

# PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

## On the Edge

Jon Somers on a project that uses interactive theatre to educate about psychosis.



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## Luck Factor

**My mother always used to say that if I were to fall off a roof, I would land in a chocolate factory.**

It is true that over the years I seem to have enjoyed more than my share of good fortune. I am a lucky man. I get used to enjoying the rub of the green, getting a lucky bounce or finding myself in a situation where it's heads you lose, tails I win.

Every so often though, even I have to shake my head in wonder at some of the things that happen to me. Just as I did last week, at the end of an incredible day which started off as a disaster.

My former features editor started the day with good news. She was coming back to work after a year's break to look after her children. She closed the phone call by saying "Oh just one thing, this mobile phone of mine is falling apart". Feeling buoyed by the news of her return I said that I would get her a new one. As I put the phone down, I realised that I had committed myself to spending £200. Very kind.

I went out for a coffee to Pinks, and set about my work with laptop and papers spread across the table and my jacket hanging loose over a spare chair. There was a commotion. Two young men came in jabbering in a

foreign language. One thrust a leaflet at me shouting "holiday, holiday". The other leaned over the other side of the table pointing to a map. Trying to be helpful, I leaned across to see what he was pointing at.

Just as they scurried through the door, I recognised their pincer manoeuvre as the old "Eastern European Double Shuffle". Looking at my jacket lying over the chair I dived across the table frantically searching for my wallet. It was there and fully intact. What a stroke of luck I thought.

Half an hour later, I reached for my mobile phone to make a call, only it was on its way to Eastern Europe. I had been done. It was so frustrating. I had only upgraded my phone a week earlier. Now I had to get two new phones. This day was turning into a disaster and I asked myself how I could turn bad luck into good.

To cut a long story short, by the end of the day I had a brand new top of the range phone for free, I recovered my own phone and put three Romanian Asylum seekers behind bars, pending deportation. They had committed fourteen other offences all over the country.

How on earth did that happen? Well it's all in a days work when you are a lucky person.

It's not though that I have been born under a lucky star or had stardust sprinkled in my hair. Professor Richard Wiseman has found that lucky people simply do four things that unlucky people don't and they do them consistently.

They make chance opportunities; they listen to their intuition; they believe in good fortune; and most importantly they turn bad luck into good.

This may seem like it is a world away from PPI, but in truth it isn't. We will have much more success in involving people in health if we make lots of chance opportunities for them, if we do what we think is intuitively right rather than be hidebound by policies, procedures and systems and if we turn bad luck into good.

The NHS does a lot of good work, yet everyday there are frustrations, failures and sometimes tragedies. We owe it to the public not to sit and dwell on misfortune, but to use these bad episodes to imagine and create a better NHS for everybody. To create good fortune around our PPI. To turn bad luck into good.

I hope the two young men enjoy their holiday. Back to Romania.

## EDITORIAL ADVISORY BOARD

### Chris Dabbs

Chris has worked in patient and public involvement at local and national levels since 1990. Chris is the Chief Executive of the Community Health Action Partnership, and explores ways towards socially-driven and mutually-owned public services. He is a Fellow of the School for Social Entrepreneurs, and chairs Passionately Curious, a social business that is working with diverse citizens and communities.

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Professor Nick Bosanquet is a health economist. He is Professor of Health Policy Imperial College and non-exec director of Richmond and Twickenham PCT. Nick works mainly on the development of new programmes in health services and remains a chronic optimist about the potential of health services to deliver better results for patients.

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Zenna is an award winning social entrepreneur. She is currently NHS Primary Care Trust Chair in Portsmouth as well as Managing Director of Social Solutions, her own social sector consultancy company. She is a sought after conference speaker and is an advisor on governmental panels and committees, exploring a range of issues including health, social engagement and social entrepreneurship. She is also Chairman of Pirates

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### Malcolm Stamp CBE, DCL, FRSA, MIHM, MMS

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David Gilbert is Senior Advisor - Patient and Community Engagement at the NHSU. He was Head of Patient and Public Involvement at the Commission for Health Improvement (CHI). He has worked at the Consumers Association, Kings Fund and Office for Public Management (OPM). He was a Community Health Council member, Chair of MIND in Barnet and user of mental health services. He led the national consultation on the NHS Plan, development of the public and patient involvement strategy in Wales. David's passions are his young sons Samuel and Adam, poetry, and (depressingly) Leeds United.

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ISSN 1742-0407  
a bearhunt publication



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# News items

## Support for the NHS helps get reconfiguration right

**A new leaflet launched by the independent expert on health service change, the Independent Reconfiguration Panel, sets out the support available to NHS chief executives and senior managers in getting reconfiguration right.**

The new leaflet aims to support local NHS organisations in meeting the challenge of health service change. It contains advice on how to access free support and guidance from the Independent Reconfiguration Panel in order to deliver successful proposals. It also provides the following best practice guidelines:

- make sure the needs of patients and the quality of patient care are central to your proposal
- consider the role of flexible working in your proposals. This may involve developing new approaches to working and redesigning roles
- assess the effect of the proposal on other services in the area
- give early consideration to transport and site access issues
- allow time for a discussion stage before the formal consultation. People want to

understand the issues, so involving the public early will help when it comes to the formal stage

- get independent validation of the responses to your consultation. Consultations are there to influence final proposals. To use the results effectively and to show that they have been used effectively, it is important that independent validation takes place

**Free copies of the leaflet are available via the Independent Reconfiguration Panel website [www.irpanel.org.uk](http://www.irpanel.org.uk)**

## 'VCS calling OSC: you're on my radar'?

**A new publication demonstrates ways in which the voluntary and community sector (VCS) and overview and scrutiny committees (OSCs) can work together to improve service delivery and encourage civil renewal.**

The guide, published by the Centre for Public Scrutiny and entitled 'On the Radar', says that joint working between VCS and OSCs is mutually beneficial because:

- the VCS can enable a stronger local government scrutiny function, by providing or facilitating more representative evidence for scrutiny reviews
- OSCs can provide the VCS with an opportunity to work directly with elected councillors to influence decision-making and policy development
- recommendations on how we can work towards even greater combined impact on services and civil renewal
- 'quick guides' to introduce the VCS and OSCs to those previously unfamiliar with their work

The report aims to provide practical guidance to both VCS organisations and OSCs on how to develop effective relationships, and includes:

- an overview of the current status of VCS / OSC joint working;
- practical examples of how effective it can be: including a Rotherham MBC scrutiny review into domestic violence

