



Newsletter

Autumn 2009

Welcome

'Turning The Tide'
4th Folk.us Conference
Tuesday 6th April 2010, Exeter
More details inside.



Hello everyone,

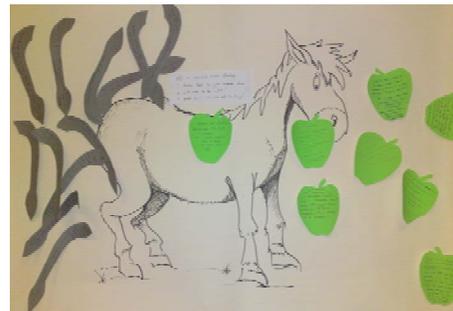
I know it has been a while! Last October, we had just got sorted with new staff in post. So it's been an exciting year of filling out our work programme, taking on some new areas of work and being guided by the interests and experiences of our members. It took ages to sort it out, but thanks to the support and encourage from our Executive Group to keep pushing, we now have new office furniture, meaning we can all fit in the same room and all work at the same time. This is revolutionary and probably more exciting for us than for you, but I thought we should mention it one last time! We should also say thank you to the Peninsula Medical School who funded it!



You might notice, that this is the biggest newsletter we ever produced, that is because we have never been busier and have had so much to say.

We have three new research projects up and running. You can read more about these further on. The 'Past Caring' team who have designed a completely carer-led initiative, with carers involved as partners in every stage of the research project. The 'See Me' Project is a dynamic disability arts project that will turn a few heads and we are working up a joint Headway and Folk.us members' project with the new steering group. Other new projects are in the pipe-line.

For strategic and policy work, there is never a quiet moment and we have lots to share: involving service users in proposal reviews, on-going work with finance and lots of interaction with the research networks are some of the areas. In more scholarly areas, members Susan Ambury and Michael Swindlehurst have been involved in writing a paper for publication about paying service users. We presented a workshop at the 'Critical Perspectives on User Involvement' Conference at Hove Town Hall in April (See the donkey below) and more writing from this will follow soon. A book chapter co-written with the workshop participants is a possibility. One participant said: 'As a service



user donkey, I know that to get research done, I will need to be 'ridden'. I prefer bosses who are not too heavy!' So some great material to work with there.

You'll see we're gearing up now for the 4th Folk.us conference, which is going to have a most stimulating programme maybe one of the best ever, so if you're not involved yet, please let us know what you'd like to do and book a free place. It will be great to see you on the day. I can't say more yet, but we have a few surprises set up for your entertainment that day too which must not be missed! And of course, there are the usual Folk.us forums and training events coming up too, so do have a look at those in this issue too. As always let us know if you have a fresh idea for us to explore.

Hope you enjoy this edition.
Rachel – your Folk.us Director

Projects we are working on:

A service user led project with Headway Devon

We are developing a local research project with people who have experienced head injuries, www.headway.org.uk. A group of service users have joined to form a steering group and we have collected possible research topics from Headway members. Talks have now started with PenCLAHRC, (more details further in the newsletter), to see if we could put forward this question to them to take on.

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

This is another local project that we are working on. It developed through discussions at our Folk.us Advisory Group. Three Folk.us members are now working with us to do this project. It has just been submitted to the Ethics Committee.



'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 enquiry. 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 her service users want to start a research project to evaluate quality of life and self esteem outcomes linked to this work. We have started to plan the work and think through the research instruments, methodology and possible funding sources required.

Finding a way to pay in the UK: Methods and mechanisms for paying service users involved in research projects'

Folk.us is also doing more policy and strategic work. We are doing some work about paying people who get involved to try and stop it being so complicated! We have just completed this literature review. It was peer reviewed by two of our Folk.us members; Michael Swindlehurst and Susan Ambury, and an external expert; Peter Beresford (many thanks to you all!). It is now with the publishers – watch this space!!



Do *you* have any research project ideas?

