



Folk.us
Annual Report
2008-2009

Folk.us Annual Report Index

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Folk.us annual report 1st April 2008 to 31st March 2009

1. Introduction

Folk.us brings the world of research and researching to people who use health or social care services across Devon. Folk.us aim is that research is focused on real experience and real lives. Our vision is that:

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.

Folk.us has over 300 members, who are service users, carers, patients, researchers and health and social care professionals from the statutory and voluntary sectors.

In 2007 Folk.us successful applied to the National Institute of Health Research for a renewal of funding to cover the period from April 2008 to March 2011. Our objectives for this three year period are to:

- Facilitate and enable high quality rigorous, collaborative research
- Support patient and public involvement within the National Institute of Health Research (NIHR) Clinical Research Network (CRN) local networks
- Develop and provide training for service users, carers and professionals to promote involvement in research
- Communicate and disseminate information about our activities and about opportunities to get involved in our work

In section two of this report we summarise what we have done between April 2008 and March 2009 to take forward these objectives.

2. Our work during 2008-2009

2.1 Facilitating and enabling high quality, rigorous, collaborative research

We undertook a number of activities during 2008/2009 to facilitate and enable high quality rigorous, collaborative research. They can be grouped under the following headings:

- Identifying and working with research projects with a local (i.e. Devon) base
- Providing an enquiry service to answer questions about involvement in research for service users, patients, carers, researchers and health and social care staff
- Funding for patients, service user or carer initiated research
- Development of an agreement about paying service users and carers
- Maintaining strong links with national organisations
- Creating opportunities for networking between patients, service users and carers to share expertise in the field of involvement in research
- Developing guidance and support systems for patients, service users and carers and those research staff they are working with to support involvement in research
- Facilitating and encouraging regional funding and approving committees to further understand involvement in research
- Responding to requests for Folk.us to be a co-applicant on research grants

We discuss each of these in more detail below.

Identifying and working with research projects with a local (i.e. Devon) base

Whilst we had planned to work closely with three research projects during 2008/2009, we did in fact support and work alongside six organisations assisting in the development of potential research projects. Four of these have resulted in the development and delivery of a research study.

Evaluation of a 'My Life, My Choice' project

We played an active part in the development and commissioning of an evaluation of a project run through West Bank Carers, the local Carers Support Network. This formed part of the national 'My Life, My Choice' project, and included services in four GP practices, with the aim of identifying carers and encouraging them to register as carers. Folk.us was involved in reviewing proposals from research teams to undertake the evaluation, and in identifying and setting up a 'Critical Friend' role within the evaluation.

Headway project

This project was initiated by two members of our Folk.us Advisory Group who have experienced a head injury. We are developing a local research project with people who have experienced head injuries who use the local Headway service, www.headway.org.uk. We have supported a group of service users to form a steering group and we have collected possible research topics from Headway members. We will now be developing a draft proposal to submit for funding consideration.

Past Caring; A service-user led research project about sharing bereaved carers narratives project

This is another local project that we are working on. The idea for the research study was initiated and developed through discussions during our Folk.us Advisory Group meetings. Three Folk.us members are now working with us to do this project. We are currently working on the proposal and aim to submit this to the Ethics Committee in June 2009. The project has been endorsed by the Princess Royal Trust for Carers. This project will focus on the experience of bereaved carers and will use a variety of creative means to capture and disseminate bereaved carers experiences.

See Me: A service user evaluation of a project to paint the bodies of disabled people.

This is a new project that has arisen due to a recent research enquiry to Folk.us. Katie Sarra, an art therapist /occupational therapist in Tiverton, has been working with disabled people on improving self esteem and body image through portrait painting, www.katiesarra.com. She and a small group of service users want to start a research project to evaluate any effects on quality of life and self esteem outcomes linked to this work. We have started to plan the work with Folk.us members and in particular to consider possible research instruments, methodology and possible funding sources required.

Positive Action

We did some initial work with Positive Action, the AIDS and HIV charity in Devon, following an approach from them requesting assistance to undertake further research about stigma and social isolation. This included several meetings and an exploration of training for some Positive Action members to support them to carry out the research. Unfortunately this project did not go ahead due to a combination of reasons, including major changes to the charity as merged with another charity. It was agreed that this was not the right time to push forward with their research and we are going to revisit the idea in 2010.

DAQual

We met with one of the researchers on the DAQual project – this project aims to evaluate mentoring services which are being run in Devon for older people by three local charities. By the time Folk.us was approached and asked to become involved with this project, much of the research had been planned and a protocol agreed. Folk.us supported the researchers to plan some workshops where older people would be encouraged people to think about what was good and what could be done better regarding the evaluation, and what other aspects, if any, the evaluation should cover. Unfortunately due to difficulties experienced within the project's remit and the timeframes involved, these workshops did not take place. However, Folk.us was involved with and facilitated a workshop for service providers to establish their views on whether the project had taken all the right things on board.