The report will be distributed to scrutiny committees in all English local authorities as well as VCS contacts via the NACVS newsletter. It can also be downloaded from [www.cfps.org.uk/publications](http://www.cfps.org.uk/publications)

## Strengthening health systems vital to achieving MDGs says WHO

In its latest report, 'Health and the Millennium Development Goals', the World Health Organisation (WHO) points to weak and inequitable health systems as a key obstacle to achieving the MDGs. The report outlines progress regarding the health goals and targets, looks beyond the numbers to analyse why improvements in health have been slow and suggests what should be done to change this. To read the full report, visit [www.who.int/mdg/publications/MDG\\_Report\\_o8\\_2005.pdf](http://www.who.int/mdg/publications/MDG_Report_o8_2005.pdf)

## Reforming the adult social services complaints procedure

**Following the Department of Health consultation 'Learning from Complaints' a reformed adult social services complaints procedure was due to be implemented in October 2005.**

However, in light of the proposed inspection reform Ministers have agreed to a further deferment to allow for consideration of the implications for health and social care complaints procedures. A further announcement will be made shortly, so in the meantime Local Authorities will need to continue to operate their existing complaints procedure.

For further information contact Jon Stanley 0113 2545815.

# News items

## New website for patients and PALS workers

**PALS online, the new website for PALS workers and volunteers, healthcare professionals and the general public went live on Wednesday 19th October 2005 with an event to mark the day for key stakeholders at the Department of Health Media Centre.**

PALS (Patient Advice and Liaison Service) exist in each NHS Trust to

- Provide information about the NHS and other health-related enquiries
- Help resolve concerns or problems when using the NHS
- Provide information about the NHS complaints procedure and how to get independent help in pursuing a complaint
- Provide information and referral to agencies and support groups outside the NHS
- Improve the NHS by listening to concerns, suggestions and experiences and ensuring

that the people who design and manage services are aware of the issues raised.

Members of the public will be able to access or find out more about their local PALS via the website. The new site will also provide the national network of PALS workers with news, training resources and opportunities to share examples of best practice.

**For more information about PALS online please contact Elissa Dobson on 01625 509155 or visit [www.pals.nhs.uk](http://www.pals.nhs.uk).**

## Local Health Campaigners Get Wired

**Groups campaigning locally on health issues have received a welcome boost from an initiative that allows them to go online for free.**

A new internet service called CampaignON.com enables groups or individuals campaigning on any issue to set up a fully fledged web site to promote their views.

The service is specifically designed to make it easier to organise letter-writing or email

campaigns targeted at local authorities, newspapers, political representatives, or individual decision makers in government and in the Health Service.

What makes the initiative particularly exciting for local campaigners is the ease and speed with which they will be able to take effective action on local health issues.

"We want to give local communities a bigger voice", says CampaignON.com director Brian

Wilson, "and to help them influence the decisions affecting their lives".

There is currently nothing else like this on the Internet. Until now only the most sophisticated and well-funded national campaigns have been able to take full advantage of the web. CampaignON.com's free and simple-to-use service is likely to change that. For more information visit [www.campaignon.com](http://www.campaignon.com) or email [feedback@campaignon.com](mailto:feedback@campaignon.com)

## Nice training review

**Community engagement for health: A preliminary review of training and development needs and existing provision for public sector organisations and their workers.**

This report from the National Institute for Health and Clinical Excellence (NICE) draws out the key findings and issues of interest to those involved in developing and supporting community engagement in the public sector and sets out recommendations for a forward programme of national work.

The document can be downloaded from [www.publichealth.nice.org.uk/page.aspx?o=518167](http://www.publichealth.nice.org.uk/page.aspx?o=518167)

## Mrs Buggins is alive and well and teaching PPI in Brum

Readers of PPI Monitor's regular column 'Dear Mrs Buggins', will be delighted to learn that there really is a Mrs Buggins. Incredibly, she is the Chairman of the Birmingham & Black Country Health Authority and she will be leading a new programme organised by The University of Warwick. The programme in PPI in the NHS runs for 5 days from 30th January 2006 and may be taken as a non-assessed course, a Postgraduate Award (PGA) or as part of a Masters Programme.

For details contact Sally Glassborrow on 0247 657 5553 or [www.warwick.ac.uk/go/pc930](http://www.warwick.ac.uk/go/pc930)

# In a 'Patient-Led NHS'

## What Role for PPI?

**In an era of markets, a plurality of providers and patient choice, where does PPI fit? Gary Fereday has some ideas.**

The delivery of health and social care is improved when the views and experiences of people using services are taken into account. Patient and public involvement (PPI) is, however, a catch-all phrase that is all too often simply seen as a "good thing" and treated as a set of activities carried out in isolation rather than a key part of business processes. Focusing on structural approaches encourages this by turning it into a task delegated to a specialist function. This has narrowed the methods that are used and led to a focus on a representation-based model.

A coherent vision setting out the purpose and benefits of involvement is crucial. We should begin by being clear about the distinct ways users need to be involved. These include:

- decisions and feedback about individual treatment
- decisions and feedback about the operation of individual services
- decisions and feedback about the operation of services in general or in particular institutions
- strategic decisions about the overall shape of services
- decisions about the allocation of resources and commissioning
- accountability for the overall NHS in an area
- accountability for particular services or institutions.

It is particularly important not to confuse users of individual services, patients in general and the public. The public or patients in general will not have a view of the care pathway for a particular condition but they will have important and legitimate views on the general design and delivery of services across an area or in a particular institution.

These different constituencies will respond to different methods of involvement. In a number of the functions listed above, representative models may not be adequate and techniques based on market research

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such as patient surveys, focus groups, mystery shoppers, patient diaries and discovery interviews can be much more effective. At the other end of the spectrum (decisions about the shape of services or major service changes) a much wider and more active engagement is required that goes well beyond standard representative models.

The mechanisms for involving the public and patients should be allowed to develop structures and ways of working that best suit the local health community. A "one size fits all" model is increasingly inappropriate as the diversity of service provision increases. The use of non-statutory service providers will create new challenges for PPI forums that will be need to be met locally.

The needs and views of certain user groups need to be actively represented to decision makers, particularly those vulnerable or 'hard to reach' patients who are traditionally marginalised and maybe more so if patient choice favours certain patient groups. PPI forums within trusts will have a key role to play in this important advocacy role.

Local authority overview and scrutiny committees (OSCs) should develop an oversight of the local structures to involve, consult and represent public interests, working with local communities to ensure that vulnerable groups or specific communities are not excluded or forgotten. OSCs should in turn help inform the Healthcare Commission's assessment of healthcare organisations performance in this area.

