



*Turning the Tide*  
*Biographies*

*6th April 2010*



## **Biographies**

**(short descriptions of the people speaking at the conference)**

## **Index**

**Chairs p 3 - 4**

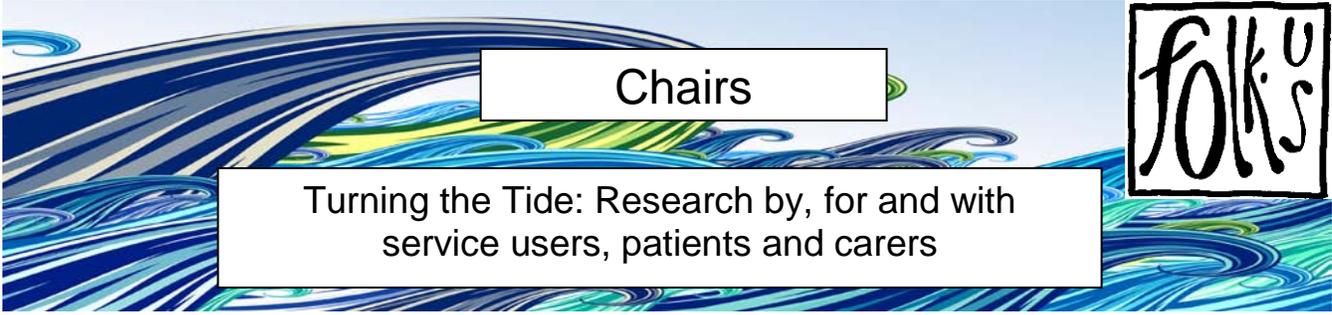
**Keynote Speakers p 5 - 6**

**Presenters p 7 -12**

**Master Class facilitators p 13 - 16**

**Poster presenters p 17 - 18**

**Conference Organisers p 19**



## Chairs

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

### **Peter Beresford OBE**



is a long term user of mental health services and also Chair of Shaping Our Lives, the national independent service user controlled organisation and network. He has a longstanding involvement in issues of participation and empowerment as writer, researcher, educator, service user and campaigner. He is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University, He is a member of the UK Department of Health Transformation of Adult Social Care Programme Board and Ministerial Reference

Group on Social Care as well as the Adult Social Care Workforce Strategy Board. He is a Trustee of the National Skills Academy for Social Care, member of the Advisory Board of the National Institute for Health Research and a member of the Advisory Group of Involve, the body set up to advise government in the UK on public and user involvement in health, public health and social care research.

**Alex O'Neil** has been Principle Research Manager (now “Programme Manager”) at Joseph Rowntree Foundation for 15 years. He has developed and managed their programmes of work with and about Older People, Approaches to Choice & Control (including Direct Payments), Choice & Control for people who are often excluded from power (people with Dementia, Learning Difficulties and similar), and user-defined projects and programmes of work on the future of Rights and Welfare. In addition to the above, he is also managing a new programme of work defined with wider groups of people who are usually excluded from power (including migrants, older people, disabled people, mental health service users, people in poverty). That programme has been called “Unheard Voices” but the group resisted that label – their experience has been that having your voice heard is often not enough. They have changed the name (with some irreverence) to “Change In Action” (CIA). No doubt there will be a sub-group called Feed Back Initiative (FBI).

## Keynote Speakers



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



### **Rachel Purtell**

Rachel is the Folk.us Director with day to day responsibility for our work at Folk.us. This role ensures that service users, patients and carers are able to have a positive and meaningful impact on research, and the structures and processes that support research in health and social care. Rachel has and does work with many people including people with learning difficulties, people who experienced mental distress, people with physical and/or sensory impairments, older people and people who are long term users of the NHS. Besides her work with Folk.us Rachel is a freelance trainer in Disability Equality Issues using a Social Model approach and one that is rooted in the lived experience of disabled people. She holds a Master of Arts in Disability Studies and has developed a nationally recognised vocational qualification in disability equality. She has a background in working for inclusive service user led organisations and voluntary organizations and delivers training for statutory organisations. Rachel is disabled women, a disability activist and a service user.



**Dean Harrison** has been involved in research for the last 7 years. He currently works on the COCOA Project (Care for Offenders and Continuity of Access), the Offender Health Research Network at Cardiff University, and in Research for Patient Benefit at Lincoln University. Dean is a recovered drug addict with experience of substance misuse and mental health services.