Having worked with these six projects with a view of taking three on to develop a research study, we have fulfilled our aim to work with three new research projects over the year. It takes time to find out what research service users want to get involved in, how they want to do it, and to develop it into a research funding proposal with them. Research is time consuming and is often not a priority for service users and services user organisations. Folk.us works with people who have shown an interest in developing a research idea and taking it forward – we know that without our support throughout the process the research will often not take place. But we also know that we cannot and should not force an organisation or group of service users to get involved in research.

Enquiry service

We provide one-to-one advice, by phone, email or in person for Devon based research projects which seek to involve service users, patients, carers and researchers. We dealt with the 27 enquiries from 1st April 2008 - 31st March 2009.

We have noted that we have received less phone enquiries than in previous year – we think this is because people are increasingly using the website as a first port of call for information.

Around half of all enquiries will lead us to set up a face-to-face meeting with an enquirer. Some of our more notable enquiries during 2008/2009 included:

- Offering advice to the COCOA project (an SDO funded research project looking at continuity of health care for prisoners) on how to pay service users for their involvement.
- Advice to a consultant on how to involve service users in a proposed research project looking at early detection of stroke.
- Advice to a researcher on how to involve service users in the development of a research project to look at how to evaluate the training of medical students at the bedside.
- The sharing of experience and information with the Consumer and Community Liaison Manager from the University of Western Australia. Their work has a dedicated position to develop a range of ways each organisation can increase participation such as establishing Consumer and Community Advisory Councils, create a range of models to increase participation, collaborating with a UK consultant to write and publish a guidebook on this work.
- Assistance in the commissioning of an evaluation of access to psychological therapies, where we reviewed the research proposal and supported a service user member of Folk.us to be a member of a panel to recruit the researcher for this project.
- Advice and assistance in involving service users in the evaluation and presentation of the ADDITION study; a large multi-national Diabetes research project involving 3000 patients

Funding for patients, service user or carer initiated research

We have worked with service users and carers in the See Me, Carers and Headway projects to help them to identify and apply for funding for their research. We also speak with the RDS and the RfPB programmes about funding such projects.

Development of an agreement about paying service users and carers

We have worked with the Care Services Improvement Partnership (CSIP) group in the South West, Devon County Council and the Devon Welfare Rights Group on this issue. This has led us to undertake a review of all guidance and policies that look at paying people for their involvement. We will be submitting a paper on this to a peer reviewed journal during the forthcoming financial year (2009/2010). This paper has been reviewed by two Folk.us service user members.

Maintaining strong links with national organisations

We have worked with a range of national organisations over the past year to help us to take forward our objectives. They include:

INVOLVE

We were part of the planning group and attended the INVOLVE conference. We supported a Folk.us member to develop and display a poster at this event.

Folk.us is a member of the RDS (Research Design Services) and INVOLVE Forum for patient and public involvement (PPI). This forum supports each of the RDS PPI leads - throughout England.

National Institute of Health Research Clinical Research Network

The Folk.us director is a co-facilitator for the NIHR CRN's course on PPI in research. 40 people attended from both the National and Local CRNs.

UK Clinical Research Collaboration

The Folk.us director acted as a 'Critical Friend' on an evaluation of patient and public involvement in the UK Clinical Research Collaboration.

Joseph Rowntree Foundation

Folk.us has been represented on a reference group for research projects looking at independent living and at older people.

Disability Studies

The Folk.us director presented a paper (as part of the main plenary) on the future of disability studies at the national Disability Studies conference, and facilitated several sessions during the conference.

PenTAG

PenTAG asked Folk.us to be an advisor on involvement issues for the collaboration which has formed the Centre for Public Health Excellence (one of two centres funded by and working with NICE). This is a joint project with the West Midlands HTA Collaboration at the University of Birmingham and aims to produce systematic reviews, evidence syntheses and economic analyses to inform NICE Public Health Programme Guidance and Public Health Intervention Guidance.

Creating opportunities for networking between patients, service users and carers to share expertise in the field of involvement in research

The Folk.us Forums are designed to be an informal learning space where a range of topics are talked about. Forums include talks about research methodologies and research projects that have involved people in interesting and new ways. Forum speakers are drawn from the national and international arena. Forums are attended by a wide range of people, including service users, carers, researchers and staff from the statutory and voluntary sector.

We held two Folk.us forums during 2008/2009. The first looked at how to get started in research, and was run by two service user/carers member, with support from Folk.us staff. The second Forum consisted of a presentation of the preliminary findings from the West Bank carers project as mentioned before.