Please get in touch with the Folk.us office. Our details are on the back of this newsletter.

Update on past projects:



Experiences of people using strong opioid drugs for chronic non-cancer pain

Two articles have been produced about this work and both appear on our website by the kind permission of British Journal of General Practice.

Dr David Seamark has given us the following update about what has happened since this project was published:

‘The pain control work continues with Sue Blake coming near the end of her MPhil. This has involved focus groups and interviews with GPs exploring their attitudes to prescribing strong opioid drugs for chronic non-cancer pain. Based on their responses we have conducted a survey of all GPs in Devon and Cornwall asking for their views on prescribing for these patients. We are just at the point of analysing the replies and then writing a paper which we plan to send to the British J of General Practice (as that was where our paper with Brian was published.) We have developed links with a pain research group at Bath University and hope to do more work in the future.

The original paper has been widely read and quoted and we have had professional contacts resulting from it. Thanks again to Folk.us for supporting that work and especially for empowering Brian to get involved in research.’

A qualitative study of migraine involving patient researchers’ (Belam, Harris, Kernick, Kline, Lindley, McWatt, Mitchell & Reinhold 2005)

This was a collaborative project undertaken by people who experience migraine and clinicians and researchers. The article appears on our website by the kind permission of the British Journal of General Practice.

David Reinhold has informed us that following on from this initial work they did a second piece of work with migraine patients interviewing GPs. This has been written up and he is currently trying to get it accepted for publication. He has also written a theoretical paper with Annie Mitchell which is in press with the Journal of Interprofessional Care (Kernick D, Mitchell A. Working with Lay People in Health Service Research: a model of co-evolution based on complexity theory. *Journal of Interprofessional Care (in press)*).

“I have developed an interest in headache in children and very recently I have been using a similar approach where school children have been interviewing other school children in a qualitative piece of work to determine the problems with headache in school. I am currently writing this up”.

David Reinhold summarises that this has led to some innovative work but what it does teach us is that we shouldn't underestimate the time it takes to move things through.

‘An Assessment of Service Provision at the point of Diagnosis of a Permanent Sight Loss in Devon’

The research led to significant changes during the research period brought about through/by influential services providers who were members of the Research Advisory Panel.

These included:

- Change to blind registration process in the RD&E to be quicker and more effective leading often to a shorter rehabilitation period
- User involvement in a new registration process
- Patients being given written information to take away with them explaining the registration process and next steps
- A more holistic approach to servicing newly registered people to include emotional support and the needs of their families
- A peer support set up at the hospital for newly registered people to meet and talk
- A library of fact sheets on eye conditions available upon request from both health and Social Services
- Provided LOD with significant experience in supporting service users to carry out future user led research
- The research findings were published as support evidence in RNIB Project Report: ‘Making The Link’

The research also led to Living Options:

- Being commissioned to carry out ‘Torbay & South Devon Visual Impairment Research Project’ funded by RNIB (2005) to find out if the closure of its rehabilitation centre for visually impaired adults (Manor House Torquay) left a gap in services, as perceived by visually impaired adults in Torquay and surrounding area of South Devon.
- The Sensory Priorities Survey 2008 which asked What helps people with Sensory loss in their daily lives? What stops people with sensory loss living how they want to live? What improvements and additional improvements are required? the report of which led to an action plan being instigated by Devon Strategic Partnership.

Full reports and summary Reports of all the above are available from info@livingoptions.org
Tel: 01392 459 222

Meet a Member.....

Brian is a former sportsman who is paying the price of injuries. Research involvement and being part of a team which has had work published (the opioid project mentioned on the previous page), has given him the opportunity to help others, along with all those who have helped him. He is an active member of Folk.us, and is currently working on the 'Bereaved Carers Project' with us.



1) What is your favourite film or television programme?

Once upon a time in America

2) Who would be your ideal dinner companion, past or present?

Robert De Niro

3) What has been your happiest day so far?

The day me wife Iris said 'yes' to marry me, and the birth of my two daughters.