## **Pat Atkinson**

Pat Atkinson is caring and committed with great strength and principles whilst very much retaining a love of art and a twinkle in her eye! With the other three research team members she shares an energy to improve the services in order to bring out the best in those needing its support.....in whatever form that might take.

## **Peter Buckingham**

Peter is a retired Construction Manager who has spent 14 yrs in East Africa and having returned home to UK in 1996, is now married to a retired College Principal and is living in Exeter. In 1997 he had a bad Road Traffic Accident in which he received a Traumatic Brain Injury. Peter now lectures on how he copes with his impairment. Peter is actively involved in training staff and students and has supported Folk-U's for many years.

## **Gill Colerick**

Gill Colerick has great awareness, sensitivity and graciousness...integrity personified. With the other three research team members she shares an energy to improve the services in order to bring out the best in those needing its support.....in whatever form that might take.

## **Rosie Davies**

ROSIE DAVIES has been a research partner and service user researcher for the past 9 years. She has worked on a variety of mental health research projects, both user-led and within universities. Most recently Rosie has been working at

the University of the West of England as co-chair of the Faculty of Health and Life Sciences Service User and Carer Involvement in Research scheme, and on a project exploring Public Involvement in Research across a range of different research areas.

### **David Evans**

David Evans is a Reader in the Faculty of Health and Life Sciences at UWE Bristol. His research interests focus on service user and community involvement in health, including involvement in research. David is currently leading two projects for Macmillan Cancer Support, on user involvement in cancer services commissioning and on advocacy and informed choice. David chairs the Empowerment Working Group of INVOLVE, the National Institute of Health Research advisory group promoting public involvement in research.

### **John Gillett**

John Gillett is a Sales co-ordinator in Agriculture for Mole Valley Farmers. He has his own business in Disability Awareness training and Access Auditing and recently became Coordinator of the See Me project.

His work takes him all over the UK and he has travelled abroad to further the understanding of the needs and expectations of those living with a disability.

### **Kerry Gray**

Kerry Gray is a leaving care young person. She studied social science at City University. All these factors made her interested in working on the health research project. They have also helped her work on the systematic review.

### **Helen Guy**

Helen completed her degree and Post-grad Diploma at the University of Gloucestershire, and is enjoying working on mental health research projects. She also does voluntary work in a local hospital.

## **Pam Herd**

Pam Herd is bright, sparkling and kind with a dubious passion for heavy rock music. With the other three research team members she shares an energy to improve the services in order to bring out the best in those needing its support.....in whatever form that might take.

## **Sue Hitchcock**

Sue is a service user with an interest in social inclusion. She works in the mental health field supporting service users with employment opportunities. She believes in equal opportunities for service users.

## **André Hutchinson**

Andre Hutchinson is passionate & driven with a love of gardening and fantastic eye for photography. With the other three research team members she shares an energy to improve the services in order to bring out the best in those needing its support.....in whatever form that might take.

## **Kristin Liabo**

Kristin Liabo is a researcher from the Institute of Education. She is interested in involving service users in research.

## **Alison Lott**

Alison is a Carer, a public Governor for 2gether NHS FT and a Carer Support Worker with Carers Gloucestershire. She believes passionately that the Service User and the Carer need a strong 'voice' to state whether the Service they receive is the Service they want.

## **Rose McCausland**

Living Lens was founded quite by chance, when Rose discovered she shared a passion for participatory approaches to change with her old friend Amy. Through their experience in development (Amy) and human rights (Rose) they saw how problems arose and persisted due to breakdowns in communication. They starting using video as a tool to build communication, allowing participants to go beyond the 'them' and 'us' mentality that had them stuck in the problem.

## **David Mulcahy**

David Mulcahy is 24 years old. He is a panel member of Islington Council's Participation Service (CAIS). In his spare time he likes sports, music and cooking.

## **Irene Philpott**

Irene has been both a carer and service user and she joined the project because she wanted to assist clients to become as independent as possible of services, and to be able to help improve both opportunities and quality of life for people with Mental Health problems. She is so very proud to have been involved in the shaping of the tool into its final form.