In the short term, the focus for public involvement (that is, related to key planning decisions and general feedback

about services) should be with the service commissioner. However, the advent of local area agreements and the development of local public service board (LPSB) structures will give the opportunity to amalgamate existing consultation mechanisms between health bodies and local authorities within a binding agreement. This would then give accountability to the LPSB to plan against consultation findings, improve the range and depth of consultation and would ensure that partners, no matter what their internal organisation, would be accountable for the services delivered. The OSC would then scrutinise health community-wide responses, covering jointly planned and integrated services.

The duty of trusts to consult on service changes does not easily sit with the development of new market mechanisms. A policy view is needed about how far current PPI methods will apply where services change as a result of the operation of patient choice. Providers need the freedom to react to changes in market conditions and the consultation process is likely to be too long to be compatible with the requirement to ensure good financial governance. It is the commissioner's responsibility to ensure that services are available but unless the service is classified as protected they do not have the power to compel a provider to continue to run particular services. It may not be possible to rely on the policy related to protected services as not only are many of the services affected by choice unlikely to be classified as protected, but the definition of a protected service is also likely to prove difficult to frame in a way that could apply nationally.

It cannot be assumed that when patients vote with their feet, the public and future patients are content with a change dictated by the operation of choice. A debate with the service, OSCs and other stakeholders is now required to ensure that the public involvement and consultation machinery is in line with the system reform agenda

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# On the Edge

**Raising awareness of mental health issues is a challenge, not least with young people. John Somers describes 'On the Edge', which uses interactive theatre to educate about psychosis. This is the winner of the Southern final of the mental health section of the Health and Social Care Awards 2005.**

"As the provider of specialist Mental Health Services within the county, Somerset Partnership fully supports the 'On the Edge' initiative. There is now much evidence that if young people in particular who experience a first episode of psychotic illness are helped as soon as their problems appear, then they have a very good chance of making a full recovery. If such early intervention is to

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happen it is essential that there is much greater awareness of mental health problems in the community at large. 'On the Edge' provides a brilliant and innovative way of doing this and, in particular, of engaging young people in these issues." (John Haines, Chief Executive, Somerset Partnership NHS & Social Care Trust).

In 1999, the Government published its National Service Framework for Mental Health, which included the innovative step of developing a national network of early intervention services for young people experiencing their first episode of psychosis in the hope of greatly improving their short-term treatment and long-term recovery. In the five years since, there has been a slow but progressive process of appointing early intervention teams across England with a brief to ensure that those in the target population in which first episodes most often occur (chiefly the 16-30 years age range) became aware of possible routes to advice, support, treatment and recovery. The problem was how should such teams make the general public, and particularly its target population, aware of these services?

Dr. Glenn Roberts had previously co-operated with John Somers, Senior Lecturer in Applied Drama at the University of Exeter, on the creation of an interactive community play about farming life, 'The Living at Hurford'. Glenn's close involvement with developing early intervention services in Devon made this a natural area for further collaboration.

The new play 'On the Edge' aimed to:

- raise awareness of mental illness, specifically to increase knowledge and understanding of psychosis
- contribute towards reducing the stigma and discrimination surrounding mental illness
- raise awareness of available help and improve help-seeking behaviour.

An Advisory Group was formed which comprised Glenn and John, plus mental health professionals, an art therapist, service users and carers and those from the voluntary mental health sector. The guiding parameters for the work were that the play should be:

- dramatically effective - it should have an impact on the audience
- 'real' - the drama should portray authentic experience
- clinically relevant - it should be useful in the context of health education aims of the project.

Having written a scenario and some dialogue which was judged authentic by the Advisory Group, John proceeded to develop the play with his final-year undergraduate students. Members of the Advisory Group maintained close contact with the project. This version toured in December 2003 and was followed by a short South West tour by Exstream Theatre Company (funded by Devon Social Services), of which John is Artistic Director. At this point, Carly Mays, Company Manager of Exstream joined the team, developing the work and planning the national tour.



Terry (Simon Little) becomes suspicious of those around him.

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Exstream received funding for a six-month tour of England which took place between October 2004 and March 2005. Most of the support came from The Wellcome Trust, but the National Institute for Mental Health in England also funded the secondment of mental health nurse Graham Carr, who acted as programme facilitator for the tour. The Devon Partnership Trust provided financial support for the educational materials, and the University of Exeter provided support in kind.

The story showed Terry, a successful and normal 17-year-old boy, in the lead up to his first episode of psychosis. His girlfriend,

Sonia, is close to him and sees some of what is happening, but she has neither the knowledge nor experience to help. A teacher realises that Terry is troubled, but lacks the time and knowledge to intervene. Terry's father is in denial and continues to encourage his son in his athletic endeavours whilst his mother, until an unavoidable crisis arises, sides with her husband. Terry's best mate, Scott, succumbs to peer pressure, labelling Terry a 'schizo' and a 'freak' in his guilty attempts to distance himself from Terry's increasingly 'weird' behaviour.

'On the Edge' comprises three phases. In phase one, audience members examine a shoebox which, they are told, has been found under a young man's bed. The contents of the box were carefully produced to seem authentic. This exercise intrigued audience members with an intentionally incomplete pre-story, which orientates them to the performance which follows a week later.

Phase two involves the performance of the play and a chance for the audience to talk to the characters to enable a better understanding of why individuals are behaving as they do and what they are feeling and thinking. When working with young people, the audience was split into smaller groups, each led by one of the cast who had stepped out of role, discussing in detail the issues affecting a particular character. The fruits of the discussions were used in giving advice to the characters on how Terry's life could positively be moved on. This interactive phase was completed by Graham, who gave a description of possible routes to recovery for Terry.

Phase three involves the use by the school or university staff of a sophisticated education support pack, 'Back from the Edge', to raise issues about the nature of psychosis and reinforce understandings about routes to recovery. Ideally, school counselling staff and local early intervention teams were involved in this phase.

The programme was also used with mental health professionals. It was performed at several mental health conferences and it was seen by substantial numbers of carers and service users. There were 123 performances, seen by over 5000 people.

An independent evaluation by Dr. Rowena Passy, assisted by Dr. Jos Dawe, is nearing

completion. Among key findings are a marked increase in awareness of and knowledge about psychosis and increased sensitivity to the potential stigmatisation of those affected. Audience members appear to be better equipped to seek help and there was an increased hope and awareness of recovery. Not unexpectedly, the play was felt to be the most memorable aspect of the programme with people deeming it to be a powerful and successful way of portraying and raising the issues surrounding psychosis. A further challenge involved seeking to build a bridge between the experience of a memorable play and enduring health educational gains that enabled behavioural change in the 'real world'. This was achieved through encouraging the host educators to hold a consolidating session after Exstream's visit and by using the drama programme as an event that could bring local mental health and educational services together.

