



**Folk.us Annual Report  
June 2005 - June 2006**

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

Annual Report June 2005 – June 2006

## Introduction

This Annual Report covers the period of June 2005 to June 2006 which includes a fairly prolonged period of negotiation with the National Coordinating Centre with respect to the extension of our contract. Due to this, the report is structured to reflect the changes in our remit and plans, following our extension. The first section of this report covers the last seven months of our activities before our contract extension. The second part is structured around the areas of work and aims which we set out in our current funded proposal.

This period has also included some challenging times. In July 2005 we moved offices once again, although we do like our new home in the 'new' Noy Scott House on the Royal Devon and Exeter Foundation Trust site. However, the most difficult part of the year has been the period without a research assistant. Hayley James left in September 2005 to study for a Masters Degree in Health Psychology at King's College. We are delighted that her experiences with Folk.us have proved to be a positive stepping stone. The timing of Hayley's departure fell during the negotiation for our contract extension, which meant we were unable to re-appoint until March 2006. However, hope was in sight as in March we appointed Dawn Fox-Davies, who has a background in Community Development in Health Projects. Dawn is proving to be a great asset to Folk.us, despite being somewhat 'thrown in at the deep end'!

The changes to Folk.us have brought with them new people and new energies to help us achieve our aims. Forming a new Executive Group has been very welcome and has given us a real sense of shared responsibility and achievements. We are working through the process of setting up a new Steering Group, which we hope will be the place for talking about ideas and new initiatives for involvement in research. Our plan to set this Group in motion is to hold an event open to everyone who is interested in Folk.us. The event will be held in Ashburton, which is geographically half way between Plymouth and Exeter. This day is also planned to re-launch Folk.us with our new remit.

We have also been in discussion with the new South West Clinical Research Networks. These still feel a little unknown to us all, but we are pleased to be involved with the burgeoning initiatives.

The appointment of a 'Critical Friend' has felt extremely positive. Through discussions with her, we have already benefited from being asked questions about why we undertake certain pieces of work and how do the many activities we contribute to actually help us to fulfil our aims and objectives. To date, this has been very useful and has helped us plan our work.

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

## Aims and how they have been met for June 2005 to December 2005

The funding for Folk.us was due to finish on 31<sup>st</sup> March 2005, and we were delighted that NCCRCD (National Co-ordinating Centre for Research Capacity Development) wished to discuss a further extension to the Folk.us contract. To ensure we were able to develop a proposal for further funding and discuss fully with the Department what they needed from us, we were given two short-term extensions to cover the period from April to December 2005 (June to September and September to December).

The aims we set out in our previous Annual Report (June 2004-May 2005) covered the period from June 2005 to December 2005. As we were not sure whether we would be invited to write a proposal for future work, one of our aims was to ensure that all our ongoing work started under our original contract was brought to a conclusion. Therefore, one of our main objectives was to collate all the publications from the Folk.us funded projects. Two of the projects which have had journal publications have now been collated <sup>1</sup>(Hounsell & Owens 2005) 'User researchers in control', and <sup>2</sup>(Belam, Harris, Kernick, Kline, Lindley, McWatt, Mitchell & Reinhold 2005), 'A qualitative study of migraine involving patient researchers', this is in preparation for a paper to be written by Folk.us which will draw on the learning from all the projects which we have funded.

We were also delighted to receive the final report of the 'An assessment of service provision at the point of diagnosis of a permanent visual loss – a user-led study' <sup>3</sup>(Living Options Devon 2004). The report is comprehensive and informative and the research team should be justly proud of their work. We are pleased to have been able to support this project.

The project 'Experiences of people using strong opioid drugs for chronic non-cancer pain' which was jointly funded by the Peninsula Primary Care Research Network (PenRen), formerly SaNDNet, and Folk.us, is still ongoing. There are plans to disseminate the findings in a peer-reviewed journal and there have already been presentations of the study.

We have continued to support Consultant Haematologist, Dr Claudius Rudin, Department of Haematology at the Royal Devon and Exeter Foundation Trust, and the very active patient and carer research committee. The group has worked on developing patient information sheets for clinical trials and is currently developing a project with a

clinical psychologist looking at the effects of being diagnosed with, and coping with, some forms of cancer.