## **Lisa Ponting**

Lisa is chair of the Norah Fry Research Centre Voice group, and also chairperson of Bristol and South Gloucestershire People First. She worked as a researcher on a 2-year national study, funded by the Big Lottery, called "Skills for Support". As part of this, she visited people to talk to them about their support and she made videos of people working with their personal assistants. Lisa thinks it is important for people to have a voice. She wants research to make a difference for other disabled people.

## **Genevieve Riley**

Genevieve is a researcher within <sup>2</sup>gether NHS Foundation Trust having worked on a variety of mental health research projects with both clinicians and service users or carers. I support the Service User & Carer Research Group within our Trust, and work with other research colleagues to encourage user involvement within all aspects of research planning. I am currently on secondment to the MHRN working on NIHR portfolio projects.

## **David Robinson**

David Robinson was at the School of Tropical Medicine in Liverpool for 5 years after spending time in Nigeria and working as a Senior House Officer in general medicine. He joined the Public Health Laboratories Service, where he became a consultant epidemiologist, having gained an MD (in cholera) and an MSc in Community Medicine. He then joined the WHO (World Health Organisation) where he worked mainly in child health and health services in many countries out of Geneva. He left WHO in 1999 and worked freelance with a wide range of organisations. He is now a user of the British health and social services having sustained a severe head injury 5 years ago.

## **Katie Sarra**

Katie is a painter who trained as an Art Therapist and worked for Hackney NHS and Social Services, with adults and young people. She is committed to exploration, research and practice in body work and performance. This includes working out how better to involve people in and through art. Katie has a community gallery and studio in Tiverton, and works as an artist, Playback Theatre performer and tantric specialist.

## **Patsy Staddon**

Patsy Staddon is a survivor of the alcohol and mental health treatment services. She was recently awarded her PhD in the sociology of women's alcohol use and

its treatment, and is particularly interested in power-sharing in the research process.

### **Ben Watkinson**

Recently having moved from a Recovery Unit, Ben now does voluntary work, and is studying at college. He enjoys doing research work and would like more projects to work on.

### **Rosemary Whitehurst**

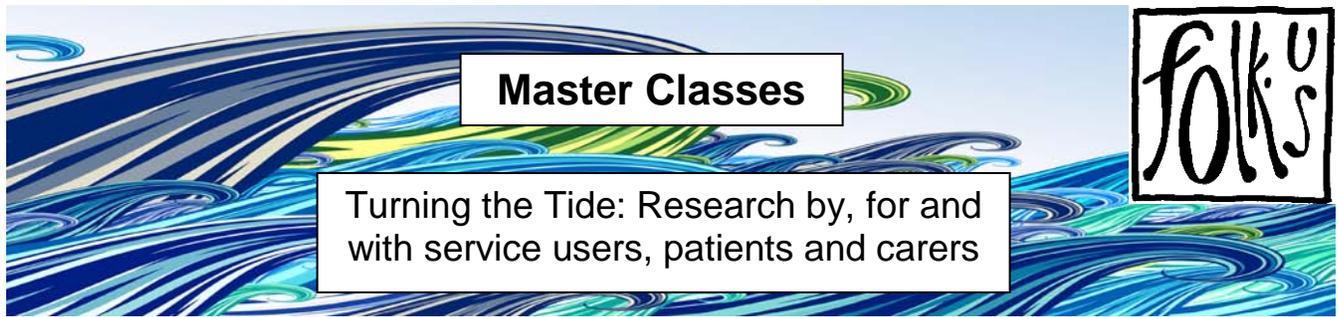
For ten years Rosemary cared for her mother who was severely disabled following a stroke. During that time she was able to combine her caring responsibilities with work for a local charity in research looking into the link between the caring role and carers health and support needs. This led subsequently to the setting up of carers support and development services throughout Devon, from which she has recently retired. Rosemary is currently the vice-chair of Carers UK, the national campaigning organisation for carers.

### **Susie Wild**

Susie is a student, trainer, service user, and researcher among many things. She wanted to become involved in the project because she felt, although her care in the system has been brilliant, that there were a few areas that needed looking at. She sometimes felt she had to fight to gain inclusion into society and often faced hurdles, with doing the project has helped her feel part of a process that can only result in good for people suffering from mental distress.

### **Val Williams**

Val is a researcher and research supporter. She worked with Lisa on the "Skills for Support" project as a research partner to WECIL (West of England Centre for Inclusive Living). She has carried out many other research projects with people with learning disabilities at the Norah Fry Research Centre at the University of Bristol.