In March 2005, 'On the Edge' was performed in London at the invitation of the national early intervention service development leads. They had identified the programme as the best available health educational resource on early psychosis and gathered a group of national leads from mental health policy and practice to consider further development prospects. On 2 August, Glenn Roberts met senior Department of Health staff to explore possible support for this work. Several initiatives are being discussed ranging from tours of the live programme to an interactive DVD.

As Southern Regional winners we are now eagerly looking forward to the Health and Social Care Awards Finals on 13 December. Watch this space!

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For a review of On the Edge in performance see: Warner, L. (2005) "Fringe benefits: a review of the interactive health education drama programme on first episode psychosis 'On the Edge'". *Mental Health Practice*, 8, 6, 22-24.

**For further information, contact Exstream Theatre Company at: [exstream@ex.ac.uk](mailto:exstream@ex.ac.uk)**

## Why, What and How

Centres for Independent Living are user-led organisations that support disabled people to design or shape the services they require to achieve independent living. Sarah Gillinson explores the experience of CILs and outlines the learning for user involvement in public services.

"Independent living is what most non-disabled people take for granted – living the life you want to live – deciding what you want to do, and then having the opportunity and, if necessary, the support, to get on and do it."

The first Centre for Independent Living (CIL) was founded in Berkeley in the late 1960s by 12 students at the University of California. These had severe physical impairments and attended lectures alongside their non-disabled friends. In other ways, their lives could not have been more different. While most undergraduates explored a newfound freedom, they were housed apart in a wing of the Student Health Service. Most of their time was constrained to the University campus, largely because the surrounding area was not set up to accommodate them.

At the same time, the campus was the scene of great demonstrations in support of the civil rights of black people. In this environment, the 12 students came to recognise that the right to lead a full and self-determined life should also be theirs. It was from this understanding that the first CIL was born. Its activities included facilitating access to a pool of personal assistants who supported the students to get up, get dressed and prepare meals, as well as helping them to navigate university bureaucracy to arrange accessible seminar venues. The Berkeley students were supported to identify their own needs and design solutions to meet them. It enabled them to lead full and active lives similar to their non-disabled friends.

What made user involvement successful at Berkeley was something more than 'choice'. It is closer to what Charles Leadbeater calls 'deep personalisation' – services arise where they are required, designed by the people who identify the need for them. Users are not just picking from a menu of options laid out by providers, but actively helping to shape them in the first place.

The results are two-fold. Decisions about service design are, in the most part, more

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appropriate and suited to user need. Even more importantly, users are fully committed to the decisions they have made. This is particularly crucial for areas like health care where patient attitudes to solutions are central to success.

Civil rights demonstrations and self-organised involvement in service design sound like fairly extreme and non-transferable methods

of achieving these aims. But this example, and its contemporary equivalents, bear some important and useful messages for stimulating and making the most of user involvement in public services.

CILs work according to one guiding principle – at every point, the disabled person should own and direct decisions. Empowering the individual to do this means working through a three-stage questioning process: 'The Why', 'The What' and 'The How' of independent living. Often organisations will be working with the person on all three questions at once. It describes an in-depth, supported self-assessment, which recognises that users travel a journey to effective involvement in service design – they have to recognise involvement as a right ('why?'), they have to be supported to identify what they want from involvement ('what?') and finally they have to work with professionals to figure out how they can achieve those aims ('how?').

The fact that CILs are user-led is crucial: they are able to connect with people's experience, understanding the context in which problems exist, and using a shared language. Being a service user "certainly helps as you use the right words and give relevant examples for the situation" (employee, North Essex Stronger Together (NEST), a support organisation for people with mental ill-health). "It gives you a bit of an advantage as you see things slightly differently."

CILs work naturally in ways that are sensitive to a particular group's requirements. People First, an organisation supporting people with learning difficulties, found that women were initially underrepresented at Problem Places – their forum for tackling problems of service provision. They found the busy environment intimidating. Scope has responded by setting up one-to-one or small group conversations, coordinating with the local residential home to make appointments with residents individually. They also found that making other activities the official focus of meetings often enabled people to talk more easily.

Creative outlets like art, or textiles work often helped people to relax – they ended up feeling comfortable talking about service provision issues that were bothering them.

User-led organisations can also create a feeling of solidarity and legitimacy. This enables people to see that their particular concerns are 'allowed' and often shared. For one People First participant, talking about her worries with other service users who were more confident and clear about their rights was vital. It helped her to pinpoint and articulate the source of anxiety, and to identify solutions to the problem.

Many organisations actively try to spread the message that 'it's not just you'. NEST produces a newsletter following peer support 'forums'. It details the proceedings of meetings and contact details for anyone who might want to become involved. The Director also has strong networks with local service providers who publish the newsletter on their websites. It is also distributed in GP surgeries, voluntary organisations and churches.

This legitimacy also allows user-led organisations to represent the collective concerns of a group. This often helps service providers to be better equipped to respond to individuals from within that group on a case-to-case basis.

Making the most of these advantages means employing four basic tools:

- peer support
- information, advice and guidance
- training
- advocacy

A combination of these might be used at any point in the 'why', 'what', 'how' questioning process:

## Peer support

This runs through all the work of user-led organisations and can be practical as well as moral – collective group expertise about local provision and solutions is obviously greater than that embedded in any individual.

## Information, advice and guidance

"Information is the power that people need" (Nick Danagher, Chief Executive, National Centre for Independent Living). And it is rarely pure 'fact'. It is intertwined with

advisers' personal experience of the system and their methods for navigating it.

Relationships built up over time can be key to making the most of information – when a first major barrier is overcome, an individual can approach a trusted adviser with other more day-to-day issues that may seem too trivial in isolation. Here, personalisation is about uncovering the person and their real needs, not just catering to those that are obvious 'on the surface'.

## Training

This is as much about training organisations to respond to users as it is about training users to engage with providers. Increasingly, user-led organisations play a consultancy role with local authorities and health care providers as well as businesses to help them do this.

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Training users to engage with services is often about building their confidence and assertiveness in seemingly unrelated ways. A volunteer at the Independent Volunteer Service in Essex was clear that putting together a more successful support package was often about building confidence, not skills – "people just need the support to recognise that what they can already do is of value." In one case, the key was as simple as joining cross-stitch club at the Women's Institute!