We ensure that Folk.us has links with a range of organisations across Devon and Plymouth. These include:

- Peninsula College of Medicine and Dentistry
- Peninsula Research Design Service

- Royal Devon and Exeter NHS Foundation Trust
- Plymouth Hospitals NHS Trust
- Torbay Hospital
- North Devon District Hospital
- Devon Partnership Trust
- University of Exeter
- University of Plymouth
- Peninsula Clinical Research Methodology Unit (to be the CTU)
- Devon Social Services
- A range of voluntary organisations in Devon
- Local Clinical Research Networks
- Participatory Appraisal Network South West (We now provide administrative support for this Network)
- Research into Practical for Adults (RiPfA)
- Research for Patient Benefit (South West region)
- PenCLAHRC

Developing guidance and support systems for patients, service users and carers and those research staff they are working with to support involvement in research

In 2002 we published guidance on the Research Governance Framework - *Research governance made simple*. This guidance was adopted by INVOLVE and is now part of the online toolkit available through the R&D Forum

'<http://www.rdforum.nhs.uk/toolkit/rgsimple.pdf>' and forms part of the most used section of their website. We have begun work to update this guidance, in partnership with Peninsula Primary Care Research Management and Governance (RM&G) Unit.

Facilitating and encouraging regional committees to further understand involvement in research

We have begun to make links with the local ethics committees based in the NHS and in universities, and with the South West Research for Patient Benefit funding committee with a view to offering training and/or support about involving service users and carers, where appropriate, during the remainder of our funding period.

Responding to requests for Folk.us to be a co-applicant on research grants

In 2007 we developed criteria for prioritising approaches from researchers who wanted to include us as co-applicants for research grants. We felt this was necessary in order to deal with the level of demand on our time that such requests make. During the past year we have used these criteria to respond to three requests for Folk.us to be a co-applicant on a research grant. We agreed to be a co-applicant on two because they met our criteria; however, neither funding application was successful.

2.2 Supporting patient and public involvement within the NIHR CRN local networks

- Work with all research networks based in the Devon area to promote and support patient, service user and carer involvement in research
- Develop criteria for assessing involvement in research across the networks

During the past financial year we have worked in two areas:

These activities are summarised below.

Work with all research networks based in the Devon area to promote and support patient, service user and carer involvement in research

At the start of the new funding period Folk.us wrote to all the local research networks, informing them about Folk.us and offering to meet and discuss ways we could support and work with each network. Over the past year we have worked with all but one of the NIHR CRN local networks. We advised the **Comprehensive Local Research Network** and the **Primary Care Research Network** on the development of two patient information days, where we did a short presentation on involvement in research, and facilitated workshops. One took place in Devon and one in Cornwall. Both were well attended.

We are on the PPI Group for the **Stroke Research Network**. We have met with the **Medicines for Children Research Network** to discuss possibilities for how we can work together. We had a stand at the **Mental Health Research Network** Hub's conference in Bristol. We continue to support the **Diabetes Research Network**. We advised the **Dementia and Neurodegenerative Diseases Research Network** on the development of a conference for NHS staff and interested service users, patients and carers. We also had a stand at their conference.

In addition, we worked with the Peninsula Medical School to develop a bid to become a **Collaboration for Leadership in Applied Health Research and Care** (CLAHRC). We helped the PenCLAHRC to develop a comprehensive strategy for involvement, in both studies and across the structure of the initiative. We also took an active role in the recruitment of a PPI lead. PenCLAHRC aims to embed research and educational activity to fuel the partnership between the NHS and academia.

Develop criteria for assessing involvement in research across the networks

We have begun to explore whether it would be possible to develop criteria for assessing involvement, which could be used across all of the networks. This work will continue in 2009/2010 with a view to the development of some criteria for piloting in early 2010.

2.3 Developing and providing training for service users, carers and professionals to promote involvement in research

We undertook a number of activities during 2008/2009 to develop and provide training for service users, carers and professionals to promote involvement in research. They can be grouped under the following headings:

- Training for service users, patients and carers
- Training for researchers
- Training for students
- Training outside Devon

We discuss each of these in more detail below.

Training for service users, patients and carers

We have used the employment of a research fellow to review our training plans. She has spent time talking with service users about their training needs. In response to this she is developing a programme of training for service users on a range of research methodologies. The first training session, in response to requests from service users, was about grounded theory, and was held in December 2008. It was attended by 11 people. We had very positive feedback commenting on, how interesting it was, how clearly presented the workshop was, and that the workshop was pitched at the right level where it

could be understood and enjoyed.