Also ongoing is a collaborative project between Folk.us and service users: *'A qualitative study of haemodialysis patients' perspectives on psychosocial support*. We worked very hard on this research project, obtaining ethics and research governance approval, setting up a steering group (with service users, service providers and Folk.us) and conducting the research interviews. We conducted 10 qualitative interviews with people on dialysis between June and September of 2005, just managing to fit them in before Hayley, our research assistant, left. The analysis and plans for dissemination are still ongoing.

Another aim was to catalogue and update some of the Folk.us policies and procedures. Most of the Folk.us office procedures are now documented, including how to use the ordering and purchasing systems, how to make room bookings and how to update and make changes to the website. However, updating other Folk.us policies has proved more difficult. For example, the national information on payment and involvement appears to be changing as new guidance comes into the public domain such as <sup>4</sup>'Reward and recognition: The principles and practice of service user payment and reimbursement in health and social care' (Jan 2006), and hence it has been difficult to update our policy on paying service users.

We had also planned to scope and pull together any learning from all the research projects that Folk.us has been involved with. Again this has proved to be very demanding as we have struggled to define what 'Folk.us had been involved with' actually means, particularly as there are very many projects which we have given advice to and supported. Given the time consuming nature of this piece of work and the lack of a research assistant during this period this remains an ongoing piece of work.

Another aim was to develop a formal Folk.us protocol and policy for working with national research projects and organisations. It was felt to be important to have such a protocol to ensure that the Folk.us role was not misrepresented on any grant applications. Folk.us is always very clear that we do not represent service users, rather our involvement should add to the evidence around service user and carer involvement or facilitate and support such involvement. This has proved an interesting piece of work and is ongoing. The work we are doing with our 'Critical Friend' is proving very helpful to our thinking about our role in relation to working on projects.

We have produced one Folk.us Newsletter, the Special Conference Edition Newsletter, in which we summarised the Folk.us conference 'Folk.us Revealed: the Untold Story' held on 23rd March 2005.

Our final aim for the period between June and December was to continue to respond to requests for training and requests to speak at conferences on issues about involving people in research.

Locally, we have supported and helped to design and run the Conference for the Learning and Development team at Devon Social Services. We continued to support and attend meetings with the Participatory Appraisal Network. We continue to attend the Local NHS R&D Forums.

We supported and facilitated an event held in June for the Peninsula Medical School, talking with patients, service users and carers and other interested parties, about creating an involvement strategy for the School. The Folk.us Coordinator chaired the event which was held at Westbank League of Friends just outside Exeter. Approximately 30 people attended this event which consisted of an introduction to the Medical School followed by some small group work as to what involvement in the School could look like (Appendix 1). An example of the main points that were made by the people attending the event were:

- Service users/carers/patients need to be involved in drawing on everything said at this meeting to help design/write the strategy
- Strategy needs to be part of an ongoing process
- Ensure that education was grounded in *real experience*, to make sure that doctors listened to the whole story and to ensure that doctors realised that people needed to be treated as 'wholes' and not just the presenting condition
- Involvement would help to change attitudes of doctors and to challenge their preconceived notions of people. For example, mental health service users, people with impairments, older people.
- Involvement could also challenge the medical model of treatment and care
- Involvement could help medical students to see people as partners (equals) in their own care

Folk.us continues to have a national (and international) profile. We have attended and participated in a consultation run by SCIE, (Social Care Institution for Excellence), on the Government green paper:

<sup>5</sup>'Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England' (2005). The Folk.us Coordinator presented a session called 'Learning Lessons From Involving Patients In Research – The Folk.us Experience' at the 'Where is the Patient's Voice in Health Professional Education?' conference which was held at the University of British Columbia, Vancouver. The conference was interesting because of the number of British based researchers that were there. It was encouraging to see the amount of involvement that Britain had to share with an international audience.

Folk.us also continues to have strong links with the Joseph Rowntree Foundation. We are actively involved with their Research Reference Group on Independent Living, and we have acted as informal reviewers for some research proposals for the 'Standards we expected' project which will cost up to £310,000. This is a three year project seeking to learn ways of overcoming the specific and general barriers to person-centred Social Care. This will be achieved by working with 'change' sites to pilot and work through different approaches to Social Care.