4) How did you come to be involved with Folk.us?

Through a meeting at Honiton with my GP, Dr David Seemark, and Rachel Purtell.

5) What have you personally got out of being involved in research?

I have gained confidence, reassurance about my health, and met many great people.

6) What words of advice would you give to a service user who is thinking about getting involved in research?

Give it a try, you never know what can be learnt or gained if you don't give it a try.

Seize the moment!

7) If you could choose a research project to get up and running, what would it be?

The real in depth relationship between doctor and patient. Truth, sincerity and openness would have to be a paramount issue or it would not work.

Website Updates



We have got some new items on our website so take a look:

www.folkus.org.uk.

If you do not have access to a computer and would like to be sent copies of any of these items then please let us know.

Personal stories from three of our members:

David Robinson – Head Injury
– An Insider’s Way of Managing It

Andy Palmer – A Wealth of knowledge
– living with Parkinson’s Disease

Peter Buckingham – Brain Injury
– ‘A hidden disability’

(Let us know if you would like to share your personal story).

“There is certainly a point in us accepting that things have happened and that we now have this or that mental or physical problem, to some extent - possibly for life. That does not mean that we sit back and do nothing. We are no different from anyone else, and if they want to get fit, or change their habits, or become somewhat different they work for it.”

“Do you suffer from your illness or because of it. I think there is a big difference. The difference is whether you take a positive or negative attitude with regards to getting on with your life and the direction that it takes.”

“After my discharge it seemed as if the Health Service didn't exist. I maintained contact by giving talks on my experience to the NHS staff who treated me.”

Communication Strategy – how to communicate at Folk.us Meetings.

This was put together by the Executive Group and gives guidelines on how to conduct meetings to make sure everyone is heard and feels comfortable.

Folk.us guidelines for service users peer reviewing journal articles.

This document has been prepared to help Folk.us members /service users who are interested in reading and commenting on journal articles and other written papers before they are submitted for consideration for publication.

Have a look at our **discussion forum**...we need to hear more of your opinions.

There are discussions about:

- Pets, Children and Partners involvement with Folk.us events
- Economic evaluations in health/social care
- Evaluating service user involvement
- Recruiting people without making judgements
- Alternative ways of chairing meetings

If you have any problems with registering then please phone or email us.

Other News



For more information look
at:
www.clahrc-peninsula.nihr.ac.uk

My name is Andy Gibson and I have recently been appointed as Research Fellow for Patient and Public Involvement with the Peninsula Collaboration for Leadership in Applied Health Research and Care or PenCLAHRC for short. PenCLAHRC is a new collaboration of Universities and NHS organisations in the South West of England which aims to deliver high-quality health research that improves medical practice. An important part of this work will be ensuring that the research carried out by PenCLAHRC addresses issues that are relevant to patients and carers and results in beneficial new treatments and services. My job is to help ensure that this happens by developing meaningful involvement of service users and carers throughout the PenCLAHRC research process. My initial task is to meet the people already doing PPI work in the Peninsula, and to facilitate patient and carer involvement in the generation and structuring of research questions. I'm working closely with Folk.us so that my work builds on, rather than duplicate, the excellent PPI work already underway locally.

Chronic illness and Self-management A research study at the Peninsula Medical School

I am Lucy Moore and I am a research student at the Peninsula Medical School in Exeter. I am carrying out a study to explore how older people with heart problems and other long term conditions manage and cope at home, how they care for themselves and what kind of support they seek. I have recently received support and guidance from a user involvement group and would like to share this positive experience.

Members of the Peninsula Stroke Research Network and the Peninsula Cardiac and Stroke Network were invited to help me with the design of a 'health diary' I wanted to give to patients as part of my study. I was particularly interested in how the diary should look, how many questions should be included and what kinds of questions would be helpful when asking older people how they manage and cope with chronic illness on a day-to day basis.

