



*Turning the Tide
Programme*

6th April 2010





10.00 am Chair Peter Beresford

Peter will open the conference with a welcome address. Peter said: 'Dear friends, I want to add my welcome to you to a day that should really be a help to all of us who want to take forward Research by, for and with Service Users. When it comes to trying to get involved, it can sometimes feel as though you are swimming against the tide, with very strong and difficult currents to deal with. But I think this conference is well named – because we are at a time of real change – where Turning The Tide for the better is a real possibility. I am a service user researcher committed to increasing user involvement in research and ensuring it gets the credit, support and resources it should have. I hope that everyone coming to this conference will feel that the conference gives them opportunities both to learn more from each other and to express their own voice and experience.'

10.10am KEYNOTE 1: Rachel Purtell

Welcome to 'Turning the Tide' the Folk.us conference. 'Turning the tide' 'Holding back the flood' and there's a host of another phrases we could use to talk about involvement in research. I'm asking the question 'Can involvement still shake the trees?' We know there are still huge issues and barriers facing meaningful involvement in research, including time issues, money issues, too much tokenism, different agendas that compete, structures that don't sit well when involving people, the use of jargon is still rife. But what I want to talk about is why we still do involvement and why it still matters. We can shake the trees and turn them on their heads if we try!

10.30am Scott Walker - Building Involvement Session

This is the first and only time that everyone at this conference will be together in this way. To get the most out of this special occasion, this session aims to get people talking to each other through doing a joint task. Its goal is to build involvement in the conference itself. The session will be led by Scott Walker, a local Devon-based artist who specialises in cartoon design and creative workshops. Using Scott's materials to release our creative juices, we aim to brainstorm the characteristics of involvement that each of us brings to the conference. The workshop aims to be fun and enlivening. It is designed in a very open way for you to get out of it what you want.

11.10am PRESENTATION SESSIONS - morning

1. Lisa Ponting & Val Williams –‘The Voice’: Doing research as people with the label of learning disability

This is a short talk from members of the Voice group at Norah Fry Research Centre, about the ways in which we do research as people with the label of 'learning disability'. We have strong ideas about the things that should be researched, and also about the type of support we need. We will talk about a project we finished two years ago, called 'Skills for Support. We worked as a team with a non-disabled researcher, and with supporters. We will also talk about a project we are planning, about hate crime and bullying. We want to make sure research makes a difference, and we will show an example of how our research has helped people to be trainers for their own supporters.

2. Peter Buckingham & David Robinson - Developing a user led research initiative with Brain Injured People

We will talk about the process of developing a research project with people with brain injuries at Headway, Devon. The project plans to look at peer support and rehabilitation after brain injury. It is a service-user led focus group study of the views and experiences of people with brain injuries in Devon. This presentation will concentrate on describing the

process of setting up the research. It will describe why we want to do the project, how the project team got together and how we focused the topic. We will talk about some of the challenges involved in this process. We will also explore how this project may be different from a project on the same topic that does not originate with service users themselves.

3. Sue Hitchcock, Alison Lott & Genevieve Riley- 'INCLUDE ME': Creating a service user led evaluation tool

Since 2004 the National Social Inclusion Programme (NSIP) has coordinated the delivery of an action plan to address social exclusion and has developed a set of capabilities that capture best practice to drive the transformation of services and promote socially inclusive outcomes. The INCLUDE ME Project was a subsequent user led project that successfully tendered to NSIP to create a service user lead evaluation tool that could assess and monitor the extent to which a service demonstrates inclusive capabilities. Using a modified Delphi approach, a team of 6 service users and carers, supported by a Trust Researcher, identified the priorities for inclusive practice within Gloucestershire. These priorities were then incorporated into a service user and carer assessment tool. This paper will present the tool and report on the process of its development, and challenges faced by the project team in meeting the expectations of different partner agencies.

4. John Gillett & Katie Sarra -'See Me': Disabled people's evaluation of having their bodies painted.

'See Me' is an evaluation, led by disabled people, to look at an innovative project to paint the bodies of disabled people. A Tiverton artist has been doing oil paintings of disabled people. Some of these people, on the receiving end of being painted were inspired to think more about the actual experience of being painted, what it can do for you and how it leaves you feeling afterwards. In this presentation we will talk about working together with researchers to undertake active research examining artistic practice and fit with disabled

people's needs, body image and self esteem. We will show some of the paintings and talk about planning the project, looking for funding, running initial focus groups and setting before and after measures.