## Advocacy

Scope defines advocacy as: "taking action to support people to say what they want or communicate their views, secure their human rights, represent their interests and obtain services they need." Ideally, every person would be able to self-advocate – to speak up for themselves and represent their own interests. In reality, levels of participation vary hugely. An advocate's involvement may simply be about "levelling the playing field" – for example, changing the balance of power by sitting next to someone in a hospital review. The individual always defines the goal and sanctions the means.

Empowering anyone to shape the services they use, regardless of background, education, starting point or aims, means acknowledging the full 'why' 'what' 'how' journey of participation and supporting people to get on it at any point. Crucially, the success of many user-led organisations in achieving comes from the understanding that it may not be enough to discuss options logically or academically. What peer support of different kinds does is to make participation demonstrably possible, which for difficult, life-changing decisions can be the crucial ingredient.

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This article is based on research that Demos undertook with a variety of user-led organisations between January and March 2005. It formed the backbone of Independent Living; the right to be equal citizens by Sarah Gillinson, Hannah Green and Paul Miller, which can be downloaded for free at [www.demos.co.uk](http://www.demos.co.uk)

# Folk.us Revealed

Embedding patient, service user and carer into the structures of research support is a challenging task. Rachel Purtell charts the experience of Folk.us, a unique organisation working across the NHS and different illness and impairment groups in North and East Devon.

## Background

In 1997, a multi-disciplinary group including service users and carers were developing training for managers in health and social care. It became clear that if service users, carers and patients were excluded from deciding what research took place and how research was developed, there would always be a 'missing link' between research and its implementation into practice.

From this networking, a regional conference, 'Research: who's it for anyway?', took place in 1999. This brought together local research professionals, service users, patients and carers to discuss research and develop ways that people could become involved. The Director of the NHS Executive South West attended and, with others, was inspired to see that involving patients and the public in research would improve its quality and usefulness. Folk.us (Forum for Collaboration with Users in Research) was invited to submit a proposal, which was accepted and it emerged in 2000 as a funded research project, based in the School of Psychology at the University of Exeter.

The aim of Folk.us is to create a health and social care research culture that is meaningfully controlled/influenced by service users, patients and carers so that research and implementation is focused at all stages on ordinary folks' real concerns in North and East Devon. It promotes the idea that they can play an active and important role guiding and designing research. This challenges the more traditional view that they are 'passive subjects' of research.

The original idea was that Folk.us would be a network of people, researchers, health and social practitioners, service users, patients and carers who were interested in research. The network would connect and bring people together with a hope that good collaborative research would follow. One of Folk.us' first activities was a 'scoping study on lay involvement in research; lessons from

other fields' commissioned by INVOLVE. This work led to the Small Voices, Big Noises<sup>1</sup> publication.

In 2003, Folk.us moved to the Royal Devon and Exeter NHS Foundation Trust to work out of the Research and Development Support Unit within the Peninsula Medical School. This move was a strong indication that Folk.us was becoming embedded in the local NHS research support structures.

The National Co-ordinating Centre for Research Capacity Development currently funds Folk.us, on behalf of the Department of Health. The budget of about £49,000 per year includes a part-time staff team of Co-ordinator, Research Assistant and Grant Holder. Folk.us is guided by a Management Steering Group, which includes researchers, service users, and health and social care practitioners.

The aim of Folk.us is to create a health and social care research culture that is meaningfully controlled/influenced by service users, patients and carers so that research and implementation is focused at all stages on ordinary folks' real concerns in North and East Devon.

As Folk.us has developed, it has become clear that a network supporting involvement in research could only work if there was an infrastructure to support collaborative research. There was, however, no such infrastructure in the NHS or academic systems. This meant that Folk.us had to take a different approach and it set about looking at various systems to see what was possible.

## Folk.us work

Folk.us has continued to run a network, with 290 members from diverse backgrounds, including older people and people with acquired impairments. We meet regularly at Folk.us Forums and many members get involved in research projects. Folk.us has also been a partner on two national research projects commissioned and funded by INVOLVE<sup>2</sup>:

- an evaluation of Consumer Involvement in the London Primary Care Studies Programme with the Peninsula Medical School, North & East Devon RDSU and service users
- 'Shaping Our Lives' which was an exploration of user controlled research – what is it and how is it to be done?

There have been four main strands to the Folk.us work:

- Running and developing an enquiry service for all people interested in involvement in research in the North and East Devon area.
- Development and delivery of training sessions for researchers, practitioners, service users, patients and carers about how to involve people.
- Offering practical support on how to involve people to local research projects.
- Developing Information and policies for involving people.

The two Folk.us activities that have had the greatest impact have been three small research grants for collaborative projects and the Folk.us training sessions.

## Small Research Grants

The research grants were part of our original funding and allowed Folk.us to award money to research projects that were designed and developed in real collaboration with service users. The grants were only small, no more than £2000 each. It became clear, however, that for Folk.us to award and administer the grants we would have to develop and negotiate a different system to what the NHS and University would normally use. This was not least because in some cases the lead applicants were service users, whereas traditionally they tend to be employed researchers with academic or NHS backgrounds. We also had to develop a process that would guide service users, patients and carers on how to develop a credible research proposal.

Working through the various stages of awarding the grants meant that the principles and underpinning values of involving people had to be shared and communicated with departments that would not necessarily be seen as needing this knowledge, such as University finance and contracting departments. This has meant that the very structures of the research process had to facilitate the involvement of service users and carers.

Two of the projects have had articles published in 'peer reviewed' journals<sup>3, 4</sup>. 'Experiences of people using strong opioid drugs for chronic non-cancer pain' was jointly funded by Folk.us and Peninsula Primary Care Research Network. The patient-researcher came up with the idea and has worked alongside the GPs and researchers doing the project, which is still under way.

## Folk.us Training

Folk.us has developed training workshops that are delivered both locally and nationally. These are designed to be accessible both to NHS and academic research practitioners and to service users and patients. In many ways, our training is unusual, as we do not deliver a message about how to involve people. We have resisted the temptation to develop a 'blueprint' for involvement in research even though there is a good deal of pressure to do so. Our training gives the basic principles about involvement in research, such as:

- Good involvement is about power sharing.
- Good involvement is not the aim in itself

The National Co-ordinating Centre for Research Capacity Development currently funds Folk.us, on behalf of the Department of Health.

but involvement is to lead to a better outcome for all.

- Good involvement is a continuous process of negotiation and review with those we seek to involve.
- The only people who can tell you how to involve are those you wish to involve and those who wish to get involved – which is why there is no 'blueprint'!

