held a forum of Folk.us members to discuss the project. The contribution from Folk.us staff and members influenced the project that is now running.

Folk.us has also advised PenTAG on a research proposal to evaluate the cost-effectiveness of case finding for Hepatitis C in general practice. This project proposes that people are offered a test for Hepatitis C either by self testing or by attending the GP's Surgery. The proposal is currently being developed. Folk.us has offered some thoughts about how people might be involved on a steering group and how people might be contacted, we have also looked at the patient information sheet.

Folk.us members have also been involved on the advisory group developing a study for Acoustic Cueing Therapy Study (NDACTS) (Metronome Study). This is a study looking at the use of a metronome

as a possible intervention to help with some aspects of Parkinson's Disease. Folk.us staff have advised the researchers about involvement and members of the advisory group have attended a Folk.us training session.

SWARBIC (South West Association for Research into Brain Injury in Children)

SWARBIC is a university-based group of people involved in supporting research into childhood brain injury. Membership comprises university researchers, clinicians, and representatives from the charity and independent sectors who provide services in this area. The aim of the group is to raise the profile of need via research. Projects so far have included epidemiological studies; follow-up of social, emotional and cognitive functioning after brain injury; children's recognition of emotion following brain injury; and studies on Attention Deficit Hyperactivity Disorder and brain injury. Some intervention studies will be commencing in the near future. The group meet every 3-6 months at the School of Psychology, University of Exeter. Folk.us has attended one meeting and has held discussions and given advice about involvement in these potential proposals. Folk.us will continue to support this group.

Peninsula Primary Care Research Management & Governance Committee

The Peninsula Primary Care Research Management and Governance (RM&G) Unit was established in 2003 to provide RM&G service to the Primary Care Trusts across Devon and Cornwall. Folk.us has been a member of the Committee since 2005. The Unit is funded by the Department of Health to provide a centralised shared resource to handle administrative functions, the registration of research projects, conducting the associated checks and undertaking monitoring and auditing so that all research carried out within Devon and Cornwall is conducted in compliance with the Research Governance Framework for Health and Social Care. The Unit has undergone some changes related to the restructuring of the Primary Care Trusts. We are also delighted that the Research & Development Manager, Ms Pam de Clive Lowe, has joined the Folk.us Steering Group and the Unit's staff regularly attend Folk.us events. The Unit provides the central point of co-ordination, handling the research governance approval process for the four PCTs in Devon and Cornwall.

Royal Devon and Exeter NHS Foundation Trust Research Committee

Folk.us continues to support and be available to the Committee and we have met with new service user and patient members. We offer training sessions to service users and patients and all the clinical members of the Committee.

General Folk.us Information

Enquiries to Folk.us for the period of July 2006 – July 2007

Total number of enquiries: 102

Folk.us Publications: 3

Specific Research Enquiries 51

General information 17

Enquiries about training 31

Geographical areas of Enquiries:

Devon & Plymouth 62

Rest of UK 31

Unknown 9

Facilitating & Enabling Collaborative Research Activities related to Folk.us and its people

Folk.us Co-ordinator working with Twocan Associates has facilitated five workshops for the National Patient Safety Agency. All the workshops were for people who have experienced poor or damaging treatment through the NHS. Therefore the facilitation needed to be both independent and sensitive. Subjects raised at the workshops have included MRSA, hospital cleanliness, design of General Practice facilities and the services provided by the National Clinical Assessment Service.

The Folk.us Co-ordinator, with colleagues in the field of involvement, has also facilitated workshops for the Healthcare Commission, these have included workshops about maternity services for disabled women and the Voluntary Sector's views about Hospital inspections.

Networking

- Aims were: Hold three Folk.us Forums
- Produce 4 Folk.us Newsletters

Folk.us developed the Wake up to Folk.us day held in July 2006 in Ashburton to help establish the new structure of Folk.us. This day was very successful and included a wide range of service users and researchers. Approximately 40 people attended. The day included a presentation about Folk.us, how it is funded and run and what our activities are. During the day we asked people to think about the new Folk.us Steering Group, what it should do and who it should include. We were delighted that ten people from that day wanted to join the Steering

Group. Another presentation was given by Roger Steel from Involve outlining the changes in the way Research is organised and highlighting the new Clinical Research Networks, UKCRN and UKCRC.

Folk.us has now held three Steering Group meetings and all of them have been very helpful. The group has been instrumental in redesigning the Folk.us leaflet and coming up with a new strap line which is 'We need you to get involved to make research into health and social care relevant, radical and really, really useful'. The group are an invaluable source of information about what is happening in the region from a diverse range of perspectives. The Steering Group includes patients who have undertaken research, service users from a wide range of services, carers and carer representatives, research governance managers, research administrators, researchers from the Peninsula Research and Development Support Unit and lecturers from Universities of Exeter and Plymouth and Peninsula College of Medicine and Dentistry.

Folk.us Forums

The Critical Friend Report in September 2006 about the 'Role of Folk.us' was very useful and thought provoking with regard to our activities. This led Folk.us to have a critical look at the purpose and audience of our regular Forums. We approached Tom McAusland, Complaints Manager and Shared Service for Devon NHS Partnership Trust, who has been involved with Folk.us since its inception. Tom wrote a very helpful paper outlining the issues with the Forums and suggested different things the Forums could potentially achieve. When Folk.us began Forums were seen as an opportunity for issues to be raised and to inform Folk.us' work and activities. However, as Folk.us developed this has been less obvious, as the Forums attract a wide, varied and often transient audience which has meant there has been a lack of consistency. Following Tom's paper, Forums have been designed as stand-alone events which will attract different audiences who are interested in the particular topic or subject that each Forum addresses. This different approach to the Forums is complementary to the new Steering Group which has become the most appropriate place to inform our work.

In May 2007 Folk.us held a Forum about Participatory Appraisal research methods - this was the first forum we have held in Plymouth and the people who attended said they found it very informative.

Forums planned for September and December are on Patient Involvement in Clinical Trials and Patient Involvement in the development of treatment for people who are HIV Positive and those who have AIDS.

Involve Empowerment Sub-Group

Involve invited the Folk.us Coordinator to attend the Empowerment Sub-Group which feeds into the main Involve Group responsible for governing Involve's work. The members of the main Group of Involve are appointed by the Director of Research at the Department of Health and the posts are publicly advertised. The Folk.us Co-ordinator joined for an interim period after previous members had stood down and before the appointments of new members.

Folk.us Membership figures

Folk.us has 17 new members this year. Our figures are slightly below last year's numbers, however this is due to the database being completely updated and the figures reflect members who have moved posts or areas rather than a decline in interest about our work.

Total Members	272
Service Users	61
User-Representatives	35
Professionals	176

Clinical Networks and other Networks

During the negotiations for Folk.us' contract with the Department of Health in 2005, the Department explicitly stated that they expected Folk.us to work with the new Clinical Networks. However, the Networks would need to commission Folk.us to work with them as the DH saw our contract funding as separate and that it should not meet the costs of working with the networks. We were delighted to be commissioned by three local networks, Diabetes, Stroke and the Primary Care network, to help with their patient and public involvement.

Folk.us, in partnership with the South West Peninsula Diabetes Local Research Network, designed and delivered two patient days for people with diabetes. The days were an opportunity for patients to have a real voice in suggesting those subjects they felt research should address. One of the areas proposed was female sexual dysfunction and Type I diabetes and a collaboration was formed with a research midwife and some of the people from the workshop to submit a proposal to UK Diabetes CRN for funding to work this idea up into a grant proposal. A report of the experience is in Appendix 2.