Training for researchers

In the past we have offered training to researchers through the Research and Development Support Unit (RDSU). With the change from RDSU's to Research Design Services (RDS's), we have reviewed our training provision for researchers, with input from staff at the new RDS and the Director of R&D at the Royal Devon and Exeter NHS Foundation Trust. In the coming funding year we will be offering 'research exchanges', where researchers will be able to access training about involvement and a chance to meet with service users, patients and carers to discuss their research ideas. This means that they will be able to get direct input from service users as well as access to support from Folk.us staff. Folk.us research exchanges will also enable service users to put forward their own research priorities.

Training for students

We have run one training session for students doing a clinical doctorate in psychology at the University of Exeter. Approximately 30 students attended.

Training outside Devon

Developed and delivered training for students doing the PhD in Health at the international residential school University of Bath. Approximately 40 students attended. The feedback from this session was that the issues we had raised about involvement had gone on to inform and inspire debate throughout the remainder of the week's residential school.

2.4 Communication and dissemination

Our activities in this area can be grouped as follows:

- Communicate effectively with service users, carers and professionals in Devon about what Folk.us is doing and listen to priorities for future activities
- Promote active involvement in Folk.us and related activities by service users, carer and professionals

We discuss each of these in more detail below.

Communicate effectively with service users, carers and professionals in Devon about what Folk.us is doing and listen to priorities for future activities

During 2008/2009 we re-developed our website with considerable input from the Folk.us Advisory Group, and added a facility to enable people to sign up for any Folk.us event, as well as a discussion forum. From the 1st April 2008 to 31st March 2009 the Folk.us website has had 925 visits.

We have begun planning for the Folk.us conference, which will be held on 6th April 2010.

Promote active involvement in Folk.us and related activities by service users, carer and professionals

We produced and circulated two newsletters during 2008/2009. Newsletters are sent to all of our members and are placed on our website. They have covered such issues as requesting research ideas, informing members of events and forums, and a section where we find out a little more about one of our members, by way of a series of questions, ie. What have you personally got out of being involved in research?

3. Management, governance and organisational structures

Governance arrangements

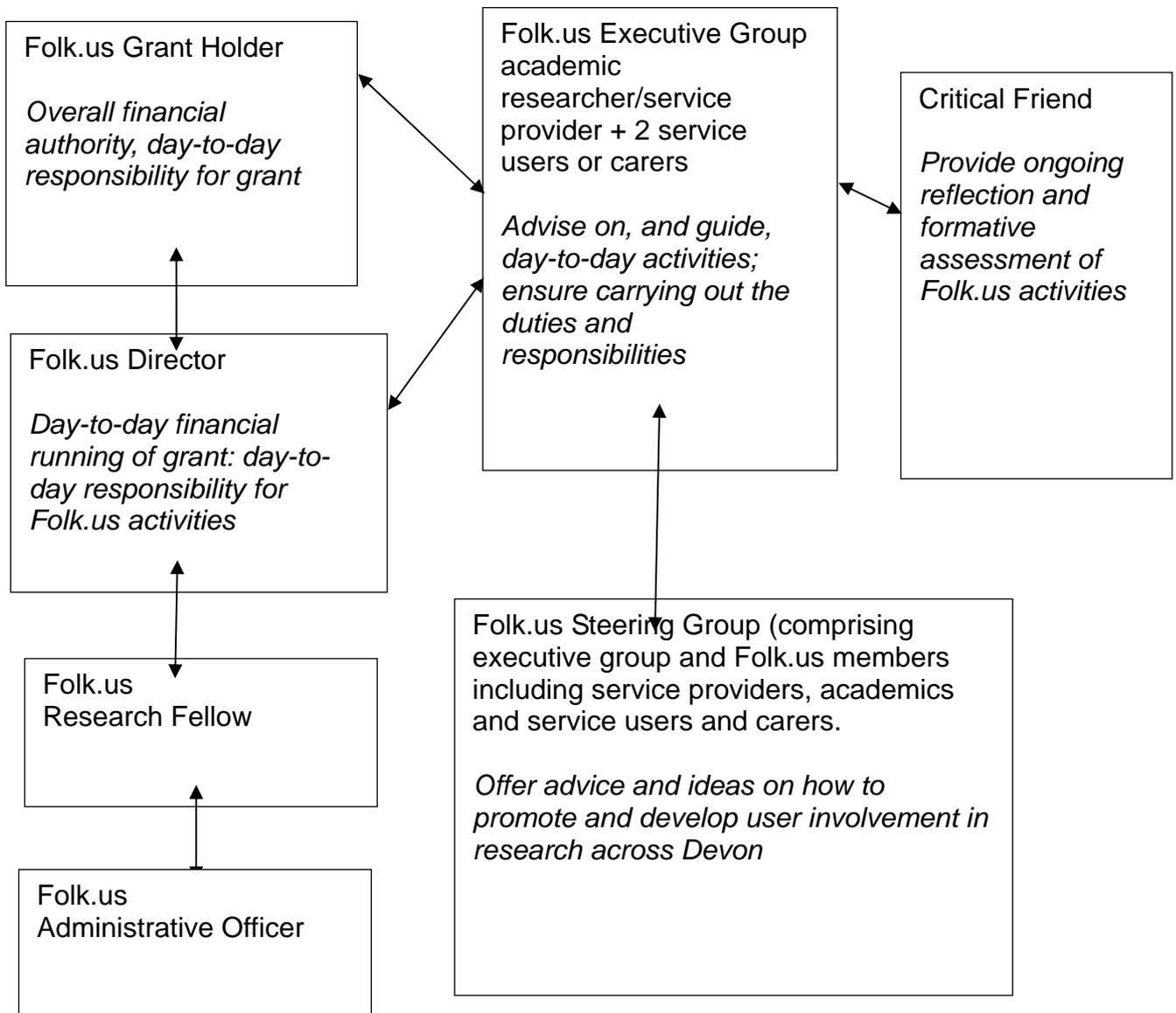
The main responsibility for the direction of Folk.us sits with the **Folk.us Executive Group**. This group provides advice and guidance on the day-to-day activities of the Grant Holder and Director, to ensure that Folk.us is carrying out its duties and responsibilities in accordance with our contract with the NIHR. The Executive Group is made up of six people: the Folk.us grant holder, Folk.us Director, one academic researcher/service provider and three patients/carers/service users. Executive Group members are paid on an hourly visiting lecturer rate for their time and attendance at Executive Group meetings. The Executive Group met four times during 2008/2009, and we have recruited two new members during this period. (Application Process Appendix 1, Terms of Reference Appendix 2)