5. Rose McCausland and Poppy- Unexpected partnerships: Trafficked women working with the Metropolitan Police

At Living Lens we overcome breakdowns in communication using video. Our goal is to launch a process of collaboration and positive change that will continue long after our project is complete. Living Lens has a track record of delivering successful projects on trafficking and other sensitive issues. We recently completed Fresh Start, a project building partnership and understanding between the Metropolitan Police and trafficked women. The project produced many unexpected results.



Programme:
Afternoon Sessions

Turning the Tide: Research by, for and with
Service Users, Patients and Carers

1.20pm Chair **Alex O'Neill**

As we continue to examine this idea of research involvement turning the tide, the afternoon sessions will bring you another spectrum of fascinating projects and ideas. These focus on different aspects of the research process and different research activities. Again, we are trying to look at work with and from very different groups of people. Then we have some Master Classes. We want to use these as another way of sharing information and hopefully a chance for every single person here to have a direct input. At the end of our Classes we will all return to the main conference hall and Peter Beresford will draw together what has come out of the day.

1.25pm **KEYNOTE 2 Dean Harrison: So what, Now what?**

This paper is a candid look at where we have got to with involving service users in research. Drawing on stories from experience, I have challenged myself to think carefully about why I started doing this, where I get my satisfaction and why I still do it. I will describe some ways things have changed over time for me. I will mention some key issues that have bothered me: paying service users, tokenism, limited chances to influence policy, troubles over professionalising service users. And from this reflection, I will move, not to solutions for the future, but honest questions we can ask ourselves to keep service user involvement worth it and attractive to you and me.

1.45pm

PRESENTATION SESSIONS - afternoon

1. Patsy Staddon – Power in the Research Process

When I began my service-user-led research for an NHS Trust, I believed my respondents had the power, as they could always say 'no!' I came to realise that service users and professionals may be affected by many factors, and that my power, and my responsibility, was much greater than I had realised. What benefited those who were involved was that we worked outside the confines of treatment centres, and people spoke to me who had never spoken about their experiences to anyone before. This was empowering for us all, yet since the research conformed to strict ethical requirements, similar methods could be used in other research.

2. André Hutchinson, Gill Colerick, Pat Atkinson & Pam Herd – Can service user stories make a difference?

Our exciting research project for Montgomeryshire, Powys: Involving service user's stories in developing mental health services: the process of capturing, enabling and supporting Service User's expertise and experiences. The research question is "what are the experiences of service users and can these be collected in such a way that informs the local planning process? The NHS National Service Framework for Mental health (1999) recommends that all mental health services must be planned and implemented in partnership with local communities and involve service users and carers. This research aims to inform those who plan mental health services in Powys, of service user's experiences of those services, especially the experiences of those who would not normally be involved in any consultation process. Andre is working alongside 6 service users as researchers and 28 stories have been audio taped to date. These are now being mapped with many key themes and opportunities for development emerging. The Research is now well under way and has been presented at the Powys Nursing Conference at Builth, to the Welsh Assembly Audit Office and the Chief Nursing Officers in Cardiff. It is hoped to present a final report in April 2010 to all stakeholders concerned and articles publishes in key nursing and social care publications.

3. Kristin Liabo, Kerry Gray & David Mulcahy - Developing a Protocol for a Systematic Review

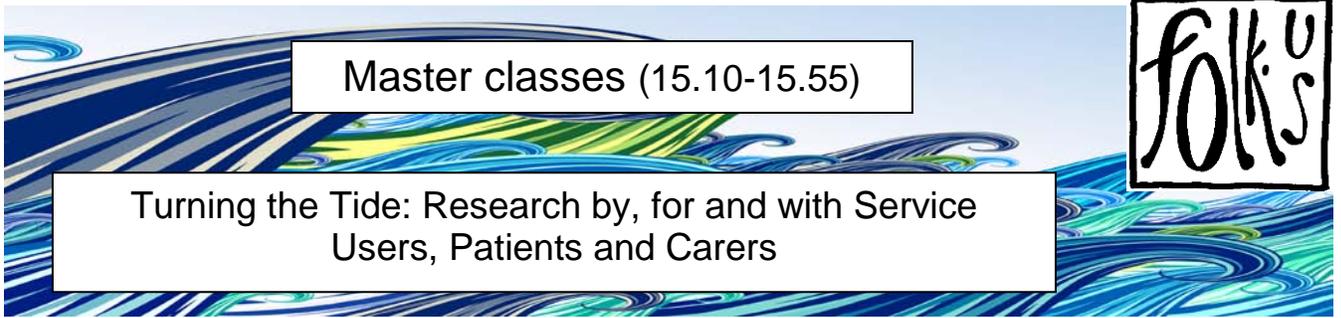
We are young people with experience of being in care, and one researcher. Our research project was initiated by the researcher, and we are working together to produce a systematic review relevant to looked after children's health. We have met over a period of one year. First, we spent some meetings discussing topics relevant to looked after children's health. We decided to focus on education, because education has a strong influence on adult health. We then spent several meetings coming up with a research question. Finally, we developed a systematic review protocol. We now have a protocol titled 'Interventions to support looked after children to stay in school'. This presentation will describe how we have worked together to produce the protocol. We will talk about how we made specific decisions and also the kinds of compromises we have had to make along the way.