Due to our deliberations with funding, we decided not to hold further events such as Folk.us Forums. However we did continue to develop our proposal for the extended contract, and held a number of discussions with our Management Steering Group over our future and with our representative at NCCRCD. During this time members helped us to clarify our thinking on two key issues. Roger Steel, from Involve wrote an informal paper for us to use when thinking about the role of a Folk.us management group. In the paper he suggested we consider: Clarifying/reviewing the terms of reference of the Folk.us Management Steering Group – a discussion paper by Roger Steel. (Appendix 2)

Another piece of work that has proved very helpful is a paper Tom McAusland prepared for us, drawing on the positive learning that came from the Folk.us Evaluation. This was particularly welcome as our experience of the evaluation had not felt particularly positive. Although Involve funded this piece of work, they decided after meeting with the Folk.us Management Steering Group that the report would not appear on the Involve website. However, despite the issues that the evaluation had raised, Tom's paper proved very helpful in highlighting the positive learning from the process (Appendix 3). It highlighted a number of questions we needed to ask ourselves, for example:

- Is the level of resource for Folk.us too low to support the range of activities we want to undertake and the way we have been tackling them in the past?
- Is there a 'lack of clarity' regarding the role of Folk.us?
- Do we give too much attention to primary care research and not enough to other health and social care sectors?
- Should we give more specific attention to contact and work with the voluntary sector and with 'user involvement teams'?
- Do we need to do more to acknowledge the complexity of achieving user involvement and address the challenges of different research cultures?
- Do we need a more specific strategy for Folk.us?
- Do we need a different working relationship with INVOLVE?

This concludes our activities from June 2005 up until the end of December 2005. Much of this work has contributed to the new structures and work plan for Folk.us.

### Folk.us and changes

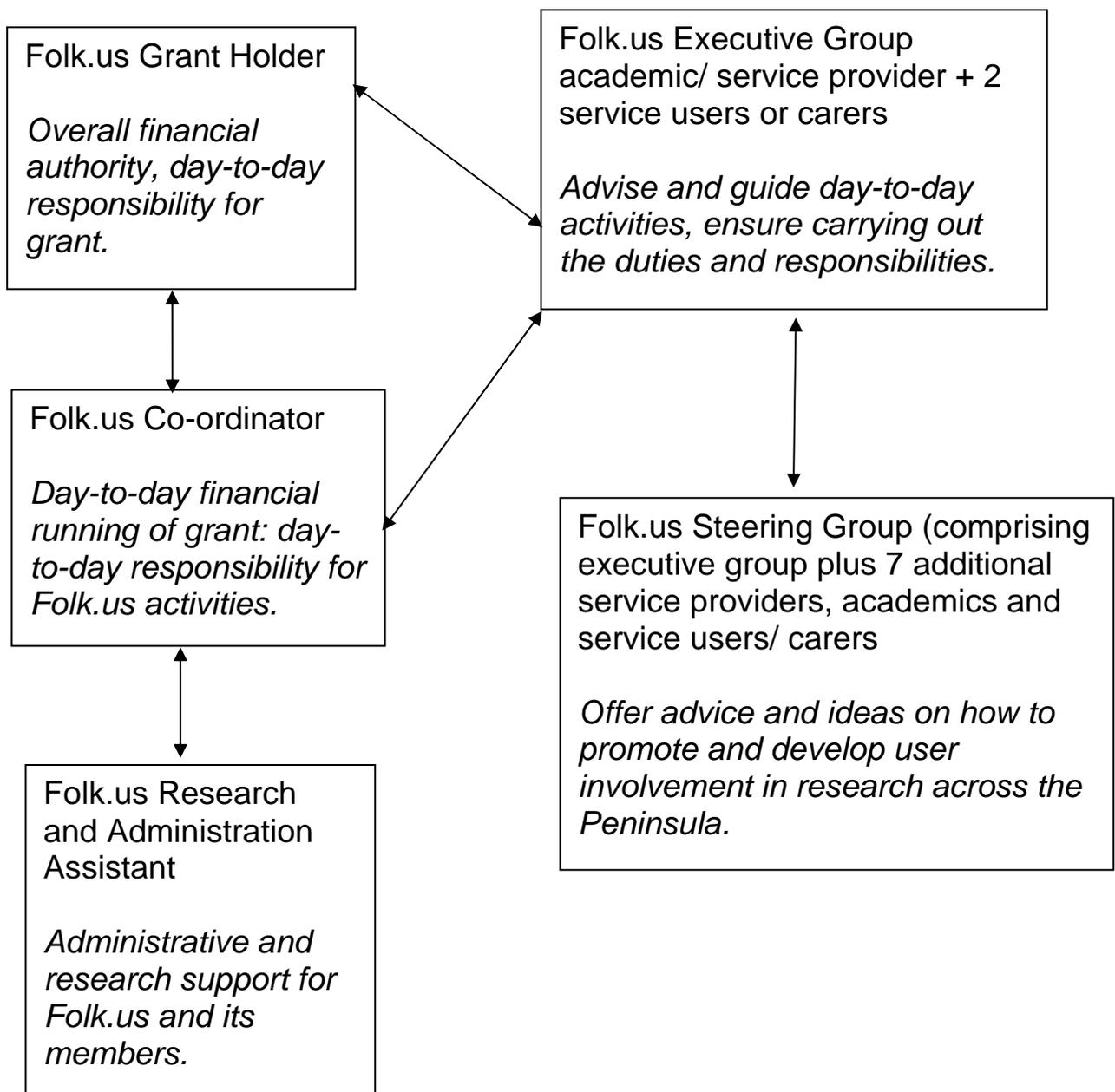
In December 2005, it was confirmed that Folk.us would receive further funding up until 31st March 2008. This funding was agreed on the basis of our new proposal, which amongst other things, set out a different structure for Folk.us and new targets and outcomes. The remaining part of this report will group our targets under the headings of our proposal. Firstly, we will give a brief overview of what the main changes are.