The Folk.us Advisory Group is made up of Folk.us members and is chaired by an Executive Group member. Advisory Group members offer advice and ideas on how to promote and develop patient, service user and carer involvement in research across Devon (including Plymouth). As a result of this remit the Advisory Group comprises of people who have knowledge and experience in this area. It is a multidisciplinary group and we have equal numbers of service users/patients/carers and professionals as members. The Advisory Group met twice during 2008/2009 and we have recruited 6 new members.

To ensure ongoing reflection of whether Folk.us is meeting its overall aims and objectives we will again seek to appoint an independent **Critical Friend**, Bec Hanley. She provides an ongoing formative assessment of Folk.us activities and critique of our decision making processes. In this year our Critical Friend helped us develop a recruitment strategy and criteria for the Executive Group.

The chart on the next page shows our management and governance arrangements.

Folk.us management and governance structure



Folk.us staff

We were able to recruit two new members of staff during 2008/2009 as a result of our renewed funding from the NIHR. Folk.us now has the following staff:

Grant Holder: Katrina Wyatt (half day per week). The Grant Holder has overall responsibility for the project, oversees the project on a day-to-day basis and has overall financial authority. She is also involved in training and in the dissemination of Folk.us activities where appropriate.

Folk.us Director: Rachel Purtell (four days per week). The Director has responsibility for the day to day running of the project, including authorisation of running costs and is responsible for the management of the Folk.us staff. She promotes the work of Folk.us, gives presentations and talks, develops training content and programmes and negotiates the role of Folk.us with Research Networks, national and local organisations. Her role includes the dissemination of Folk.us activities in journals and publications and reporting to the Department of Health annually. The Director is accountable to the Executive Group and the Grant Holder.

Research Fellow: Wendy Rickard (2.5 days per week). The Research Fellow provides research support and gives advice to research projects. Her role is to work alongside research projects, supporting service users, patients and carers, as well as researchers and research managers to create meaningful and constructive involvement. She is also responsible for contact with Folk.us members.

Administrative Officer: Abi McCullough (2.5 days per week). The Administrative Officer provides support to the Folk.us Director and Research Fellow. Her main duties are to develop and maintain office systems, communicate with the Executive Group, Folk.us Members and the Steering Group, and providing administrative support to research projects as appropriate.