Martin Lodemore from DRN (Diabetes Research Network) has said that Folk.us' knowledge and experience is helping to guide the DRN coordinating centre's patient and public involvement strategy as well as our local network. The DRN coordinating centre is now conducting a review of its patient and public involvement practices, which will include an assessment of the activities within the local research network centres. In an attempt to share good practice, it is hoped an internal guide will be produced with suggested methods of engaging with local communities, and initiating meaningful and effective involvement. The workshops conducted in our South West & Peninsula region will therefore contribute to the DRN's future patient and public involvement strategies across the network.

Folk.us is also working with the Primary Care Research Network South West. The network is establishing itself and Folk.us is on their advisory group.

Folk.us is also advising the South West Peninsula Stroke Research Network on ways of involving people and will be doing more with this network in the coming year. Potentially Folk.us will be facilitating some patient workshops for the Network.

The Folk.us Co-ordinator also met with Marianne Miles UKCRN in July 2006 to explain what Folk.us does and to hear how the UKCRN will be developing patient and public involvement. There was some discussion about whether Folk.us may pilot some generic Patient and Public Involvement activities relating to all the Networks on behalf of UKCRN.

The Folk.us Co-ordinator, in partnership with Twocan Associates, developed a proposal and has been commissioned to deliver training in public and patient involvement by UKCRN nationally. This training is offered to all the National and Local Clinical Research Networks and we have delivered two training days, one in London and one in Birmingham.

South West Participatory Appraisal (PA) Network

In 2001 Folk.us colleagues Dr Lisa Thorne and Annie Mitchell were instrumental in bringing PA to the South West, Dr Thorne encountered PA methods while researching 'Small Voices, Big Noises - Lay involvement in health research: lessons from other fields' (2001 Baxter, Thorne & Mitchell). Folk.us acted as the host for the first two training courses on PA held in Devon. The Network is an informal group and has new members joining regularly. In October 2006 Folk.us supported two evenings introducing a wide range of people to PA. Devon Social Services and Devon Partnership Trust providers are now developing

consultations and evaluations using PA methods with the help of the Network.

InvoNET

InvoNET is hosted by Involve and is a network of people from a variety of backgrounds, such as health and social care, academia, voluntary agencies, patients, service users and carers who are interested in working to build evidence, knowledge and learning about public involvement in NHS, public health and social care research. Folk.us staff and members have attended two events held by InvoNET. At these events Folk.us has raised its concern about the usefulness of a separate evidence base for involvement, as it could potentially reinforce the message that 'involvement' in research is unique and on its own, as opposed to the message that meaningful involvement should be strived for in all research within the Health and Social Care fields.

Target Access to Resources

- Aim: Attend national and local conferences and events as appropriate

Folk.us Roadshows

The Folk.us Roadshow is an idea being developed by the Folk.us Research Assistant. The aim is to raise awareness of both Folk.us and research within the general public who are using a variety of services including health and social care. The first roadshow was held at Derriford Hospital in Plymouth and involved a display which showed the story of a Folk.us member, who is a patient, as an example of involvement in research. The patient had come up with, and worked on, a research project alongside their local GP practice. The project led to two publications in the British Journal of General Practice, (Ruel, 2007 and Blake, Ruel, Seamark, & Seamark 2007). This was a project that was part funded by Folk.us. The Roadshow was hosted by the Folk.us Research Assistant and a member of the Folk.us Steering Group. Whilst we are keen to develop the idea further, as there was limited interest in the event we are mindful of the significant resource implications in running such events.

Involve Conference

Folk.us staff and members attended the Involve Conference held in September 2006. We were delighted that four projects we have assisted with and supported were presented to an international audience: **"Research ethics: what do you think?"**, Rachael Carrick, Trainee Clinical Psychologist, University of Exeter and L.T. Merwood, Service User Representative, **"Experiences of patients requiring strong opioid drugs for chronic non-cancer pain: a patient initiated study"** David Seamark, Lead Researcher General Practitioner, Sue Blake, Research Assistant, Brian Ruel, Patient and Clare Seamark, General Practitioner, The Honiton

Practice. **“User controlled research: building together on what we know and exploring next steps”**, Peter Beresford, Centre for Citizen Participation, Brunel University and Shaping Our Lives, Michael Turner, Shaping Our Lives. **Service user research and why it hurts** Patsy Staddon, Postgraduate Researcher, University of Plymouth Women's Independent Alcohol Support.

Conference Planning Group Involve:

Involve invited the Folk.us co-ordinator to be on the planning group for the Involve Conference in November 2008. The group's role is to give ideas and help to shape the content and themes of the Conference. We have attended two meetings and will continue to support the Conference.

Folk.us Website redevelopment:

We were delighted to be able to commission a service user with Myalgic Encephalomyelitis (ME) to redevelop our Folk.us Website which was in desperate need of an overhaul. It was a good arrangement as the costs involved have been very minor for a full redesign. Our service user was willing to undertake this project because he was learning web development and felt the Folk.us project was an ideal opportunity to hone his skills and get a feel for being in a working routine again. Early on we realised that there were problems with our old site, not least that it was using out of date software! The new site will be up and running by the end of September 2007. It has a fresh and clean look, we have edited the text considerably and there are hyperlinks to take people to different parts of the site. However, we believe that the site is easy to navigate and we are very pleased with the new website.

The current website still attracts a number of visitors.

Total number of visits 771

United Kingdom	597
United States	25
Europe	61
Canada	79
Rest of world or unknown	9

Cross-cutting themes

The Folk.us Co-ordinator attended the Disability Studies Conference – ‘Research and Learning’ in September 2006. Disability Emancipatory Research has pioneered many of the methods and principles we now use when involving people in research and this conference provided

many examples of topics that would not have been researched if it were not for service users and disabled people identifying their own research agenda.

The Folk.us Co-ordinator continues to be a member of the Joseph Rowntree Foundation Independent Living Research Reference Group. This group has no direct decision making powers but does advise the Foundation's Independent Living Research Committee who commissions all the research the Foundation undertakes in the Independent Living Programme. The Committee has been very appreciative of the comments and assessments the Reference Group has made in relation to the Programme. The Reference Group has commented on proposals and given feedback to research projects. The Independent Living Research Programme at JRF has commissioned approximately £700,000 of research over three years - a substantial amount is service user led and delivered research. By the end of the Programme the total spent including dissemination and publishing will be approaching £3/4 million. We are very pleased to be involved in the Programme.

Disability History Conference

The Folk.us Co-ordinator attended the Reassessing Disability: New Approaches to Disability History Conference hosted by the Peninsula College of Medicine and Dentistry. This was the inaugural conference and aimed to explore ways of 'doing' disability history and to debate the future of disability history as an academic discipline. This was a stimulating conference and Folk.us will be happy to assist the Disability History Group to think about and encourage a more active role for Disabled People themselves within the work the group undertakes.