The training has been well received by many people, such as these research staff:

"This was highly relevant to a currently developing research proposal."

"Great to know that there are so many parallels between user involvement in research and the general world of patient and public involvement".

"Good to stress that involvement should be in at (or before) the start! Nice to have such enthusiastic speakers who managed to make this aspect of research so human and grounded in common sense."

## Why do we do it?

Folk.us Revealed: The Untold Story, the third Folk.us conference, was held in March 2005. We asked the mixed audience about why involve service users, patients and carers in the design and development of research. Their answers were:

- "research that means something"

- "improve the quality of research"
- "to tackle real issues"
- "relevant and meaningful research needs to include all the stakeholders"
- "should have impact – influence practice and change things make a difference and see things from a different perspective"
- "to know that we are asking the right questions"
- "making a difference for users and researchers – help to generate better research"
- "discover new problems from new and diverse voices"
- "services that actually meet needs, it makes sense"
- "real resolutions creating debate, discussion and understanding"

Folk.us has provided opportunities for people to work together in partnership across professions and social boundaries. We have seen the beginning of cultural changes in research and practice locally. Involvement is slowly becoming accepted as part of the way research is developed and the value of involving service users, patients and carers as research partners in being understood. Long may it continue!

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# Testing the boundaries

Mental health and learning disability services have a rooted and growing recent history of involving service users. They have much to offer – as well as to learn – about new ways of working for all NHS foundation trusts, as Valerie Howell illustrates from Cornwall.

Many specialist mental health and learning disability trusts are also called “partnership trusts”, largely to reflect our legal partnerships with local authority social service departments. Most of us now provide integrated health and social care services. This means that health and social care staff work in single teams, to single budgets and in a single management structure. However, our designation as partnership trusts also signals our broader values base, and our commitment to working with those who use our services, their carers, our staff and the wider public. There has been an increasing recognition of the contribution that service users have to make both to their own care, but also to the broader development of mental health and learning disability services. Service users are therefore routinely involved in contributing to their own care plans. Through organised service user groups they also routinely contribute to service planning, the management of services, and the evaluation and monitoring of services. The same also holds true for carers.

The first wave of mental health and learning disability trusts began to develop their applications for NHS foundation trust (NHSFT) status in November 2004. Our cultures of close working with multiple partners have made NHSFT status an attractive prospect for mental health trusts. Apart from the financial flexibilities and freedoms offered by NHSFT status, there has been a sense of “fit” between its emphasis on mutuality and our own values. Many of us have begun to question the appropriateness of an NHS body as a vehicle for delivering mental health and learning disability services. Our service users are very articulate about what matters to them. Their priorities are usually:

- decent housing
- something meaningful to do during the day
- good family and friendship networks

■ enough money for a decent quality of life

With priorities that are often about a broader social care agenda, the value of locating mental health and learning disability services within a care and treatment agency becomes questionable.

As NHSFTs, however, our staff, service users and the local community would become eligible to become members, to elect Governors, and therefore to exercise a stronger role in the organisation. This has been one of the main drivers for Cornwall Partnership Trust deciding to pursue an

application for NHSFT status. We feel that the new models of governance of NHSFTs will facilitate greater participation by a range of stakeholders. We also feel that working with local people and our staff in new ways offers us an opportunity to tackle the stigma and discrimination that can affect people with a mental health problem or learning disability.

Having agreed on the potential benefits of NHSFT status, we began the process of meeting with those we saw as our main partners. This included the local authority social services department, the district councils, the local strategic partnership, the user and carer groups who we routinely work with, as well as our own staff. We found support and encouragement from these partners, who were quick to agree with the potential benefits of NHSFT status. We also began to realise, however, that whilst we were talking to statutory partners and key local organisations, we were not expanding and broadening the scope of our networks and partnerships. In this sense, we were failing to interest the general public in our work and our application.

A re-evaluation of our approaches led us to try new ways of working, and to experiment with different ways of connecting with local people. We took stock of the environment we live and work in, and asked ourselves when and where local people come together in large numbers, and what were the community organisations that really influence our community. This prompted a series of innovative approaches to engaging local people. We realised that as a rural county, local agricultural shows are major events in Cornwall’s life, and we have had stalls and staff in attendance at two major agricultural shows, with others planned for later in the year. Our attendance at these events, armed with information about the Trust, our NHSFT application, and more generally about mental health and learning disability services, has prompted

The first wave of mental health and learning disability trusts began to develop their applications for NHS foundation trust (NHSFT) status in November 2004. Our cultures of close working with multiple partners have made NHSFT status an attractive prospect for mental health trusts.

real discussion and debate with local people, and has helped us sign up several hundred prospective members.

Equally, we also realised that long-standing community groups such as Women's Institutes, Young Farmers and parish councils were important ways into local communities, and often the opinion leaders in local communities. Our forays into these groups have been varied, but have often promoted real questioning about the role of our organisation, the ways in which we care for people, the level and type of mental health need in the local community, and the value of membership.

Finally, we were also keen to connect with young people in the county, and took a view early on that we would like to open up membership of the NHSFT to people aged 11 and upwards. This was because we felt that young people have a real contribution to make to their care and to the development of our services, and also because we felt that involving young people in mental health and learning disability issues at an early stage would give us the best chance of reducing stigma and discrimination. We have as a result begun a programme of work through the local youth service with the local youth MPs and youth forum. They are helping to contribute to our ideas about becoming an NHSFT, and are also keen to establish ways of contributing to the overall work of the Trust. Their existing networks are far more effective than any new ones we might create.

As a result of this review of our approach to NHSFT status, we already have a growing membership of over 1,500 people, and more importantly we have found ourselves connecting with our local community in new and innovative ways. We were nervous about this new approach, expecting to meet stigma and discrimination, and a lack of interest from the general public. In fact, we have found that local people, many of whom have family experience of mental health problems, are keen to support their local NHS.

As an organisation, our learning from this exercise can be summarised as:

- Take the time to identify the opinion-forming organisations in your community. They will already have established networks.
- Research who in your own staff group

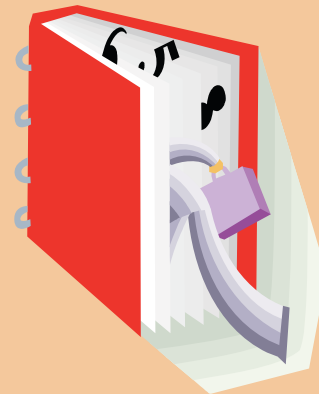
already belongs to these organisations and can help build your relationship with them.