4. Finances

National Co-ordinating Centre for Research Capacity Development

Infrastructure: Annual Report Financial Statement

Reporting Year: 2008/09

Name of Institution: University of Exeter - Peninsula College of Medicine and Dentistry
NCCRC D Reference: RNC/021/007
Your Reference: 2806 RR100221

Reporting Period: 1st April 2008 - 31st March 2009

Contract Start Date: Contract End Date: 31st March 2010

Section A: Summary

Actual Income Received from NCCRC D	123,356.00
Actual Expenditure	116,372.02
Carried Forward from Previous Year	0.00
(Over)/Underspend	6,983.98

Section B: Salaries

Name	Job Title	Scale	Salary Point	WTE	Contract Status	Salary Cost
R Purtell	Research Fellow	F	36	80%		33,339.19
W Rickard	Research Fellow	F	32	50%		15,267.46
A McCullough	Administrator	D	14	50%		8,750.41

4. Finances

Salaries Sub Total

57,357.06

Contribution to Full Economic Cost

50,272.08

Section C: Expenses

Consumables

701.86

Consultancy

3,302.64

Conferences Dissemination

821.33

Service User

378.90

Forums

0.00

Travel & Subsistence

3,538.15

Expenses Sub Total

8,742.88

Section D: Equipment

Equipment

Equipment Sub Total

0.00

GRAND TOTAL

116,372.02

Section E: Declaration

4. Finances

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: 19th August 2009 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): ANNE SHRUBSHALL
Date: 19th August 2009 Position: DEPUTY FINANCE DIRECTOR

Section F

<u>FOR NCCRCD USE ONLY</u>	
Notes:	
Statement Checked By:	Date:
Statement Authorised By:	Date:

5. Aims for 2009 -2011

A. Facilitate and enable high quality, rigorous collaborative research

1. To carrying on supporting the current three projects and to identify and work with 3 new research projects with a local (Devon) base. The priority remains to work with projects from service user, patient or carer groups that Folk.us has not worked with in the past or to work in new areas of research.
2. Continue to provide an enquiry service answering questions about involvement in research for service users, patients, carers, researchers and health and social care staff, and to keep relevant and current information available through our website.
3. Support funding for patient, service user or carer initiated research projects by continuing to work with funding bodies.
4. Continue to raise issues about payment for involvement where necessary and work with structures and systems to change their policies where needed.
5. Promote Folk.us to local support groups, have a visible presence at a variety of places where patients, service users and carers gather (eg hospital waiting areas).
6. Continue to maintain strong links with National Organisations by maintaining a present on the national area and continuing to work with Involve.
7. Create opportunities for networking between patients, service users and carers to share expertise in the field of involvement in research and delivering the public and patient involvement agenda in research, through Forums and new research exchanges.
8. Further develop guidance and support systems for patients, service users and carers and those research staff they are working with to support involvement in research.
9. Continue to facilitate and encourage regional approving Committees eg RfPB and LRECs to further understand involvement in research in line with national policy and thinking on public & patient involvement in research.
10. Continue to respond to requests for Folk.us to be a co-applicant on research grants.

B. Support the public and patient involvement agenda in research within the UKCRN local networks

1. Continue to work with all research networks based in the Devon area to promote and support patient, service user and carer involvement in research.
2. Continue to facilitate knowledge and understanding of involvement issues within the governance arrangements for the networks.
3. Continue to develop criteria for assessing involvement in research across the Networks (funding from another source will be sought for the piloting of these criteria).

C. Develop and provide training for service users, carers and professionals to promote involvement in research

1. Continue to offer training about involvement in research and research methods to service users, patients, carers, researchers, research managers, approving committees and students to support the public and patient involvement in Research.
2. Review how best to achieve knowledge about involvement in research using training as one method along side real involvement activity.
3. Continue to respond to requests to deliver training outside Devon.

D. Communication and dissemination

1. Continue to communicate effectively with service users, carers and professionals in Devon about what Folk.us is doing and listen to priorities for future activities.

Continue to promote active involvement in Folk.us and related activities by service users, carers and professionals.

E. Governance

1. Continue to support the Executive Group to continue to oversee the finances, management of activities and recruitment of Folk.us staff.
2. Recruit new members to the Executive Group as required.
3. Support Folk.us Steering Group to continue to reflect on the work of Folk.us and to inform the work we undertake and take action based on the group's direction.
4. Continue to use an independent advisor to reflect on the work of Folk.us and its internal processes.
5. Report Folk.us activities and resource allocation to funders.

6. Conclusion

This has been an exciting year for Folk.us with our new staff team and lots of activities. We have met all our targets and plans for the first year of our renewed funding and are confident that we shall stay on target and meet next years objectives.

The next year should see the fruition of some of our work and the beginning of new projects. Issues about involving people in research, who are not from academic or clinical background are still as contested and debated as ever they were.

Discourses about the nature of evidence to support involvement are diverse and challenging and Folk.us continues to have a voice, supported by our membership, in those discourses.

Sometimes it seems that the debates and the agendas of 'PPI' have become more prevalent than the actual practice of involving people to have a voice and reach solution together, or for Folk.us to inform the design, delivery and practice of research. It remains our firm view that discourses need to be based on the practice of involving people and that those debates and challenges need to have those involved at the heart where the discussions are happening.