## New Vision Statement

Folk.us 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.

## New Structure

A new structure was proposed for Folk.us:



## The Executive Group

The main responsibility for the direction of Folk.us will lie with the Executive Group. This is to be made up of five people: The Folk.us

Grant Holder, Folk.us Co-ordinator, one academic researcher and two patients/service users. These five people are all co-applicants on the Folk.us proposal. The Executive Group will meet formally at least four times a year; however it is anticipated that the group will meet whenever necessary, in response to the needs of Folk.us.

### The Folk.us Steering Group

We are setting up a Folk.us Steering Group. It is anticipated that the members of the group will offer advice and ideas on how to promote and develop patient, service user and carer involvement in research across Devon. The Steering group will be made up of people who have knowledge and experience in this area. This Group will be multidisciplinary and will have equal numbers of service users/patients/carers and professionals as members. It is anticipated that the Folk.us Steering Group will meet three times a year.

Obviously all the new structures and groups will take some time to set up and to work, as involvement is part of a process that takes time. However, we are fortunate that people who know us and work with us are willing to help us move forward into our new era.

## Aims and how they have been met for January 2006 – June 2006

In the new proposal we set out a number of activities and plans to be achieved by June 2006. We are pleased to report we have either met these aims or we have further developed our plans to meet them. The following information is laid out using the headings we have used in the funded proposal. This tracks our activities under each of the six areas of work.

### Training

Our aim for training was to:

- Run three training sessions on the need for service user, carer and patient involvement in research in Devon, including Plymouth.

We have actually run nine different training events during this six-month period:

- We were invited to speak on the Peninsula Medical School Contemporary Issues Module (a Postgraduate module), to talk about the issues surrounding patient involvement, what they are and where they arise from.
- We were invited to speak with the selection group for Doctorate of Clinical Psychology, prior to them selecting of new candidates at the University to Plymouth. Although the invitation was to discuss how to involve people in the selection process, as our training was on the day of selection, it was unlikely to be able to have much of an impact.
- We delivered 3 training sessions on involving people in research for the Peninsula RDSU (Research and Development Support Unit). The training took place in the localities of each RDSU. It was aimed primarily, but not exclusively, at researchers or those with a research role. The number of people enrolled for each session was: Plymouth 16, Truro 14, and Exeter 30. The feedback ranged from Good to Excellent. One comment was:

“I will let my colleagues know about these workshops and encourage them to attend if they are planning any research”.
- As a result of the RDSU workshop at Plymouth, we were asked to run a similar session for research nurses in Plymouth.