## **Scott Walker**

Scott is adept at the art of being an artist; that is, he has many hats. From stage sets to children's books, portraits to comic strips, he is nearly master of all. Scott is, of late, often to be found in schools running workshops that bring cartoon illustration and graffiti together with riotous effect. He lives in Exeter.

## **Annie Hawton**

Annie Hawton has worked in health and social care research for the last 16 years in a variety of posts, from investigating the sleep patterns of children with asthma, to developing methods for the economic evaluation of treatments for people with multiple sclerosis. Annie has also held posts in health and social care where her role has been to help staff and service users conduct their own research.

## **Geoff Barr**

Geoff has spent most of his career teaching at Exeter College, Exeter. From there, he moved on to work for the Open University, Exeter University and Peninsula Medical School. He always teaches social sciences of some sort. He is a member of the Folk.us Executive and a lay researcher in health. Geoff is also a member of the Folk.us Conference Planning Group.

## **Derek C Stewart, OBE**

Born a number of years ago in Scotland, Derek was treated successfully for cancer of the larynx in 1995. A former teacher working with challenging pupils in Glasgow then Nottinghamshire, Derek became involved in numerous aspects of

patient involvement at a local, network and national levels. As former Chair of the Consumer Liaison Group, Derek assisted with the increase in patient participation in the establishment and work of the National Cancer Research Institute. Derek is a Trustee for onCore UK, the national cancer tissue resource, Chair of the Confederation of Cancer Biobanks and a member of the Cancer Reform Strategy Advisory Board.

From 2001 until 2006 Derek was Chair of a Primary Care Trust in Gedling, Nottinghamshire. From 2005 until 2010 Derek took on the role as Chair of Nottingham City Crime and Drugs Partnership where crime is now down by more than 42% and more than 3000 people have received drug treatment. Derek still works as a freelance consultant with his own company providing training on patient and public involvement across charity and public sector throughout the UK. This contribution to health services in particular cancer led to being awarded an OBE in the Queen's Birthday Honours list 2006. Most recently, Derek was appointed as an Associate Director for patient and public involvement for the National Institute for Health Research – Clinical Research Networks Coordinating Centre based in Leeds and London. Derek lives in Nottinghamshire.

### **Wendy Rickard**

Wendy is the Folk.us Research Fellow, helping Service Users, Patients and Carers to develop research projects that change the culture in which research is produced. Wendy was previously an Associate Director of the Institute of Primary Care and Public Health at London South Bank University, where she worked as Reader in Public Health Research. She also worked closely with the British Library Sound Archive on projects with people with HIV, sex workers, homeless people and other groups. Service User Involvement in this research and lecturing defined it and made it what it was. It also took Wendy into a range of pioneering activist groups.

## **Deirdre Ford**

Deirdre Ford is a Lecturer in Social Work at Plymouth University who has worked in practice with people who have learning disabilities and mental health problems.

Together with a clinical psychologist she co-ordinates the Service Users and Carers Consultative Group who support the professional education of social work and clinical psychology students at Plymouth. She regards service user and carer participation as a vital and welcome requirement that has revolutionised social work education.

## **Paul Henderson**

Paul Henderson has spent 21 years working in the regional press. He has been part of the senior management teams with groups such as Newscom, Newsquest and CN and has worked on/with major regional daily and weekly newspapers such as the Bristol Evening Post, Birmingham Evening Mail, Southern Daily Echo, North West Evening Mail, Gloucestershire Gazette series, Western Gazette and Somerset County Gazette.

## **Elaine Hewis**

Elaine Hewis is a trainer and lecturer in mental health from the lived experience. She does a lot of work around suicide and self harm. She has experience of talking on live radio, working on a channel 4 documentary, newspaper interviews and someone has just written a book including extracts of her work. She is married with 2 children and a grandson.

## **Annie Mitchell**

Annie Mitchell worked with others to set up Folk.us over ten years ago. She is Clinical Director for the Doctorate in Clinical Psychology at Plymouth University and clinical psychologist at the Kidney Unit, RDE (Wonford) Hospital. Her children are grown up, and in her spare time she is a member of a Women's Playback Theatre Company.

## **Judith Belam**

As one of a group of patient researchers, Judith took part in a project into the experience and management of migraine. She is also currently a lay consultant on a research study looking at suicide prevention. She used to teach French at the University of Exeter but now works in research support and administration at Devon Partnership NHS Trust. Judith lives near Exeter where she settled with her family after some years of living abroad.