- Identify and make your presence known at major events in the community's life.
- Allow time and resources for all of the above, ensuring that staff who attend have enough information and support to play their role well.
- Be prepared to work to different patterns, and in particular to attend evening, weekend and bank holiday meetings.
- Produce clear information for local people on who you are, what you do, what you are asking them for, and the benefits for the local community.
- Be flexible in your approach – take risks and experiment, adapting your approach as you go.
- Tailor your contact with each group to what they need. Some will want a formal presentation, others an informal chat. Take the trouble to find out before you meet them.
- Review all of your material to make sure that it's jargon free.

Mental health trusts have prided themselves on their partnerships and their ability to work with others. However, building a NHSFT application and trying to embrace concepts of mutuality and local accountability has taught us that our definition of partnership has in fact been very narrow. We have focused on statutory sector partners at the expense of our local communities. This limited set of relationships can perpetuate the sense of a virtual institution for our client groups. If people with a mental health problem or learning disability are genuinely to be supported to become full citizens in their local communities, then more needs to be done to build the understanding, support and capacity of local communities. We have found a local community that is willing to engage in this with us. Becoming an NHSFT appears to offer a real opportunity to make a step change for our clients.

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# Research as Empowerment?

**A recent series of seminars has explored service user involvement in health and social care research. Roger Steel describes how the seminars came about, what was discussed, and the key messages that arose.**

The Toronto Group is a group of researchers, user researchers, service users and practitioners from the UK who first met at an international conference held in Toronto, Canada, in 1997, to explore the issue of empowering research for service users. The Group secured a grant from the Joseph Rowntree Foundation (JRF) to run a series of four seminars to look at key aspects of service user involvement in research:

1. involvement in mainstream or conventional research
2. involvement in peer review (where research proposals are independently reviewed either for commissioning or evaluation purposes)
3. involving people from black and minority ethnic communities
4. involvement in 'emancipatory' research (where service users initiate and lead research which is designed to overcome participants disempowerment as service users).

The seminar planning group consisted of eight representatives from different organisations, at least half of whom were service users. Alongside the JRF funding, contributions were made by INVOLVE, REU (formerly the Race Equality Unit), Folk.us (Devon), the Centre for Citizen Participation at Brunel University, and the Mental Health Foundation. The Social Care Institute for Excellence (SCIE) provided the financial administration.

The seminars themselves attracted a wide variety of people from across the country, with a good mix of service users, user researchers, researchers and research commissioners. Some participants came to just one seminar, whilst others came to more. A few attended the whole series.

Each seminar started with three or four short talks giving different views on the issue in question. There followed small facilitated discussion groups involving all participants, where the issues were further explored and then recommendations made for good practice. The key general points raised at one

seminar were then fed into the next in order to provide a degree of continuity.

A number of issues were raised at each seminar, and there was some overlap between them. For example, participants highlighted that power imbalance between users and researchers remained an issue. This meant that involvement is still not mainstream practice, or that practice is quite poor. There were, however, good examples of involving people in research, and these pointed to standards of

- resources
- relationships
- pursuing outcomes as a result of research

There was a consensus that 'quality' research is crucial, but that some academic definitions of quality need to be reviewed, as these

The Toronto Group is a group of researchers, user researchers, service users and practitioners from the UK who first met at an international conference held in Toronto, Canada, in 1997, to explore the issue of empowering research for service users.

might reflect academic perspectives and priorities rather than reflecting peoples' real experiences.

The first seminar, in London, looked at user involvement in mainstream (conventional) research. Participants identified important good practice issues as:

- commitment to make research accessible to those whose lives it reflects
- commitment to act on the results of the research
- users being involved from the start to finish of research projects
- funders being equally committed to resourcing and prioritising user involvement
- training and support being available for users and researchers

The second seminar, in Birmingham, concerned user involvement in 'peer review'. Peer review is used to gain independent expert views on research, whether early on during commissioning at the research proposal stage, or much later when the research report has been nearly or finally completed. This is so the value, relevance, and competence of the research can be independently ascertained.

Service users are increasingly being asked to peer review research which might have an impact on the services that affect them. The consensus was that peer review at both proposal and reporting stages of research was a central process. There were a number of examples of involving service users in this, which pointed to standards on supporting people to take part and giving feedback on their developing practice.

Participants made these recommendations for good practice for service user involvement in peer review:

- research funders attend to their overall process of involvement, including numbers, roles, training, and support for users
- the funding organisation is committed to listening to the views of service users (and other reviewers) to give feedback on the process and results
- practice should be inclusive for a number of groups – such as people with learning

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difficulties and people with sensory impairments

- service users should be encouraged and supported to comment on any aspect of the proposal or report, and not just about user involvement

The third seminar, in Manchester, was about involving in research people from black and minority ethnic communities, from which almost all of the seminar participants came. Some communities are still under-represented in research, such as people newly arrived in the UK, and Chinese communities. By contrast, other black and ethnic minority groups are over-researched and feel they gain little from participating in research which does not improve support and services to them. They feel that research can sometimes even serve to further marginalise their communities. Participants felt that it was important that research was grounded in their experiences and made a positive difference. Several recommendations were made for good practice:

- researchers build relationships with people from the communities they research
- people from black and minority ethnic communities are involved as partners throughout the research process
- the research addresses questions that communities agree are important in their lives
- people from black and minority ethnic communities are themselves researchers or co-researchers
- specific attention is paid to practical arrangements such as an interpretation, translation, appropriate venues and refreshments
- there is a commitment from everyone to use the research to bring about change, and to feedback what has happened
- user-researchers have the same responsibilities as conventional researchers, and emancipatory research cannot be an end in itself – for it to be valued by users it needs to lead to changes

The final seminar, in York, discussed emancipatory research. This is research controlled by service users and is designed to liberate research participants from the social stigma and marginalisation they experience as users of services. With origins lie in the black civil rights movement in America, it is often used by disabled people and mental health service users in their own research. The approach is an alternative to conventional research which, although often presented as unbiased, objective and neutral, is often perceived by service users as grounded unquestioningly in the views of those who have power. Recommendations made were:

- definitions of emancipatory research and user involvement in research need to be debated and shared more widely
- it need not be limited to qualitative approaches
- there is a need to evaluate best practice in emancipatory research
- more funding is needed for emancipatory approaches, and a proportion of funding set aside for this would help to address some of the power imbalances
- emancipatory research needs to be judged by the same standards of involvement and purpose as any other research
- the outcomes of the research in strengthening the community involved are crucial

It was the consensus from all the seminars that they should lead to change which would be of benefit to service users. To this end, Bec Hanley wrote a full report for the Toronto Seminar Group, which has been published by the JRF. This is currently being widely disseminated to research organisations and service user groups.