- We were invited to speak at the National Health Services Research and Pharmacy Practice Conference to talk about involvement in research. The conference was held at the University of Bath.
- Each year we deliver a session about involving people in research to First Year Doctorate of Clinical Psychology students at the University of Exeter. This is to ensure they are considering the issues in advance of undertaking the research required for their Doctorate.
- We were invited to deliver a seminar on the Social Model of Disability and Involvement in Research by the School of Education at the University of Exeter.

### Facilitating & Enabling Collaborative Research

Our aims are:

- Identify Key Research & Development Managers in Secondary, Acute and Primary Care as well as Social Care in Devon, including Plymouth, and publicise Folk.us activities.
- Identify key patients / service users / carers in Devon, including Plymouth.

During this period we have made progress on all our aims in this area.

- We continued to analyse the data from the '*A qualitative study of haemodialysis patients' perspectives on psychosocial support*' and discussed with the steering group and Principle Investigator how best to ensure the results are meaningful to the participants and can be used practically within the kidney unit.
- We continue to support the Haematology Research Committee at the Royal Devon and Exeter Hospital by attending meetings. We have suggested that contact is made with the Clinical Psychology Department at Exeter University to see if a student would like to undertake a patient-initiated research project suggested by the committee.
- We have been invited onto, and agreed to be, a member of the Research Governance and Management Committee Peninsula Primary Care.

- We continue to be active on the Research Committee of BCO DP/NCIL (British Council of Disabled People / National Centre Independent Living).
- Enquiries to Folk.us. The following figures are for the period of June 2005 to June 2006. As explained earlier in the report, Folk.us was without administrative support for some time and therefore the figures here are approximate.

Total number of enquiries: 61

Folk.us Publications: 3

Specific Research Enquiries: 26

General information 23

Enquiries about training 9

Geographical areas of enquiries:

North and East (Mid and Exeter) Devon: 20

Bristol and South West England: 14

Rest of UK: 10

Abroad: 7

Unknown: 10

## Networking

The aims for Networking are to:

- Hold two Folk.us Forums (one in Plymouth and one in Exeter)
- Produce 2 Folk.us Newsletters

It was felt that the Folk.us forums should be looked at again to understand the best format for them and to ensure they meet the wider needs of the Folk.us membership. The Executive Group approached Tom McAusland to ask him to produce a short working document to give us some critical thinking about the Forums, their purpose and what they can realistically achieve. Whilst this was ongoing it was decided not to hold any forums during this period. However, we did decide that an event was needed to re-launch Folk.us and we started to draw up plans for what became the 'Wake Up to Folk.us Day'.

- We produced one Folk.us newsletter which introduced our new research assistant and invited people to the 'Wake Up to Folk.us Day' planned for July 2005.

- We continue to support the South West Participatory Appraisal Network by attending meetings.
- The membership continues to increase, although this year it was only by three:

|                      |     |
|----------------------|-----|
| Total Members        | 293 |
| Service Users        | 58  |
| User-Representatives | 33  |
| Professionals        | 190 |
| Not Specified        | 12  |

### New and Clinical Networks

Our aims for working with the new clinical networks were clearly shaped by our discussions with NCCRCO when negotiating our contract extension. We are required to work with the new networks, but this is not work that falls into our funding and therefore the new networks need to fund any support they require from Folk.us as part of their activities.

- To target activities with key research active NHS organisations in Devon and with the South West Peninsula Clinical Networks (including Secondary, Primary and Community Care).
- Form strategic links with local research developments such as the newly emerging clinical networks and research partnerships

Folk.us was costed into three proposals for local Clinical research networks: Diabetes, Primary Care, Stroke. However, Folk.us was only included in the actual writing of the Primary Care proposal, which was a positive collaborative process. We are interested and eager to see how our relationship with the Networks develops. However, we are mindful that there may be a difference in how our role is written in the proposals and what we will deliver in line with our values and good involvement practice. So far we have met with the leads and managers of both the Diabetes and Primary Care Networks.

We have also maintained contact with other Networks including:

- South West Participatory Appraisal Network

- Research into Practice for Adults (RIPfA)
- Invonet, a new network hosted by Involve was launched that aims to bring together researchers interested in Service User Involvement.