Evaluation of 11 primary care projects

In 2005 the evaluation of whether service user or carer involvement had had any impact on 11 projects based in Primary Care in London was completed. The Project was commissioned by Involve and was undertaken by the Peninsula Medical School, employing two researchers, one of whom was a service user-researcher, and Folk.us. The summary of the project is available through Involve (2005 Barnard, Carter, Britten, Purtell, Wyatt, & Ellis). The overall findings of the evaluation have also been written for a peer-reviewed journal, again as a collaboration between Folk.us, the Medical School and the service user researcher. The article is currently being considered for publication by Family Practice.

Targets for Management and Probity

As outlined earlier in the report (page 9) we held a very successful 'Wake up to Folk.us' day.

The Executive Group has met 3 times this year and has regularly monitored our finances and approved the workplan for 2006 to 2008.

Critical Friend

Our Critical Friend has undertaken work on 'The Role of Folk.us' (Appendix 3). This report highlighted to us the need for our literature and website to be clearer and that we needed a new 'strap line'. All of these have now been achieved with the assistance of our Steering Group. Our Critical Friend also helped with the redevelopment of the Folk.us Training (Appendix 1). We have also designed a strategy based on the Critical Friend's findings for 'How we Prioritise Grants'. This is in response to Folk.us being asked to be involved with or a Co-applicant on grant proposals (Appendix 4). We felt it was important to have a strategy which was transparent about which proposals we would be co-applicants on, what Folk.us would offer and what we would ask for in return. Overall the Critical Friend has been a great asset to Folk.us and has helped to create clear thinking and design processes where they have been needed.

Folk.us Staff Appraisals

All Folk.us Staff have been appraised this year. Areas of further development have been discussed and further training has been sought if appropriate.

Key Folk.us people

Katrina Wyatt – Folk.us Grant holder and Principal Investigator

I have been involved in the design and submission of two major proposed pieces of research, both of which had considerable service user and carer input in the development of the proposal. The NCCHTA has awarded the Peninsula College of Medicine and Dentistry £1.2million to look at the natural history of lysosomal storage disorders and treatments over three years. We have held two days to work with the support groups for these disorders and will continue to work collaboratively with them on the outcomes of the study and the wider impacts on carers and families. The other grant is from the Cerebra Foundation to work in partnership with Cerebra and its members to answer the questions about interventions which they regard as being of key importance. The Cerebra Unit, based within Child Health, Peninsula

College of Medicine and Dentistry will work in partnership with service users and carers to address issues of importance for disabled children and their families; including asking the questions, designing the research, delivering the research and analyzing and disseminating the results. As well as being involved in Folk.us training I also teach on the Leading Improvement in the Peninsula Leadership programme, about the importance of participatory research and community regeneration. I have been fortunate enough to have three papers published this year and have submitted a fourth:

Durie R, Wyatt K. New communities, new relations: The impact of community organization on health outcomes. Soc Sci Med. 2007

Campbell B, Thomson H, Slater J, MB, Coward C, Wyatt KM, Sweeney K. Extracting information from hospital records: what patients think about consent. Quality and Safety in Health Care. 2007

Winder R, Richards S Wyatt K, Campbell C. Receiving specialist welfare benefit advice within Social Services: a qualitative interview study of older people and their carers. Research, Policy & Planning 2007

Wyatt KM, Britten N, Carter M, Mahiniti V, Barnard A, Hawton A. The impact of consumer involvement in research; an evaluation of consumer involvement in the London Primary Care Studies Programme. Family Practice Submitted June 2007

All of these papers involved consumers in the design of the research and all bar one in the delivery of the research project. One paper, Wyatt et al, has a service user as a co-author.

Andy Palmer Folk.us Executive Group Member

After my initial diagnosis I continued working for six years until Parkinson's Disease forced me into retirement from farming on 1st November 1996. At the time my father was in hospital, so it filled my time which made giving up a really busy farming career much easier with less time to think about what I used to be doing.

Since retiring from Farming I have become very busy with Parkinson's Disease (PD) care and support work, mainly going to meetings to try and improve Health and Social Care Services for all People with Parkinson's. I also attend meetings to represent the younger person with PD. This I feel achieves 2 aims, the first aim is I represent the interests of People with Parkinson's in all aspects of health and social care and secondly by attending these meetings it shows people how Parkinson's can affect a

person, in that they never see me portraying the same problems during different meetings, thus reinforcing the personal battle I have with Parkinson's Disease, which I think has been a major factor in getting the providers of services in Devon to look at the needs of People with Parkinson's Disease with a subjective outlook.

Meetings that I attend and organisations I belong to include: Devon Young Parkinson's Network that I'm the Lead for; Exeter Branch Parkinson's Disease Society where I'm the Health & Social Care Liaison Officer; Devon Primary Care Trust Patient and Public Involvement (PPI) Forum; Parkinson Disease Nurse Specialist Working group lead, I also represent the PPI Forum on 4 other Local Implementation Groups; also I am involved in Folk-us research groups, Executive Committee, and many more.

I truly believe that there is life after diagnosis with Parkinson's Disease, I have done so much since my initial diagnosis and feel that keeping active is the key to coping with the disease.

Annie Mitchell

By the time I left the Exeter DClin it had become the norm on the Programme for all Doctorate researchers to engage meaningfully with service users/ carers in the research process. Furthermore, Programme members who were external examiners for other Programmes nationally (eg Dr Christine Curle Dr Cath Haslam and myself,) are now pro-active in expecting user involvement in Doctorate research on other programmes around the country, thereby significantly influencing the national clinical psychology research culture. Since taking up post as Clinical Director for the Doctorate in Clinical Psychology at University of Plymouth, in partnership with Social Work I have been able to establish user and carer consultation to the Doctorate Programme with increased user involvement in research specified as one of four key areas for development, with a small amount of dedicated staff time to promote user involvement in training. All my papers submitted for the RAE exercise have been specifically identified within the Faculty as exemplars of user involvement in research. Nationally, I have been a member of an advisory group developing national guidelines on user involvement in clinical psychology training for the British Psychological Society. I am a member of the organising group for the annual UK Community Psychology Conference in York, with user and public involvement integral to the conference programme.

Annie Mitchell supervised Rachel Carrick's PhD; a Delphi study of service user's views on ethical issues in research. This has been satisfactorily completed and submitted for publication.

Rosemary Humphrey

My most interesting new work this year has been my role as one of the two lay members of the South East Coast Regional Funding Committee of the Research for Patient Benefit (RfPB) programme. This new programme, run by the National Institute for Health Research, has two lay members on each of its ten regional committees across England.

The work involves reviewing the proposals for funding projects in the region that will arise from daily practice in the NHS, with the potential to make a difference to health care or health care experiences. I feel welcomed at the committee and am able to make my views known. The (essential) PPI content of the bids is quite variable, with some excellent examples of user involvement but there are still many which lack understanding of what constitutes real involvement. In May I also attended a very useful workshop for all the lay members of RfPB committees.

I have continued my involvement with the Cochrane Skin Group, providing consumer peer review to two reviews. I remain a member of the Royal College of General Practitioners' Patient Partnership Group and represented it on the panel to choose the Research Paper of the Year. In the papers submitted this year there was disappointingly little evidence of user involvement in research.

Outcomes – 'What does Folk.us aim to achieve?'

Given the size and resources of Folk.us we feel we have achieved our aims, listed here, to the highest standards and the best of our ability over the last year.

- Further develop and support a network that covers Devon, including Plymouth, bringing together knowledge and expertise about involving people in research.

We have held training activities, Folk.us Forums and have worked with research projects in Plymouth. We are now actively working with the three Clinical Networks which cover the South West Peninsula. Our Steering Group has members from across Devon.