The response to my request for help was very positive and I had offers from over 45 members. People either offered feedback by telephone, email, by letter or at one of their regular public involvement meetings. Several members also agreed to meet once a week over a month to discuss the kinds of questions, layout and design of the diary. Everyone involved was kind enough to share their experiences of managing with a chronic condition and their comments and opinions were helpful in shaping the way I structured the diary and the research study as a whole.

The Torbay and Devon NHS research ethics committee has now approved the study (Reference no: 09/H0202/47). The next step will be to send letters of invitation to general practices in the county of Devon to invite them to help. Practices that chose to participate will then be asked to invite 30 patients to take part.

I hope this study will lead to a better understanding about how older people manage and cope with chronic conditions. Advice and support from the user involvement group has been invaluable.

If you have any comments concerning this study you are welcome to contact me: **Lucy Moore: Post-graduate Research Student at The Peninsula Medical School**, Institute of Health Service Research, St Luke's campus, Exeter, EX1 2LU. **Telephone: 01392 262858.**
Email: lucy.moore@pms.ac.uk

Folk.us Training Workshops

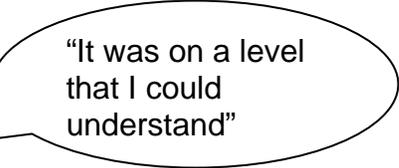
In response to members, Folk.us has agreed to put on a number of accessible research methods workshops to help service users think about the research that they most want to do. The first of our new series was a 'Grounded Theory Workshop' which took place on 11th December at Exeter University and attracted a fascinating group of participants. This workshop introduced Grounded Theory as an exciting method for qualitative health research. It was aimed particularly at service users to wet appetites, to satisfy curiosities, to demystify complex methods and to give people a chance to have a go and see if they liked it.

We explored how Grounded Theory affects the way a research study is conducted, from preparation through to the format and style of interviews and the approach to analysis. We experimented with different Grounded Theory techniques, with opportunities to apply them to real data. No previous experience was necessary, there were no right and wrong answers and everyone's contributions was welcomed and valued.

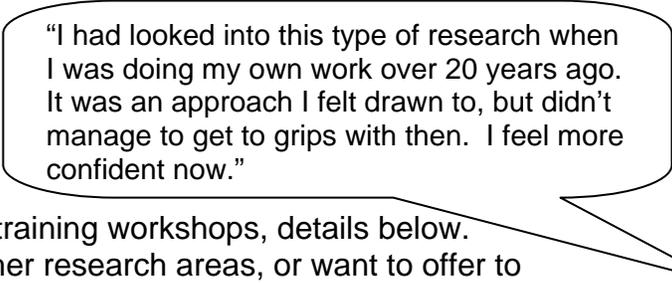
The feedback made us think we should definitely follow up with more methods workshops.



"I enjoyed it very much"



"It was on a level that I could understand"



"I had looked into this type of research when I was doing my own work over 20 years ago. It was an approach I felt drawn to, but didn't manage to get to grips with then. I feel more confident now."

So we plan two forthcoming qualitative methods training workshops, details below. If any members want particular training in any other research areas, or want to offer to provide training to members, perhaps in partnership with others, please do let us know.

Qualitative Methods I: What methods could I use? Research design and planning

This workshop will consider a range of qualitative methods: different types of interview, focus group, observation, participative video and text-based designs. It will introduce and share examples of how they can and cannot be used and we will think through how to adapt them for innovative service user project designs. The workshop will encourage everyone to try out new approaches and gain depth about approaches already used.

Monday 7th December 2009, 10.30am – 1.30pm and will include a light lunch. It will be held in Exeter, venue will be confirmed shortly.

Qualitative Methods II: Making qualitative designs work

This second qualitative workshop will look at the nitty gritty of preparing question guides, observation recording units, sound recording, communication techniques and other practical aspects of actually preparing and doing qualitative research. It will provide opportunities to hone interview skills, practice facilitating groups and use technical equipment within a supportive environment.