Rachel Purtell – Folk.us Director
October 2009

Appendix 1



Application for Folk.us Executive Group Member



Folk.us is delighted to report that we have been awarded funding for a further two years from the Department of Health. This funding takes us up to March 2010.

As you probably know, it is our role to bring the world of research and researching to people who use health and social care services across Devon. We do this by supporting and creating opportunities for both collaborative research and service user, patient and carer-initiated research. Our grant from the Department of Health is administered by the Peninsula College of Medicine and Dentistry.

Folk.us will have four part-time members of staff by May 2008. Our membership of approximately 300 people is made up of service users, patients and carers, people who work for health and social care service providers, and academics and researchers.

Folk.us has an Advisory Group whose role is to guide and help our work. We also have an Executive Group whose role is to support and inform Folk.us and ensure that we are following our work plan and adhering to our aims and objectives.

The Folk.us Executive Group includes the Folk.us Grant Holder, Director/Coordinator, a representative from the academic field/health professional researcher and two service users (patients or carers). The Executive Group meets four times a year and receive an attendance fee (at visiting lecturer rates) and travel expenses for each meeting.

We need a new service user, patient or carer member to join the Folk.us Executive Group

**Are you interested in joining the Folk.us Executive Group?
If so read on!**

What would you need to do as a member of the Folk.us Executive Group?

We would like you to attend and take an active part in meetings of the Executive Group. If possible, we would like all the members of the Folk.us Executive Group to come to each of the meetings. There will be four meetings a year in Devon (mostly Exeter). We do realise that there may be times when not everyone can get to a meeting, when this happens we will need the Folk.us Grantholder or the Director and a service user or carer member to be at the meeting. Any decisions taken at these meetings will need to be agreed by the Folk.us Grantholder.

We would like you to help oversee the implementation of the Folk.us work plan, and to monitor whether Folk.us is meeting its stated objectives each quarter. (Have we done what we said we would do).

We would like you to ensure that the Folk.us budget is being managed appropriately. (Have we spent our money on the right things and not spent too much).

We would like you to feel able to challenge and question Folk.us activities. (Ask about what we have done and why we did it).

We would like you to have an interest in national research initiatives and policies.

We would like you to be available for consultation (by phone or email) for matters arising between Executive Group meetings.

We would like you to attend as many Folk.us events as possible. (Come along to our Forums, Advisory Group meetings and our Conference, when you can).

We would like you to read and comment on Folk.us publications such as new policies, annual reports and the website etc., as necessary.

We would like you to attend training (if necessary) in line with University requirements e.g. with regard to recruitment. This will be done in negotiation with you and with the full support of Folk.us.

Please turnover

How long would you be a Folk.us Executive Group Member for?

Tenure is for the length of the funding period, possibly renewable. (This means that you would be a member for two years, the length of our current grant).

If possible, we would like you to give three months notice of resignation from the Executive Group.

What would you need to bring to the role?

You need to be:

- 1) Either a service user, a carer or patient (with a lot of experience of being a patient).
- 2) Current member of Folk.us and have some experience of working with Folk.us either on the Folk.us Advisory Group (which used to be called the Steering Group) or in some other way.

You need to be willing to work as part of a group, and to listen to others' views and to reach decisions and/or recommendations in a relatively short period of time.

How do you apply?

Please fill in the application form and send it back to Rachel at Folk.us using the address on the form.

What happens once you apply to join the Folk.us Executive Group?

The Folk.us Grantholder (Katrina), the Folk.us Director (Rachel), and the Folk.us Executive Group member who is a service user (Andrew), will look at the applications.

We will agree who should be asked to come and talk to us further on **Friday 9th May 2008 between 12 and 2pm.**



Rachel will contact you either by letter or phone to tell you if you need to come in on the 9th May. On that day Katrina and Andrew will meet with each person and then decide who would be best as an Executive Group Member.



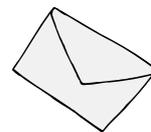
For more information please ring Rachel on: 01392 403049



Folk.us Executive Group Member Application

Please return this form by Wednesday 30th April 2008.

To: Rachel Purtell, at Folk.us, Room 407, Noy Scott House,
Royal Devon & Exeter hospital, Barrack Road, Exeter EX2 5DW.



Your Name: _____

Your Address: _____

_____ Postcode _____

Your telephone number: _____ Your email: _____

Do you need anything for 9th May 2008, eg special Diet?

Can you give an example of when you have taking part in a meeting?

Can you think of a question you might ask Folk.us about our work?

Can you say something about a national research initiative or policy?

Please turnover



Please can you say one thing that you feel is important about your experience as a service user, or carer or patient?

Please can you say something about how you have worked with Folk.us?

Please say what you like about working in a group?

Please tell us why you would like to join the Folk.us Executive Group?