## **Caroline White**

Caroline White is a woman with learning disabilities who has been a researcher using Participatory Appraisal (PA) Approach. Caroline worked on a project finding out about the experiences of people with learning disabilities and learning difficulties who had been bullied. Caroline is a member of the South West PA Network.



### **Steve Williams**

Steve was approached by his GP for involvement in the project with the idea of improving service provision to future patients in primary health care relating to back pain. He was pleasantly surprised to engage with a wide variety of professionals, gaining key knowledge and allowing free dialogue. The teams looked at ways of improving timescales using the PDSA (Plan-Do-Study-Act) cycles to gauge success (a very good tool). Steve has personally benefited a great deal from the experience taking full responsibility for his condition. "Thank you for the experience and enabling me to take responsibility".

### **Carole Cooper**

Carole has suffered back problems for more than 40 years and her previous negative experiences inspired her become a patient representative, firstly on the Back Pain group at her local hospital and then with the LIMBIC research team developing workshops for the Practices. "The project showed GPs learning from patients, taking it on board and listening to what we've been saying".

### **Louise Worswick**

Louise is the project manager of LIMBIC with a researcher role also. She has led the project through the various stages from the development of the research protocol through to designing and delivering the workshops and now to the evaluation stage. "The most exciting part of this project has been seeing practitioners change their opinions of the value of user involvement"

## **Philip Bell**

Originally trained as a nurse in the RAF, I was invalided out after nine years service. I have had a mixed career, working with pharmaceutical companies and companies like Lloyds TSB Bank where I was a senior systems analyst. Taking early retirement when I was 50. Fed up with retirement! I then combined my PhD (Sociology) with volunteering for a charity and subsequently worked for them. I have worked for charities such as Parkinson's, Steps and Emmaus. My last post was that of Chief Officer (maternity cover) for a Community Health Council. I really am retired now apart from my involvement with medical and health research as a lay person.

## **Sylvia Downs**

Sylvia is 83 and a user, she suffers from Aged Macular Degeneration. For many years she has been a carer for members of the family. When she came to Exeter she joined Folk.us in its early days to do research into the selection, training and support of carers and users. She also worked with the Clinical Psychologists in the role of an older person. This work resulted in some publications by Folk.us and the Clinical Psychologists. She has spent her life in research and last year received a Lifetime award from the British Psychological Society for her University and Consultancy work.

## **Roy Norris**

Diagnosed with Type II diabetes in 2009, having survived cancer for 40 years Roy has a personal interest in medical research which probably saved his life all those years ago. He now has an interest in dying with Diabetes as opposed to dying of Diabetes and research is essential if he is to achieve that goal after another 40 years! Elected Chair of the Powys Association of Voluntary Organisations in 2008. A Beekeeper and is Treasurer of Montgomeryshire Beekeepers. South Wales Regional Advisor for Comic Relief Since 2003. Deputy chair of the Ambulance Services Benevolent Fund since July 2006.



## **Abi McCullough**

Abi is the Folk.us administrator. She is the first point of contact for all enquiries and provides administrative support for the Folk.us office. She is married with 2 children.

## **Mo Taylor**

Mo (Maureen) Taylor is presently involved in research with Sheri Hilchin at Wonford House, Exeter, on self directed support/direct payments, and is on the Carer/Service User Forum at St Michaels Hospital, Newton Abbot. Mo is inspired to do this work as she has a family member who experiences mental health problems and she wishes to aid his recovery. She is particularly interested in research projects about: creativity aiding recovery, nutrition education for people with mental health problems, healing power of nature, being in green space as an antidote to depression, dancing and singing; Biodanza system developed by Rolando Toro from Brazil, how other countries have better developed ways of coping with mental health problems particularly Italy. Here patients are allocated to family units, not isolated and excluded in hospitals, chocolate and sea vegetables as alternative medication for depression, Buddhist meditation (proven to alter brain patterns). Mo is a BA (hons), A.T.D., Cert Ed, artist. She is inspired by nature, celtic mythology, Rea Irish ancestry and influenced by eastern mysticism. She is an ex college lecturer/art teacher and she currently has exhibitions at the COOL House, and Space Invaders, both in Torquay, and at The Hub at Brixham.