- To develop an environment where high quality and rigorous research undertaken in the South West Peninsula is developed in partnership with patients, service users and carers.

We have run and facilitated a number of events, Training, Forums and Patient Days that bring together service users, patients and clinicians and researcher from both academia and the NHS, where partnership working is put into practice and ideas and issues are debated from each point of view.

- To support partner organisations to develop grants where the proposed research has been initiated by patients, service users and/or carers, using the Folk.us criteria to assess the projects.

As the RfPB Programme develops there will be more opportunity for active involvement in these activities. There has also been some success within the new networks who we are encouraging to have specific resources available, or to seek resources to specifically fund patient initiated research ideas.

- To develop a context within Devon, including Plymouth, where research is no longer seen as something that is 'done to' people but is 'done with' people that use health and social services.

This remains ongoing and is a central theme throughout all our activities, we have explicitly explained to the networks some of our reasons for the way in which we work.

- To facilitate meaningful involvement to ensure that service users, patients and carers feel confident about their involvement in research.

This is being achieved through our proactive training and support of individuals by working with research projects, and through people's involvement in our Steering Group.

- To facilitate meaningful involvement to enable service providers, researchers, and practitioners to feel confident about involving people in research.

Many of our activities have been for mixed audiences, which we feel has enabled people to be less nervous about involvement. We also continue to support individual researchers and service users, patients or carers involved with research projects.

- To produce Peninsula wide criteria for assessing service user, patient and carer involvement in research proposals to support the Research Governance process.

We have started to develop of our own strategy for making decisions about being a Co-applicant on grant proposals. We shall develop this further into generic criteria.

- To reflect on, and learn from, sessions with a Critical Friend to enable continuous development of Folk.us' activities.

The Critical Friend has proved to be invaluable in helping us identify the issues in our selected areas for reflection and development. They have also facilitated our discussions ensuring we have arrived at workable and real solutions.

- To disseminate the work of Folk.us widely and in appropriate formats through Folk.us newsletters, conferences, workshops and written documents including publications in appropriate journals.

We are still preparing a paper that will be a synthesis of our learning from the projects we have supported financially. The paper will also include what processes we have in place that would have been helpful while we were supporting these projects.

It is anticipated that the new Steering Group members will also be actively involved in disseminating information about Folk.us

- Continue to record enquiries and website visits and monitor the site's usefulness.

This is ongoing and we will see if there is any significant change in figures where the new site is up and running.

- Continue to collect feedback from all training events.

We have collected feedback from the majority of our events and have made alterations where suggested. However in general the feedback has been very positive and the main comments have been about where breaks should occur in the day and more generally that more people need to hear what our training contains.

- Report annually to the NCCRCD

This is our Annual Report for 2006-2007

Conclusion

We feel that this last year has been a very productive year for Folk.us, which is hopefully evident from this Annual Report. The structures that support and provide governance for Folk.us are working very well and are allowing us to adapt and respond to the changing NHS and Social Care research structures very effectively.

Similarly our ongoing work with the Folk.us Critical Friend has been central in allowing us to reflect on whether and how we are meeting our aims and objectives and in the further development of Folk.us.

We have developed and delivered three new training packages across our geographical area. The new structure of the training which sees service users, patients and carers, sharing lunch with academics and NHS and social care research staff appears to be very successful in promoting collaboration.

It appears that our role advising on, and supporting involvement remains very much needed by the research community, both locally, and more widely with the new clinical networks. We are being asked more and more to support, advise and assist with South West Peninsula wide research proposals and projects. The creation of more local Clinical Research Networks, all of whom have a remit for meaningful involvement, means we anticipate that the demands on Folk.us will grow. Whilst this is a very welcome development, we are mindful that we need to achieve the right balance in supporting these new developments and remaining able to respond to local research projects and networks.

This concludes our report for 2006-2007. We would like to thank all our members and everyone who has given their time and energy to Folk.us this year. It is a privilege to work with, support and be supported by our members all of whom make Folk.us what it is.

Rachel Purtell – Folk.us Co-ordinator
Katrina Wyatt – Folk.us Grant Holder

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Folk.us Finances

The report shows an 'overspend' to date of £7,638.79. This includes the TOTAL COST of the activity and ONLY the Department of Health funding. In fact, an additional £17,250 of cash has been raised from other sources over the period of this funding therefore the true position as at 31 May 2007 is a cash balance in hand of £9,611.21.

Folk.us Finances

National Co-ordinating Centre for Research Capacity Development

Infrastructure: Annual Report Financial Statement

Reporting Year: 2006/07

Name of Institution: University of Exeter - Peninsula College of Medicine and Dentistry
NCCRC D Reference: ZRC/002/002/023
Your Reference: 2806 M1156A

Reporting Period: 1st June 2006 - 31st May 2007

Contract Start Date: **Contract End Date:** 31st March 2008

Section A: Summary

Actual Income Received from NCCRC D	65,000.00
Actual Expenditure	67,089.22
Carried Forward from Previous Year	-5,549.57
Over/Underspend	-7,638.79

Section B: Salaries

Name	Job Title	Scale	Salary Point	WTE	Contract Status	Salary Cost
K Wyatt	Senior Research Fellow	G	43	10%	Left 2/9/05	4,224.62
R Purtell	Co-ordinator	F	36	80%		30,470.85
H James	Research Assistant					0.00
D Davies	Research Assistant	E	24	50%		12,968.92

Salaries Sub Total

47,664.39

Indirect costs @ 20% on £47,664.39

9,532.87

Section C: Expenses

Consumables	2,401.43
Travel	2,415.49
Support Users and Consultancy	1,137.50
Staff Training	0.00
Meetings	1,603.45
Website costs	519.76
"Critical Friend"	1,814.33
Expenses Sub Total	9,891.96

Section D: Equipment

Equipment

Equipment Sub Total

0.00

GRAND TOTAL

67,089.22

Section E: Declaration

i. Finance Office or Research Support Office

I certify that the above statement of expenditure is a true and accurate record of the amounts expended for the sole purpose of this Contract and in accordance with the conditions set out in the Contract.

Signed: Name (print): Catherine Serjeant

Date: 29th August 2007 Position: Research Accountant

ii. Host Institution Authorised Signatory

I certify that the above has been agreed and approved by an authorised signatory of the host institution.

Signed: Name (print):

Date: Position:

Section F

FOR NCCRCD USE ONLY -

Notes:

Statement Checked By: _____ Date: _____

Statement Authorised By: _____ Date: _____

Folk.us training strategy

1. What do we mean by training?

- 1.1 In this paper, we've seen training as the delivery of structured sessions to help people develop their skills in and/or knowledge of involvement in research.

2. Why do we offer training?

- 2.1 Folk.us has offered informal training since its inception. In 2001 the coordinator (RP) and lecturer at the RDSU (KW) developed a more structured training programme. Training serves to raise awareness about Folk.us and its role, and to tell people something about user involvement in research and enhance a culture of user involvement.
- 2.2 During the course of Folk.us's existence, training has been both responsive – delivered at the request of others (such as the RDSU), and proactive – developed and offered by Folk.us (for example 'Your services and Research' sessions funded by the grant from The Health Foundation).

3. What kind of training do we currently offer?

- 3.1 Currently the majority of the training Folk.us delivers is responsive. Broadly, two types of training session are offered – one primarily (but not exclusively) for researchers and clinicians, and one primarily for service users and carers.