4. Rosemary Whitehurst - 'Past Caring' – emancipatory research about bereaved carers

We're working on a small project where six bereaved carers will use a variety of methods (interviews, digital story telling, participative video) to do a research study of carer bereavement. We will all be participant researchers involved in research design, data collection, data management, data analysis, write up and dissemination. A high level of research training and technical support has been built in too. This presentation is about why we think this (expensive!) research design will work. It is also about the barriers and challenges we have already faced and thinking about those still to come. Is this emancipatory research?

5. Rosie Davies & David Evans – Improving collaboration in involvement in research

We have been doing a project on improving support for public involvement in health research. Many different organisations are trying to work out how best to involve people. Rather than doing this alone, a group of fourteen NHS Trusts, universities and research networks have come together to share their experiences and learn from each other. Patients and service users who have helped with research in these organisations have also taken part. Our short presentation will share some of our key findings and recommendations which will focus on how organisations could better work together to improve support for public involvement in research



Master classes (15.10-15.55)

Turning the Tide: Research by, for and with Service Users, Patients and Carers

1) Show me the Dosh – What funding is out there and how do I get it?

Annie Hawton & Geoff Barr

What funding is out there and how do I get it? How do I find a funder who might be interested in my work? Which funders are particularly interested in research involvement? How do I approach funders? What might improve my chances of success? What makes my research attractive to fund? In this workshop an experienced health/social care researcher and a Service User researcher will take you through what funding is out there and how to get your hands on it. They will run through examples of some funders who are currently showing an interest in funding involvement in health and social care research. There will be plenty of chances to contribute your experiences and they hope to gather lots of funding examples from service users.

2) Velvet Voices – Tips to develop your public voice.

Derek Stewart

How do you feel about speaking in public? How do other service users, patients and carers feel? Are there any tricks and tips to make public speaking less stressful and more fun? What makes my research attractive to people listening? How do I select certain moments from my story to highlight specific issues? In this workshop an accomplished public speaker will take you through some tips and tricks. He will give you opportunity to try out some new ideas in a relaxed and friendly group. There will also be chances to share your past experiences.

3) Speed Date Research Ideas – Bring your research ideas to shape and get advice.

Wendy Rickard & Deirdre Ford

Do you have a research idea that you would like to turn into a research question or get others interested in? Do you want to make the involvement of service users, patients and carers central to your design? Would you like to meet others who are imagining and planning research and share ideas about how to take it forward? This master class aims to be fast and fun, taking research ideas brought by delegates and in some cases turning them into research questions and projects. For other ideas, we may find delegates at the master class who want to join you to work up your idea in a more long term process. Together we hope to explore paths to sketch out a way forward. The master class hopes to help shape and share new research ideas that have strong involvement. Everyone's contribution will determine how this master class turns out. Bring your ideas.

4) Talking to the Press – Tips to get stories into newspapers and TV

Paul Henderson & Elaine Hewis

How do you gain access to the media (newspapers, TV and radio) and get your voice heard? How do you get your stories about research out to the public? In this workshop a top media professional and a service user researcher with lots of experience of working with the media will take you through what makes a news story, how to approach journalists and deal with the press, and how to use images. There will be tips on writing press releases to increase the potential of them being published as well as how to handle and stay in control of media interviews.

5) Feeling & Emotions with Research – How do you feel when your research finishes?