Thank you for fill in this application. Please send it to Rachel at the address given at the beginning of the form. Rachel will be in touch with you about your application.

Appendix 2

Terms of reference of the Folk.us Executive Group and Advisory Group

1. Reasons why Folk.us Executive Group and Advisory Group terms of reference and working practices need reviewing:

- Folk.us is about to take on an extension to the existing contract which expands its work across Devon and concentrates its work into some very specific activity areas. This has important implications for Folk.us capacity. It is important that 'governance' arrangements fully support capacity for the new contract.
- The current expectations concerning communication, reporting and responsibilities between the groups and the director and grant holder need to be sufficiently clear.
- Clarifying roles and responsibilities will make Folk.us easier to run.

Grant Holder - half a day/week: The Grant Holder has overall responsibility for the project, oversees the project on a day-to-day basis and has overall financial authority. The Grant Holder will also be involved in training activities and in dissemination of Folk.us activities where appropriate.

Folk.us Director - 4 days/week: The Director will have responsibility for the day to day running of the project, including authorisation of running costs and will be responsible for the management of the Folk.us staff, e.g. the Research Fellow and Administrative Officer. The Director will promote the work of Folk.us, give presentations and talks, develop training content and programmes and will negotiate the Folk.us role with Research Networks, national and local organisations. Their role will include dissemination of Folk.us activities in journals and publications, reporting to the Department of Health annually. The Director will be accountable to the Executive Group and the Grant Holder.

Research Fellow - 2.5 days/week: The Research Fellow will provide research support and give advice to research projects under the guidance of the Director. Their role will be to work alongside research projects supporting service users, patients and carers and to researchers and research managers to create meaningful and constructive involvement. They will also be responsible for and oversee contact with Folk.us members.

Administrative Officer - 2.5 days/ week: The Administrative Officer will provide support to the Folk.us Director and Research Fellow. Main duties will be maintaining office systems, communicating as directed with the Executive Group, Folk.us Members and the Steering Group, and providing administrative support to research projects as appropriate.

2. The Executive Group (who are not part of the Folk.us core personnel), will be paid on a hourly visiting lecturer rate for their time and attendance at Executive Group meetings.

- The members of Executive Group have no legal responsibilities or duties.
- The members' roles are voluntary and informal
- Members of the Group should be one person working within academia or NHS healthcare services with a research interest, one person who has substantial experience using healthcare

services (and Social Care Services) and one person who has substantial experience using healthcare services (and Social Care Services) or who has experience as an informal carer for someone who substantially uses healthcare services (and Social Care Services). All members need to have some knowledge of the work Folk.us undertakes. (Grantholder and Director are permanent members of the group).

- To be available to advise and guide the day-to-day activities of Folk.us based on the reporting of activities from the Director.
- To beware of the contractual agreement and raise questions about Folk.us activities so they adhere to the agreement.
- To beware of the financial situation of Folk.us and raise questions to ensure finances are used in accordance with carrying out the Contractual agreement and Folk.us Workplan.
- The role is time limited.
- The Grantholder is informal accountable to the Executive Group but formally accountable to the Head of Department in the Grantholding Organisation (Peninsula College of Medicine and Dentistry) who is in turn accountable to the funding body (Department of Health).
- The Director is informal accountable to the Executive Group but formally accountable to the Grantholder (if they are also the line manager).

If there is a concern that is not address then the members can seek readdress through?? PMDC and ultimately through the Department of Health?

3. The Advisory Group

The Folk.us Steering Group is made up of Folk.us members and is chaired by an Executive Group member. The members of the Advisory Group offer advice and ideas on how to promote and develop patient, service user and carer involvement in research across Devon (including Plymouth). As a result of this remit the Advisory Group comprises of people who have knowledge and experience in this area. It is a multidisciplinary group and we have at least equal numbers of service users/patients/carers and professionals as members.

- The members of Advisory Group have no legal responsibilities or duties.
- The members' roles are voluntary and informal
- Members of the Group should be people working within academia or NHS healthcare services with a research interest, and people who have substantial experience using healthcare services (and Social Care Services) and people who have experience as an informal carer for someone who substantially uses healthcare services (and Social Care Services). (Grantholder and Director, Folk.us Staff and Executive Group members are permanent members of the group).
- The group advise on activities that Folk.us need to be aware of.
- To suggested activities Folk.us could undertake
- Folk.us Director reports on activities to the group.
- The role is time limited.

If there is a concern that is not address then the members can seek readdress through?? The Executive Group then PCMD and ultimately through the Department of Health?

4. Relationship between Executive Group and Advisory Group

- The relationship between the Executive Group and Advisory Group is informal
- Reporting to each group is the responsibility of the Director and Folk.us Staff.