3.2 *Training aimed primarily at researchers and clinicians*

Three training sessions per year are delivered at the request of the Peninsula RDSU, in Exeter, Plymouth and Cornwall (Truro). These sessions cover what user involvement in research is and what the key issues are. There is an emphasis on the importance of building relationships, with projects that Folk.us has been involved with being used as examples.

The sessions usually last about 40 minutes, and are structured through a PowerPoint presentation, interspersed with questions and discussion. Rachel and Katrina developed these sessions and deliver them together. This seems to work well - the collaboration between researchers and service users that we want to encourage is modelled through Katrina (as a research academic) and Rachel (as a service user) working together.

These sessions are primarily attended by researchers and clinicians working in the NHS or Health related services and institutions, although service users are welcome to attend.

3.3 Training aimed primarily at service users and carers

Training has also been developed which is aimed primarily at service users and carers. This training explains what research is and why it is important, looks at the different types of research approaches and what involvement is. These sessions are usually longer (about 2 hours). They are more participatory, with small group discussion as well as presentations. They're also more responsive – the content can be changed in response to the expressed needs of those who attend.

This training was developed by Rachel and Katrina, and is delivered by them. The most recent example of this type of training is the session offered to people affected by Type 2 diabetes, who are interested in getting involved in the new local Diabetes Clinical Research Network.

4. How is the training evaluated?

4.1 Currently Folk.us evaluates the training using evaluation forms. For the Peninsula RDSU training, the standard RDSU form is used. This asks about educational value of the session, organisation of session and general satisfaction. For other training, a simple evaluation form developed by Folk.us is used. This asks questions such as what people most liked about the session, and what could have been improved.

4.2 The training Folk.us offers currently is well received, although the evaluation forms can only show people's views about the training – not about what impact the training has had. Katrina and Rachel judge success not just through the evaluation forms, but also by whether people choose to get involved with Folk.us after the session, for example through asking to receive the newsletter, taking part in a collaborative project, asking Folk.us for more help etc.

5. What does Folk.us want from training in the future?

5.1 It's important that any training offered by Folk.us helps to achieve the overall aims and objectives of Folk.us, and complements other areas of work. The aim of Folk.us is to *'work to support and develop patient, service user and carer involvement in health and social care research activities to ensure that those who use services and those who care for those who use services inform and guide research at all stages'* (taken from the funding proposal to the Department of Health). The key targets

for Folk.us over the rest of this funding period (Dec 2006 to March 2008) are:

- To work across a wider geographical area
- To work closely with 6 research projects
- To deliver at least 3 training sessions per year
- To work with the new clinical research networks, and especially with the 3 networks that have given us funding to work with them

5.2 Training to date has already helped Folk.us to achieve some of these targets:

- Folk.us has delivered training sessions through the RDSU in Exeter, Plymouth and Truro
- Folk.us has already run 11 training sessions in this funding period
- Folk.us has run an introductory workshop for people affected by Type 2 diabetes. A similar event for people with Type 1 diabetes will be delivered in February

5.3 Folk.us would like to have a more proactive approach to training for the remainder of this funding period, in order plan resources more effectively and hopefully reach more people.

6. What kind of training would Folk.us like to offer?

6.1 Over the next 15 months Folk.us would like to offer three different types of training:

- a) A 'basic' training similar to what is currently delivered (outlined in section 3.3 above). This training will continue to be aimed primarily at service users and carers, but will be open to researchers or clinicians if they feel this would be useful.
- b) Shorter, more concise sessions about involvement in research, again as is currently run through the RDSU (see section 3.2 above). Although Folk.us anticipates that researchers and clinicians are the primary audience for this training, it could also be attended by service users and carers who feel they already have an understanding of research.
- c) Folk.us proposes to develop a new session which will be aimed at groups of researchers and service users who are working together – for example a research network steering group. This training would focus on what involvement is, what good practice looks like and how you might check you are working together well. The new Local Clinical Research Networks steering groups would currently be the primary audience for this type of training.

7. Why these types of training?

7.1 Folk.us feels that offering these three different types of training will help them to meet their targets. For example, working with the new local Clinical Research Stroke Network, Folk.us can offer a session for stroke survivors and those close to them based on the 'basic' session offered currently. They could then offer a session for the Stroke Network Steering Group (which includes some stroke survivors) to help them to think about how they will work effectively together.

8. Who should deliver this training?

8.1 Folk.us suggests two people act as facilitators at all training sessions. Folk.us would like Dawn to be able to offer training in addition to Rachel and Katrina, so that there is a pool of three potential trainers rather than two. At this stage Folk.us does not think they need to ask anyone else to provide training. It was considered as an option but ruled out for two key reasons:

- Training offers a major opportunity for Folk.us to build relationships with service users, researchers, clinicians and others. It seems sensible for those most employed with Folk.us to offer this training
- Folk.us wants to be sure that the standard of training offered by them remains high. At this stage it seems more effective to keep the number of trainers small than to explore ways to monitoring quality. If others were to offer training, a further package of training would need to be developed to allow training the trainers. This could take more time than delivering the training themselves.

8.2 However, Folk.us is aware of the need to bring in additional people who have expertise in communicating with specific groups to help deliver some training. For example, some stroke survivors have problems with speech, memory and/or understanding. Folk.us would want to work with organisations that have expertise in the area of communication to support the training offered to stroke survivors.

9. When should the training be offered?

9.1 Folk.us proposes developing a training programme, which could be publicised at the planned roadshows a package that can be taken to a range of venues, for a presentation to various audiences indicating the possibilities that exist for people to get involved in or initiate research, as well as through the website and in other ways. This last sentence doesn't make sense! The programme would consist of:

- The three sessions currently offered through the RDSU in Exeter, Plymouth and Truro
- More 'basic' sessions in Plymouth and Exeter about two months after the RDSU sessions. These sessions could be publicised at the RDSU training, so that any researchers who involve service users as a result of the RDSU training could then suggest they may like to attend this later training.

9.2 We also propose to offer any of the three types of training outlined in section 6.1 in response to requests free of charge within Devon and Plymouth. Outside of this area Folk.us would need to negotiate fees. .

10. How could this training be evaluated?

10.1 There doesn't seem to be a cost effective way of evaluating the *impact* of training. It is suggested that Folk.us continues to ask people to complete evaluation forms, so that they have some knowledge of what people think of the training sessions. In addition, they would like to explore asking people who come to the basic sessions (because these are longer) about why they came at the beginning of the session, and then to ask them to revisit their reasons at the end of the day.

11. Identifying other training needs

11.1 Folk.us is aware that some people who develop an interest in user involvement in research (both service users and researchers) may want to continue their learning. At this stage, however, Folk.us does not feel it's appropriate to offer these people further training through Folk.us. Instead, they would like to develop and reinvigorate the Forums as an opportunity for shared learning (this is in line with the suggestion made by Tom McAusland's paper 'A funny thing happened on the way to Folk.us?'). This would involve:

- Asking people what they'd like to learn more about
- Putting together a programme of forum sessions based on these issues, where people could share what they know as well as hearing from someone with experience in this area.