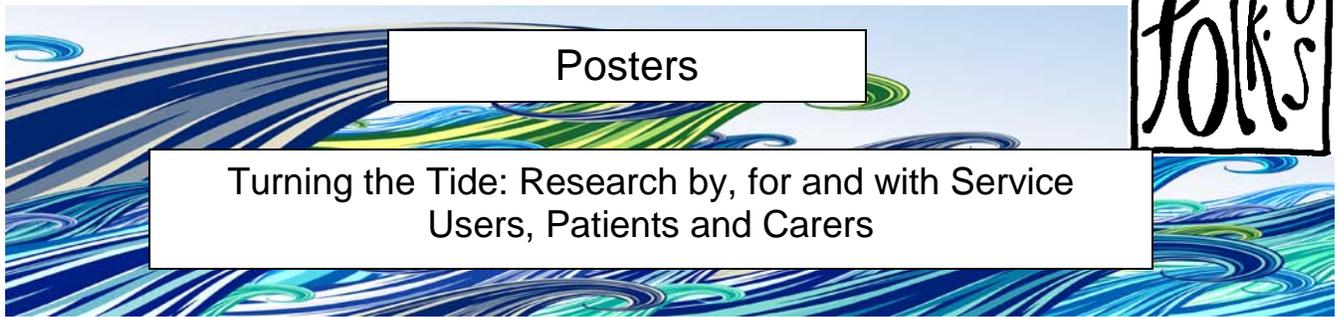
Annie Mitchell & Judith Belam

How do you feel when your research finishes? Research often brings out a whole range of challenging emotions and feelings as you go through each stage from thinking through ideas through to doing research, analysing it and writing it up. Then there might be a time for telling others about the work and thinking about what you're going to do next. What feelings are service users, patients and carers left with? What do you and others do with these feelings? This master class will sensitively explore some of these feelings and emotions. The master class leaders are a clinical psychologist with strong commitment to involving service users, patients and carers in research, and a patient researcher, who worked together in research on migraine. They will share their own experiences of partnership in their project as well as exploring those of master class attenders.

6) Service User Led Open Session.

Caroline White & Rachel Purtell

With the growth of interest in Service User, Patient and Carer involvement in research, there have been some exciting changes in the way research is planned, carried out and discussed. But some things haven't perhaps changed as much as Service Users, Patients and Carers might like. In particular, Service Users rarely get the chance to control research agendas and lead debates. This master class is an open session for Service Users, Patients and Carers to discuss and debate anything they wish related to research involvement. It aims to give participants the power to decide how this master class works. The plan is that delegates in the master class work together for the session. The master class leaders are themselves Service users, Patients or Carers with lots of experience in enabling others to have a voice.



LIMBIC: Learning to Improve the Management of Back Pain in the Community

Steve Williams, Carole Cooper, Louise Worswick

Learning to Improve the Management of Back Pain in the Community (LIMBIC) is a research project which has seen a team from the School of Health & Social Care at Bournemouth University share their expertise and healthcare knowledge with local General Practice teams and their patients to develop improvements in the way they treat and prevent back pain through self-management. Patient representatives have influenced the project by advising Practices about maintaining a focus on what is important to patients in undertaking their improvement projects. The LIMBIC project team, along with the patient representatives made a film which told the story of the LIMBIC project journey. The poster illustration we have brought to the conference describes the story of the filming day. LIMBIC is funded by an award from the Health Foundation Engaging with Quality in Primary Care award scheme.

The Involving People Project

Lynne Thomas, David Rea, Philip Bell

There is an increasing demand for patient and public involvement in research from funders and ethics committees and involvement is written into the Welsh Assembly Government Research Governance Framework. Involving People was set up in 2006 to enable the effective involvement of patients, carers and service users in health and social care research in Wales. By involvement in research we mean **active** involvement, where people are not just the subjects of research but are working **with** researchers to plan, manage, carry out and present research. This could mean discussing research ideas and priorities to checking patient leaflets or helping to spread the results of research.

There are over **230** people on the Involving People network. Over **180** are classed as patients, service users or carers. Since the project began, over **300** network members have been put forward to take an active role within the design and development of research projects.

Passing the 70 plus

Sylvia Downs

As we get older we feel, amongst other things, that our short term memory is a problem. Also we notice that the age of 70 can have sinister meaning regarding three score years and ten. Our aim therefore, in a little book, "Passing the 70 Plus", is to help older people and their carers to share things that help them, both to continue learning and to get the best out of life, lightening their feelings with laughter. (Laughter with, not at, older people).