### Target Access to Resources

Our aims in this area are brief as we like to work responsively to these issues.

- Attend national and local conferences and events as appropriate
- Create and develop Policy and Guidance

We have met these aims by:

- We developed the 'Research Governance made Simple' leaflet in 2003 and this continues to be used by a variety of health and social care services across England and we are being asked to further develop it to meet the needs of a wide range of people.
- We attended the Involve review and consultation about the Guidance for Researchers held in Birmingham.
- The Folk.us website has needed updating and redeveloping for some time. Some of the problems have been due to having new computers in the office, these also require new software for updating the site. Staff will need training to operate the new programs. We are arranging training for Folk.us staff and we are seeking someone to work with us to redevelop the Folk.us website. We are also ordering new software.

The website still attracts a number of visitors. Again these are approximate figures for June 2005 to June 2006:

Total number of visits 564

|                             |     |
|-----------------------------|-----|
| United Kingdom              | 523 |
| United States               | 8   |
| Europe                      | 2   |
| Canada                      | 4   |
| Rest of world<br>or unknown | 27  |

- In May 2006 we began updating the Folk.us Database of Members which has coincided with sending out details of the 'Wake up to Folk.us' day.
- Given our new remit we have also decided to revise and update the Folk.us leaflet. We have begun discussions with the Executive Group about the format and the content will be informed by the new Steering Group

### Cross-cutting themes

We did not have any specific aims in this section but the activities we have undertaken that seem to cut across areas of interest and work are:

- Working with Devon Social Services Learning & Development to plan their conference and continued learning and development of staff. This includes increasing their understanding of, and willingness to develop, service user involvement.
- We attended a CoRec Consultation about Research Ethics which was organised by INVOLVE and the National Patient Safety Agency.
- We attended a Direct Payments Seminar held at the University of Leeds. This seminar brought together much of the research about the system of direct payments in social care.
- We continue to be a member of the Joseph Rowntree Foundation - Independent Living Research Reference Group
- We also attended a workshop about the issues raised when paying people for their involvement activities who are in receipt of state benefits. This workshop was arranged by Devon County Council and delivered by Devon Welfare Rights Unit. This was a useful day which confirmed that this remains a very complicated issue.

### Targets for Management and Probity

Our aims were to:

- Hold two Executive Group Meetings
- Approach the existing members of the Management Steering Group and invite them to be part of the new Steering Group. Also ask if they

can suggest people who could inform our work as described in the section 'New Structures' (page \*\*).

- Advertise and appoint a new Research Assistant
- Appointment of Critical Friend. The appointment of a Critical Friend has a two-fold purpose; to ensure Folk.us is meeting its stated aims and objectives and to provide a regular opportunity for reflection. Funding for this role was earmarked from the small under-spend from the Folk.us grant. (Up until December 2005)

We have met these aims by:

- We held two Executive Management Group meetings. The Executive Group comprises Mrs Rosemary Humphreys – service user, Mr Andy Palmer – service users, Ms Annie Mitchell - Clinical Director of Doctorate in Clinical Psychology, Ms Rachel Purtell - Folk.us Co-ordinator and Dr Katrina Wyatt - Folk.us Grant Holder.
- All of the people who were part of the previous Management Steering Group were invited to join the steering group. However, as the locality which Folk.us covers is wider under the new contract and the remit for the group has altered, it was decided to hold an event to tell people about the new contract and to discuss what the new Steering Group should look like and do. Planning for a 'Wake up to Folk.us Day' to be held in July 2006, began.
- To advertise and recruit a new research assistant for a half time research and administration post, a job description was agreed and the post was advertised. We had 16 applications for this position. Interviews for post were conducted by Rosemary Humphreys, Andy Palmer, Katrina Wyatt, Rachel Purtell and Mary Carter (PMS). Five short-listed applicants were asked to give a brief presentation on 'What does Service User Involvement mean to you, and how would you help Folk.us develop its work?' We were delighted that Ms Dawn Fox-Davies agreed to be the new Folk.us Research Assistant. Dawn started in April 2006. Immediately prior to taking up the post of Folk.us Research Assistant, Dawn attended 2 training sessions: the NHS induction training and an RDSU workshop: "Introduction to quantitative research methods" to review the principle features of research methodology. She has also attended an RDSU workshop on "Writing a Scientific Research Paper". Both the Coordinator and the Research Assistant will be undertaking training for the Website.