12. What needs to be done to make all this happen?

12.1 If the Executive Group agrees with these proposals, Folk.us will need to:

- Make some changes to the 'basic' training session
- Make very minor changes to the session offered through the RDSU

- Agree dates for both of these types of sessions and publicise these
- Develop the training for groups on working together. Dawn, Rachel and Katrina will develop this, as all three should be able to offer it. They may work with someone who would be a potential recipient of this training, to make sure they've got the content right
- Get an agreement from the research networks that this training should be offered to steering groups.

Bec Hanley

In Discussion with: Dawn Fox-Davies, Rachel Purtell, Katrina Wyatt
January 2007



**Folk.us report reflecting on the
workshops held for
People with Diabetes (Type 1 and Type 2)
Commissioned by the Peninsula Diabetes Local
Research Network**

**Dr Katrina Wyatt
Rachel Purtell - MA
of Folk.us**

Revised 22nd March 2007

Contents:

	Page
Executive Summary	1
Introduction	2
Summary and explanation	3
Points to consider	8
Working with Folk.us	9
Overall view of the process	9

Executive Summary

Folk.us is a Department of Health funded research Programme to develop and support the involvement of Service Users, Patients and Carers in research to enhance a change in culture.

Folk.us is delighted to be working with the Peninsula Diabetes Local Research Network (DRN) to support the meaningful involvement of people with diabetes in the network.

Folk.us assisted with the workshop for people with Type 1 diabetes and the workshop for people with Type 2 diabetes.

Each workshop had a similar format, the content of the workshops was negotiated with the DRN prior to the event to create a positive involvement day.

Both workshops were attended by people with diabetes, clinicians involved in the Network and the Network manager and administrator.

People with diabetes attending the workshops appeared to be enthusiastic about the prospect of being involved in the Network and everyone who attended appeared to be engaged through out the day.

Suggestions for areas of research from both workshops had considerable overlap, suggesting that a future event that includes people with Type 1 and Type 2 diabetes might be appropriate.

Feedback from people attending revealed that they found the event informative and enjoyable. The only criticism was that the morning of the second workshop was a little long.

Folk.us recommends building on this initial engagement process and developing structures and processes for ongoing involvement as the Network develops. This would include a constant process of checking with people with diabetes as to whether the process of involvement and the structures of the Network are working well to support involvement.

Introduction

Folk.us is a research programme funded by NCCRCD which aims to change the research culture of the NHS and Social Care in Devon to support the meaningful involvement of patients, service users and carers in research.

The Diabetes Research Network (DRN) for the South West Peninsula was created in 2006 and Folk.us is cited in the funded proposal as the organisation to assist with service user and patient involvement in the Network's activities. It is worth noting that while it is part of Folk.us's role to advise and support such involvement, it was *not* involved with the design of the proposal and hence did not comment on the financial arrangements to support involvement.

Folk.us was asked to assist with an initial workshop, held in November 2006 and then a second one held in February 2007. The first workshop was aimed at people with type 2 diabetes and the second workshop was for people with type 1 diabetes. Some of the people are already involved in the Management committee of the Diabetes Research Network for the South West Peninsula.

Folk.us has now developed an acute sense of what works in creating the conditions for patient, service user and carer involvement in research. Having reflected on our experience we used our knowledge to inform the design of the workshops for the Diabetes Research Network in order to create a positive involvement event.

Summary and Explanation of Event

Given the importance of creating an environment where people feel comfortable to talk and raise issues - Folk.us negotiated with the DRN before the first workshop as to the layout of the day. We felt that the initial suggestion of asking people to prioritise research areas for the network could be seen as daunting and pre-supposed that people have a certain level of knowledge about research and about the extent to which they would want to be involved. This approach would not allow sufficient time for people to discuss their own experiences and draw out important issues. Instead it would mean that people were given a set of issues to which the Network had considered to be important rather than service user or patients. Therefore it was agreed that we would explain Folk.us experiences of involvement and facilitate any discussions about research and research ideas that people attending were interested in. The same structure was used for the second workshop as the feedback from the first workshop suggested this format was successful.

The programme for the two workshops put into practice what we see as the principles for meaningful involvement.

Both workshops started with an explanation by Rosemary Sowden, the Network Manager about what the Network is and what it is for. The first workshop did not include a clinical lead during the morning, in the second one a clinical lead was there for the initial explanation about the network and then left and returned to lead the afternoon session.

The first part of the morning was to establish the first principle of involvement, which is to be clear about what the project is. However, whilst clarity is important, the point is not to curtail the depth and breadth of people's involvement in terms of what they wish to think about or comment on. This was slightly skewed in the second workshop as during the first part when the function of the network was being explained, the clinical lead commented that the structures of the network were set and it was the content which people were being asked to comment on. Folk.us responded to this comment by pointing out that structures may need to change to make good involvement possible and that people must comment on these structures if they felt they may not be working well during the network's development, otherwise the network will not be able to sustain good involvement.

Following the introduction about the Network, we did a presentation about Folk.us and explained what we see as the principles of involvement in research. Firstly we explained that when we talk about

‘involvement’ we do not mean being a ‘participant’ (or what some people might still think of as being a ‘subject’ of research). Service user involvement in research is about a process which allows and supports service users, patients and carers to be a ‘research partner’. The principles of involvement here are about power sharing and forming relationships. Involvement in research requires a different kind of relationship from that of the consulting room. That is not to say that the consulting room dynamic is not appropriate in that setting, but involvement is about a different dynamic. It is about expertise coming from service users and patients to work in partnership with the expertise of clinicians and researchers to create good collaborative research. One way of developing this type of relationship is by encouraging service users and patients to ask questions about research. To exercise this point throughout the morning sessions we encouraged the people attending the workshop to ask questions of us and to consider questions for the clinical leads who would be present in the afternoon sessions.

During our session we explained some of the activities Folk.us undertakes and described where service users and patients can be involved in the different stages of a piece of research. In our experience these stages are:

- suggesting a research idea
- developing ideas into a question
- designing the project
- collecting the results
- interpreting the results
- disseminating the findings

It is our belief that involvement is a process that takes time and it is unrealistic to expect people to be able to engage in setting a question or deciding on research priorities in one afternoon. This was supported by a comment made in the afternoon of the second workshop, when one of the participants commented that they felt research priorities and research questions could not be decided on during a single afternoon. A similar comment was on the written feedback from that session:

“Needed more time to discuss research priorities. Quite a lot squeezed into the afternoon. I think we identified wide ranging issues, that needed more time to unpick. Was a useful starting point though.”

We think that diagram 1 is a simple and accurate way to explain the difference between the journey of patients and service users in the research process, compared to that of clinicians or researchers. In our

view this also explains, for the main part, why research priorities cannot be established in one afternoon.

It is important to understand that these events are not 'Focus Groups' where people were asked to discuss research issues, rather these events were part of a process where service users and patients offer their experiences and thoughts in partnership to create research, not as evidence to be analysed and scrutinised. Most crucially decisions about what to do with the views expressed during the workshop are taken jointly between service users, patients and clinicians and researchers. Therefore the information is not 'owned' solely by the researchers, which again is different to information gathered during a focus group. Also issues of who is 'representative' do not apply in the way they would if the process was about finding a 'sample' to take part. Whilst it is important to think about who might have useful and helpful experiences to contribute, a further principle of involvement when inviting people to work in partnership with researchers and clinicians, is to think about how those people are going to be supported and what help is to be offered to assist them.