Thursday 21st January 2010, 10.30am – 1.30pm and will include a light lunch. It will be held in Exeter, venue will be confirmed shortly.

If you would like to take part in either, or both, of these workshops, please complete and return this form to us, or book your place on-line at www.folkus.org.uk

Folk.us Workshops

Qualitative Methods I: What methods could I use? Research design and planning
7th December 2009, 10.30-1.30pm (incl. lunch), Exeter (venue t.b.c.)

Qualitative Methods II: Making qualitative designs work
21st January 2010, 10.30-1.30pm (incl. lunch), Exeter (venue t.b.c)

Name:

**Phone
Number:**

Please tick the following:

I would like to attend both workshops

**I would just like to attend the first workshop in December:
Qualitative Methods I: What methods could I use?
Research design and planning**

**I would just like to attend the second workshop in January:
Qualitative Methods II: Making qualitative designs work**

Address:

Email:

Do you have any special dietary requirements?

Is there anything you need us to do to for this meeting?

Please return this form to: Folk.us, Room 407, Noy Scott House,

Royal Devon and Exeter Hospital, Exeter, EX2 5DW

For more information phone the Folk.us Office on 01392 403049 or email folk.us@ex.ac.uk

Folk.us Forum

Older People's Project: Medication Safety and Chronic Illness

Thursday 19th November 2009, 12.00 – 14.00, Exeter (venue t.b.c.)

Free to Everybody
A light lunch will be provided

Come and meet other people interested in Involvement in Research and hear a presentation:

Anne will be talking about how she has been supporting a panel of 10 consumers (aged 67 – 90) for the past 3 years who have been involved in 2 research projects. The consumer panel have identified issues that have potential to impact on safety and lead to hospitalisation for adverse medical events, ie. Lack of proper dosing, instructions of medicines. The consumers have also raised other issues like the confusion surrounding generic medicines and continuity of care.

“All these issues have been raised and driven by having consumer involvement in these projects and not anything that was expected by the researchers when the projects were developed”

Anne Mackenzie from the Centre for Health Services Research, Perth, Australia

If you would like to come along, please complete and return this form to us, or book your place on-line at www.folkus.org.uk

Name:

**Phone
Number:**

Address:

Email:

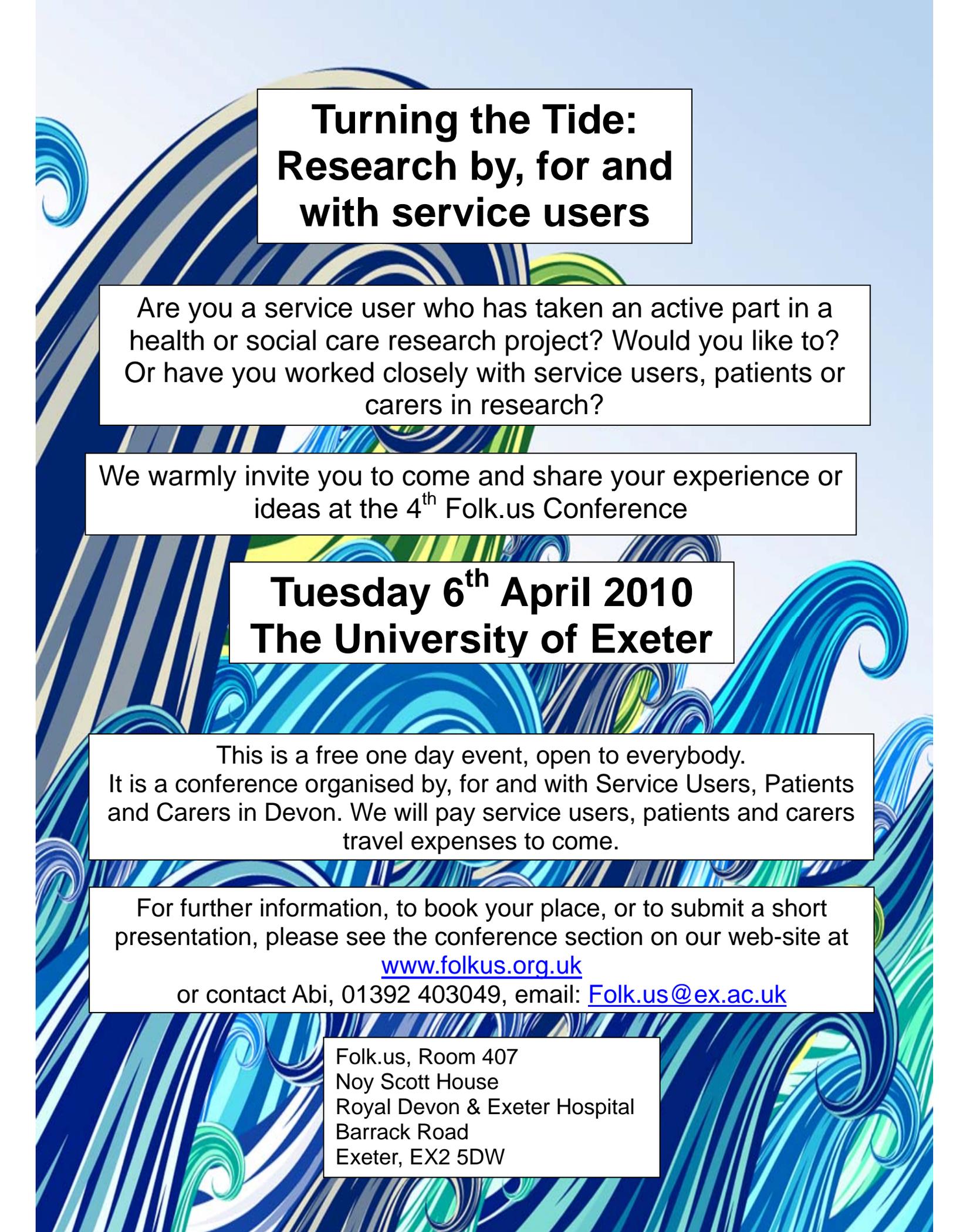
Do you have any special dietary requirements?

Is there anything you need us to do to for this meeting?

Please return this form to: Folk.us, Room 407, Noy Scott House,

Royal Devon and Exeter Hospital, Exeter, EX2 5DW

For more information phone the Folk.us Office on 01392 403049 or email folk.us@ex.ac.uk



Turning the Tide: Research by, for and with service users

Are you a service user who has taken an active part in a health or social care research project? Would you like to? Or have you worked closely with service users, patients or carers in research?

We warmly invite you to come and share your experience or ideas at the 4th Folk.us Conference

**Tuesday 6th April 2010
The University of Exeter**

This is a free one day event, open to everybody. It is a conference organised by, for and with Service Users, Patients and Carers in Devon. We will pay service users, patients and carers travel expenses to come.

For further information, to book your place, or to submit a short presentation, please see the conference section on our web-site at

www.folkus.org.uk

or contact Abi, 01392 403049, email: Folk.us@ex.ac.uk

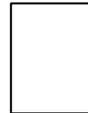
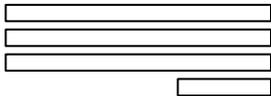
Folk.us, Room 407
Noy Scott House
Royal Devon & Exeter Hospital
Barrack Road
Exeter, EX2 5DW



Programme 2009/10

19 th November 2009	The Older Peoples Project Forum: Medication Safety and Chronic Illness	Exeter
7 th December 2009	Qualitative Methods I: What methods could I use? Research design and planning	Exeter
21 st January 2010	Qualitative Methods II: Making qualitative designs work	Exeter
6 th April 2010	Folk.us Conference 'Turning the Tide'	Exeter

Folk.us Contact Details:



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



Tel: 01392 403049

Email: folk.us@exeter.ac.uk

www.folkus.org.uk



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