- The Executive Group met with Bec Hanley to discuss the possibility of her becoming the Folk.us 'Critical Friend'. A proposal (Appendix 4) was put to the Executive following the meeting which included a list of possible areas for reflection. The role was outlined as:
  - To help Folk.us to reflect on where it has been and where it is going, acting as a pair of fresh eyes.
  - To help Folk.us to think about different ways of achieving its aims and objectives.
  - To bring in experience and ideas from other areas and organisations.
  - To promote dialogue – to reflect *with* Folk.us and its stakeholders, not to do an evaluation *to(of)* Folk.us.
  - To help Folk.us to think about what (activities) the organisation is doing well and what needs improvement.
  - To offer constructive criticism as well as positive feedback.
  - To record the learning, so that Folk.us and others can benefit.

The Group agreed to appoint Bec on the basis of the proposal and decided that the first area for reflection should be about “What is the role of Folk.us?”

## Folk.us Finances

This year has been a difficult one for Folk.us as we have encountered uncertainty about our future. We are delighted once again to have a small surplus in our budget going into the new financial arrangements, enabling us to appoint a Critical Friend and to redevelop the website (Full and signed Accounts Appendix 5) .

### GRAND TOTAL

56,806.11

### 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: 14th February 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

## Outcomes – ‘What does Folk.us aim to achieve?’

We feel that that we have gone some way to achieving all our aims set for the duration of this funding period. In this first six months we have managed:

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

We have expanded our training activities into Plymouth and are working with networks with a Peninsula wide remit. The new Folk.us Steering Group members will cover this revised geographical area.

- 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 are continuing to support collaborative research projects and facilitating events.

- 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.

There has not been a lot of opportunity for us to do this given the last year of changing our structure and remit. However, we anticipate that the new Steering Group will assist in creating opportunities for more partnership working.

- 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.

- 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.

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

This is done through training and support of individuals by working 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.

This is ongoing. We are hoping to have such criteria for 2006-2007 which is also connected to us developing our own terms of engagement.

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

We are continuing to do this.

- 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 preparing a paper that will be a synthesis of our learning from the projects we have supported financially. We will be seeking opportunities for publication of the paper.

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.

- Continue to collect feedback from all training events.

We are developing our own feedback forms.

- Report annually to the NCCRCD

This is our Annual Report for 2005-2006

## **Conclusion**

We are delighted that our work has received funding until March 2008, and appreciate that this has come at what has been a difficult period for NHS research, with changes in structures and funding arrangements. Despite the difficulties that Folk.us has encountered this year we have succeeded in achieving a lot, as is clear from this report. The obvious and most notable achievement has been the successful proposal to expand and develop our work for a further 27 months. The creation of this proposal was a true collaboration between academics and service users. It was funded with no changes required to the remit, making it a testimony to real partnership working. However, due to the pressures of writing a new proposal and not being able to replace our Research Assistant for over 5 months, we have struggled to keep up with some of the less evident tasks such as logging enquires.

We are pleased to report that the creation of the Executive Group is proving to be an effective way to oversee Folk.us work and it has improved the efficiency with which we can make decisions about what we undertake.

The appointment of a Research Assistant has ensured that we are again able to retain our high standards in terms of office procedures and we are able to take on the range of projects outlined in the proposal.

We also see the appointment of a Critical Friend as a very positive step in helping us to learn and reflect on Folk.us and how we meet our aims and objectives. Given our disappointment with the lack of distillable learning from our evaluation we see the work with our Critical Friend as central to the development of Folk.us and planning the future.

The new Steering Group we feel will bring new enthusiasm to our work and will help to guide the direction we take in the next months of our contract.

It appears that our role advising on, and supporting involvement remains very much needed by the research community, both locally, and at times nationally. We are being asked more and more to support, advise and assist with South West Peninsula wide research proposals and projects. The creation of local Clinical Research Networks all of whom have a remit for meaningful involvement, means we anticipate the demands on Folk.us to 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 2005-2006. We would like to thank all our members and everyone who has given their time and energy to Folk.us this year. It is our members which make Folk.us the organisation we are and without them, there would be no need for us.

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

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