Our plan had been to include in our Folk.us presentation some information about clinical trials, but during the first workshop it became obvious that many people attending the workshop were aware of the concept of clinical trials and indeed, some were taking part in clinical trials. So when we were asked 'what are we [people with diabetes] doing here?' by a patient attending the workshop, we felt it was appropriate to stop our presentation and facilitate a general discussion about what issues concerning diabetes really mattered to the people there. In the second workshop there was some discussion about what research is and what it is for, but we delivered the full presentation as people seemed to be happy to continue. This highlighted another key point about involvement which is, there is no one way to involve people. The actual process of involvement should be designed and negotiated with service users and patients throughout the lifespan of the project or activity. This requires a flexible and responsive approach which we consider to be paramount to achieving good involvement. The success of this approach was shown very clearly as everyone who attended raised issues and contributed to the general discussion.

We feel that our approach of recognising the importance of giving people time is a correct one, and was evident in comments made on the feedback forms received after the events:

“useful and interesting to meet other diabetics and to hear their experience.”

“I found the session extremely interesting mainly because of the experiences of other type II Participants. I could relate some of my own previous unexplained symptoms.”

“Good Structure to the day’s event/meeting”

“Lots of opportunity, for group discussion”

“Good discussion, sharing experience”

The afternoon of the first event was a general discussion with Dr Phil Evans which Folk.us was not involved with. We felt it was important to show that good involvement is the relationship between those who have responsibility for decisions and those who are affected by those decisions and not between a third party, even though the third party's role in creating the circumstances and environment for good involvement may be essential. Appendix 2 shows notes of the afternoon session from Dr Phil Evans.

In the afternoon of the second workshop, a discussion was chaired by Andrew Hattersley which Folk.us had been asked to stay for. The discussion was interesting, but possibly too focussed on obtaining a coherent list of research priorities from the people present as it began by asking everyone to give a single research area. Many of the individual issues raised were important to everyone present. One area raised by someone provoked a round of applause which would signal an important issue in everyone’s view.

Further discussion about why each different topic was important, may have led to an understanding that although some issues seem to be very different, the concerns at the centre of each topic may be quite similar, if there was sufficient time to ‘unpick’ them. This in turn can lead to a more encompassing understanding of that topic.

Overall the feedback from people attending the workshops was very good. When people were invited to comment on 'what was not so good', the only comments were that the morning session was a little too long.

The notes of the issues raised on the day are available from the Network Office.

Points to Consider

The Network should consider how it will respond to those who are willing to get involved further and how the issues raised by service users and patients will be heard by those in decision-making roles within the Network. There also should be some thought given to how this process is supported as an ongoing process.

It may well be appropriate when working on research projects that are specific to people with either Type 1 or Type 2 diabetes to have separate processes. However, there were many issues that were raised at the two events and were shared between people with Type 1 and Type 2 diabetes. It is important to remain aware of these common issues, so each group is not isolated because they appear to have little in common clinically. Moreover, a shared perspective may well lead to more rounded and more coherent research topics and projects. We feel that it is very important to remember that the Diabetes Research Network South West Peninsula is not a Type 1 or Type 2 research network, it is a Diabetes Research Network with an overall aim to encourage people to have confidence in all the research that the Network is involved in. Therefore Folk.us believes it is important that some generic activities are supported by the Network. We would suggest that the Network will only know if it is useful to bring people with Type 1 diabetes together with people with Type 2 diabetes by trying it, otherwise it remains a decision imposed on people by the Network.

Working with Folk.us

Folk.us is delighted to be working with the new Clinical Networks. To ensure a good working relationship we would ask that the following points are observed.

- Folk.us sees all materials and literature which have our Folk.us Logo on before they are sent out.
- Any events which Folk.us is asked to facilitate will give at least one month's notice to patients and service users who are invited to attend.
- Any administration relating to these events, including note taking, room booking etc is handled by the Network's administration office.
- There is clear agreement of funding for each activity Folk.us is involved with.
- Folk.us is informed of the arrangements to support service users and patients prior to activities e.g. how travel expenses will be paid, what people may expect to receive after an activity.

Overall view of the process

The success of any event to involve people, in our view, can only be commented on by those whose involvement is being sought and those who are seeking the involvement, that is to say in this case, the people with diabetes who attend the events and the Network representatives. From a Folk.us perspective, we felt these two events were successful in starting a dialogue with people who have diabetes and that the design of the events was facilitative to people contributing a great deal about the topics and subjects that really mattered to them.

It is our feeling that the people who attended these events would be very pleased to contribute further to this process. It is how this process is continued and developed that we believe will be where success can be judged.

What is the role of Folk.us? Discussion paper for the Folk.us Executive Group 12th September 2006

1. Introduction

1.1 I agreed to write a discussion paper for the Folk.us Executive Group on the role of Folk.us. The aim of this paper is to provoke discussion, and to help you to think more clearly about what the role of Folk.us should be, given the change in geographical coverage as well as the changes in the NHS R&D structures (and NHS structures more broadly).

1.2 I've structured this paper as follows:

- What's the role of Folk.us according to your contract?
- How does Folk.us describe its role?
- What are the views of some other people about the role of Folk.us?
- My reflections
- Some questions for discussion

2. The role of Folk.us according to your contract

2.1 It seems that you're still working to the original 2000 contract, which required you to: *'create a research culture which is meaningfully controlled/influenced by those who use, or care for those who use, services so that research and implementation is focused on ordinary folks' real concerns in North and East Devon.'*

2.2 In your proposal for extension of contract, you state that you will *'work to support and develop patient, service user and carer involvement in health and social care research activities to ensure that those who use services and those who care for those who use services inform and guide research at all stages.'*

2.3 In this proposal, you describe how the role of Folk.us has changed since its inception in 2000. In particular, Folk.us has:

- Created an enquiry service
- Developed training sessions
- Offered practical support to local research projects and developed information and policies about involving people

2.4 You clearly outline your plans for the funding period – both what you want to achieve and how you will do it. You describe your role as:

- Training
- Facilitating and enabling collaborative research
- Networking
- Providing access to resources

2.5 You describe additional ‘cross cutting themes’, for example producing policies about service user and carer involvement in research.

3. How does Folk.us describe its role to the outside world?

3.1 On your website, you describe the role of Folk.us as follows:

Folk.us is a Department of Health funded initiative, which was established to facilitate and promote meaningful and effective service user, patient and carer involvement, in all types of research relating to health and social care in North and East Devon....

*We provide practical support and assistance with involving service users and carers in research projects;
We develop guidance and policies about involvement in research; and
We provide training for service users and carers, and researchers, within local NHS and academic establishments.
We bring together service users, carers, researchers and practitioners to meet informally to share experiences and knowledge.*

Folk.us works with both national and local organisations... Folk.us works with Social Service organisations to build patient carer and service user involvement.

Folk.us runs workshops for service users and carers... We offer one-to-one advice and ongoing support for service users and carers with research as well as advice for health and social care professionals to assist with engaging users and carers in their research.

4. Views of some Folk.us ‘stakeholders’ about the role of Folk.us

4.1 At the ‘wake up to Folk.us’ event, I asked a number of people what they felt the role of Folk.us is, or what role they think it should have. There were a number of themes:

4.2 Folk.us is doing a good job
People were enthusiastic about what Folk.us does now. The things people liked included the fact that Folk.us is very friendly and approachable - for researchers, health and social care professionals and service users. This means that people feel they can recommend Folk.us to others with confidence.

4.3 It's hard to describe what Folk.us does
Although people were very enthusiastic about Folk.us, they found it very hard to explain what they think Folk.us actually does.

4.4 Folk.us as advice and information giver to service users and the public in general

Folk.us was seen as having a role to give advice and information about funding, as well as offering support for service users who want to undertake research. You were also seen as having a role to raise the profile of research amongst the 'general public', and especially to offer people who have been approached about getting involved in research advice and information.

Some people also saw Folk.us as having a role in telling people about the results of research, and of involving people in dissemination and implementation.

The role of Folk.us as capacity builder was seen to be important – this means Folk.us supporting service users and carers to have more of a say in research

4.5 Folk.us as advisor, information giver and influencer within the research community
Folk.us was seen as having an important role in promoting user involvement to researchers – and hopefully thereby promoting a culture of user involvement in the NHS that spreads beyond research. It was seen to be important to encourage researchers to involve service users at as early a stage in the research process as possible.

Folk.us was seen as having a role to give specific advice to help researchers get projects in which users are actively involved through ethics committees

People asked Folk.us to take a more active role in several areas:

- Promoting user involvement in research in the NHS beyond primary care
- Raising the profile of user involvement in research – perhaps by giving people practical examples of what can be done
- Promoting user involvement in research undertaken by medical doctors who undertake research.

4.6 Who is Folk.us?

A number of people were very clear that although Rachel is the main public face of Folk.us, the organisation is bigger than Rachel. Some people wanted to think about how Folk.us could use other people's expertise to 'spread the word'.

5. My reflections

5.1 Whilst you have been clear about what you want to do over the course of this funding period, it's unclear whether you're contractually obliged to do this. This is a complete technicality unless someone in authority wanted to challenge how you're setting out to achieve your aims.

5.2 I was struck by the fact that people who were obvious Folk.us enthusiasts found it hard to explain what Folk.us does, and what it's there for. I don't think this is anyone's fault – it's hard to explain, and even if you're an enthusiast, you've got lots of other things that take your time and attention. However, I do think there is merit in agreeing a short description of what the role of Folk.us is (is it the one on the website?) and always using this - in talks, leaflets, publications, at the beginning of training sessions.

5.3 The aims of Folk.us are very broad and it would be possible to focus on only one area and still feel you hadn't done enough. For example, you could spend all your time trying to promote user and carer involvement in social care research. The proposal seems a very helpful document in being clear about what you want to do, and when you want to do it. Is your new structure enabling you to effectively monitor progress against this work plan? What happens if new priorities arise? Who decides they are priorities? Can a group that meets rarely take on this role effectively?

5.4 Perhaps because the aims of Folk.us are broad, people have very wide ranging expectations of what Folk.us is or should be doing. So again there's potential for unmet expectations. Can you tell people about what your priorities are more clearly, without stifling potential for innovation and new developments?

6. Some questions for discussion

- What do you think the role of Folk.us is? Can you summarise it into a user friendly paragraph?
 - Who knows about what's in your work plan? How can you tell more people about it?
 - How can you do this whilst at the same time encouraging people to come to you with new ideas? If this is what you want?
 - Are you managing to effectively monitor progress against your work plan?
 - How can you harness the enthusiasm of others to take forward Folk.us's work?
- And to help me work in a way that's best for you: Was this the kind of paper you wanted? Did it address what you wanted it to?

Bec Hanley
August 2006

When should Folk.us agree to be named as an applicant for a research grant? Some suggested criteria

Background

Folk.us is often approached by researchers who want Folk.us to be named on an application for research funding. At the moment there are no clear written criteria about which projects to agree to work with, nor about who should make this decision. So I've worked with Rachel, Katrina and Dawn to draw up some draft criteria, a suggested process for using these, and listed what researchers can expect if Folk.us is named as an applicant.

Note that these criteria are not intended to be used to make decisions about which projects Folk.us might support in other ways (for example by giving advice about service user involvement), or which other areas of work Folk.us may get involved in (for example research committees).

What should the process for making a decision about whether to spend time discussing an application be?

If Katrina, Dawn or Rachel is approached by researchers with a request that Folk.us is named on a grant application, they should first ask two 'screening' questions:

1. Are you near to the beginning of the grant application process?
2. Are you within Folk.us's geographical area, or does your research have a study area within our geographical area? If not, will your project contribute to the evidence base about user involvement in research?

These questions should filter out applications which are complete but where researchers are looking for a Folk.us 'rubber stamp', and projects which are outside Folk.us's remit.

Suggested criteria for Folk.us becoming part of a research grant application

If the answers to the two screening questions are 'yes', the Folk.us team can then spend more time with researchers, to see if they and their grant application meet the following criteria:

1. The contribution Folk.us makes must be appropriately funded within the application
2. The role of Folk.us should be to provide advice and support for involvement, not to be a proxy for involvement.
3. The research team must be able to demonstrate a commitment to user involvement
4. The research team must be open to Folk.us making a difference to the research, through contributing to:
 - a. Refining the research question
 - b. Designing the research
 - c. Deciding who will be actively involved, and who will be approached to participate
 - d. Analysing the results of the research, and/or
 - e. Disseminating the results of the research
5. The project must offer an opportunity for Folk.us to learn – about the research topic, the research method and/or the method of involvement
6. The research must be relevant to end users
7. The research team must commit to taking an active part in meetings at key milestones during the project, to review what contribution Folk.us and/or service users/carers have made to the project
8. Folk.us must have the time available to commit to the project.

Whilst Katrina (as the Folk.us grantholder) should make the final decision about which projects Folk.us will be involved in as a named applicant, either Dawn or Rachel should also offer a view.

What should Folk.us offer in return?

If Folk.us agrees to be a named applicant in a research proposal, the Folk.us team should undertake to:

1. Spend time talking with researchers about their application
2. Read and comment on drafts of the application (at least 2 Folk.us staff will read and comment on a draft application)
3. Identify a lead Folk.us person who will be the point of contact for the researcher
4. Make a positive contribution to the project, and as far as possible do what we say we will do in the application
5. Offer ongoing advice about involvement throughout the life of the research. This will include a 30 minute session on involvement for the research team at the beginning of the project, and may also

include practical advice (for example about issues such as payment or access arrangements).

6. Help researchers to identify any training needs with regard to involvement, and the training needs of any service users/carers who get involved, with regard to involvement and/or research.
7. Offer support and advice to any service users and/or carers who get actively involved in the project
8. Enable the researchers to access to our resources and networks
9. Commit to preparing for and taking an active role in the review meetings (see criterion number 7 above). Two Folk.us representatives will attend these review meetings.
10. If agreed and funded, pull together the learning about involvement gained at the review meetings for the project's final report.

What about projects that don't meet get through the screening questions, or don't meet the criteria?

Projects that don't get through the screening questions, or don't meet the criteria, should be signposted to other organisations for advice wherever possible. For example, projects that are outside the geographical area of Folk.us could be referred to INVOLVE. For projects that are within the geographical area but do not meet other criteria, Folk.us may choose to offer other assistance or advice whilst not being named on a grant application.

Piloting these criteria and undertakings

I suggest that we pilot these suggestions, by using them on the next 3 occasions when researchers approach Folk.us requesting us to be a named applicant. The criteria should then be reviewed. It would also be helpful to review these criteria and undertakings when Folk.us makes an application for funding after 2008.