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Research as Empowerment? Report of a series of seminars organised by the Toronto Group is available from the Joseph Rowntree Foundation and can be downloaded free at [www.jrf.org.uk/bookshop/details.asp?pubID=683](http://www.jrf.org.uk/bookshop/details.asp?pubID=683)

Hard copies of the report are available at £13.95 from the Joseph Rowntree Foundation, The Homestead, 40 Water End, York, YO30 6WP. Tel: 01904 615905.

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The seminars themselves attracted a wide variety of people from across the country, with a good mix of service users, user researchers, researchers and research commissioners.

# Communities in control: creat

**Greater third sector involvement will put the public and communities in charge of public services, including areas of health and social care, argues David Hunter.**

'Communities in Control: The New Third Sector Agenda for Public Service Reform' – a new joint publication by the Association of Chief Executives of Voluntary Organisations (acevo) and the Social Market Foundation – puts pressure on Government to significantly increase the role of the third sector in delivering public services.

Third sector provision of public services is nothing new: the Coram Family charity, having worked continuously with deprived and disadvantaged children since 1739, is one example. Such longevity and success should be recognised with a greater role, especially given Government plans to create 3,500 children's centres by 2010. Government is now also beginning to champion social care services for excluded older people. Another of our members, the Hospital at Greatham, has been providing services of this type since 1273. Strange then, that the Government appears unwilling to trust charities with public service delivery.

The recent response from charities to the London bombings, where the St. John Ambulance and Red Cross were among the first ambulances to arrive at the scene, provided another illustration of the third sector's capability for meeting public needs.

One example of dramatically expanded public service delivery through the third sector in this country is the work of housing associations. In 1974, housing associations managed only 100,000 homes in the UK; they now manage over 1.8 million – holding an asset base of £60 billion, and continuing to expand. Since the late 1980s, almost all new social housing has been provided by housing associations.

'Communities in Control' identifies four key areas where a similar transfer should take place:

- children's services
- correctional services
- employment training
- independent living aids

This is not an exclusive list; rather areas that we feel are ripe for reform.

Third sector provision of public services is nothing new: the Coram Family charity, having worked continuously with deprived and disadvantaged children since 1739, is one example. Such longevity and success should be recognised with a greater role, especially given Government plans to create 3,500 children's centres by 2010. Government is now also beginning to champion social care services for excluded older people. Another of our members, the Hospital at Greatham, has been providing services of this type since 1273. Strange then, that the Government appears unwilling to trust charities with public service delivery.

acevo has been examining the question of third sector service delivery for several years, through our publications 'Who pays for Core Costs?' (1999) and 'Replacing the State' (2003). We are aware of potential pitfalls and barriers to progress, but the book tackles these in turn.

We are encouraging the Government to set up a new cross-governmental team to speed up the transfer of service delivery budgets and assets from the public sector to the third sector. We believe the cross-governmental team should include representation from central and local government, economists and the major third sector service providers, to see how and when this asset transfer can take place.

The Government will fail to meet its manifesto commitments on public service reform unless it makes better use of the third sector's expertise. Ministers need to look to examples such as Australia to see how they can do this successfully. The present government in Australia has taken steps to outsource publicly funded employment training to the independent sectors.

The two largest providers of employment training services in Australia are third sector organisations: the Salvation Army, with around 10% market share, and Mission Australia, with around 9%.

Ten years ago, provision was shared between the public, private and third sectors in roughly equal proportions. Since then, the government has withdrawn from direct service provision. Its role is now restricted to commissioning and regulation, with the private and third sectors each delivering about 50% of the services commissioned.

If Australia can revolutionise the deliver of its public services through greater use of third sector providers so can we. acevo wants to see the Cabinet Office coming up with concrete proposals within 18 months.

## Procurement Issues

A greater role for the third sector in delivering public services has implications for procurement. The current climate of unstable short-term grants for projects or contracts (usually of only one year) needs to change. Time and resources are absorbed by lengthy negotiations about relatively small amounts of money, and the sector as a whole suffers: short-term contracts pose problems

# ing better Public Services

We are encouraging the Government to set up a new cross-governmental team to speed up the transfer of service delivery budgets and assets from the public sector to the third sector. We believe the cross-governmental team should include representation from central and local government, economists and the major third sector service providers, to see how and when this asset transfer can take place.

for recruitment and retention of staff, and hamper longer-term strategic planning.

The necessity of procurement reform has been recognised by Government: the recent National Audit Office report, *Working with the Third Sector* (June 2005), highlighted the need to secure longer term funding and better contractual arrangements, and HM Treasury is to begin a series of regional seminars exploring the issue of procurement.

acevo's own publication, *Surer Funding*, established a framework for procurement issues, and we are pleased to see many of these ideas reflected in *Compact Plus*: an independent champion to identify best practice; a kite mark to recognise funders who improve their practice; and the possibility of financial penalties for

those who do not improve. In order to achieve the necessary transformation, full implementation of contractual reform at all levels of government is required, and there needs to be action on the part of the third sector if the 2002 cross-cutting review recommendations are to be fully implemented.

Procurement and contracting should not be a barrier for third service providers in delivering public services. Third sector organisations must be tougher at negotiating better deals and not accept underpriced work. Furthermore, they should be unapologetic about offering their services: they should compete on an equal playing field, on the same terms as other providers, and be valued in the same way.

Public service delivery is nothing new for the sector. 70% of acevo members are already involved in some form of service delivery. Yet spending on the sector accounts for only 1% of government spending on public services. Talk of a wholesale takeover of the state is thus exaggerated, and a greater role is hardly threatening to the status quo.

The key development in recent years has been the increasing awareness in government, and in the opposition parties, of the potential contribution the sector can make to the state's agenda. It is time to see manifesto commitments materialise into action, and to see the third sector realise its greater potential.

## David Hunter

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To order a copy of 'Communities in Control: the new Third Sector Agenda for Public Service Delivery', phone Abdul Sherzai on 0845 345 8481.

## Notes:

1. Two years ago, acevo launched a book "Replacing the State" by leading commentators Ed Mayo, Julia Unwin, John Kay, Paul Ormerod, Will Hutton and Stephen Bevan. When "Replacing the State" was launched the argument was "if" government would take on these progressive ideas of the third sector having a greater share of public sector delivery. Subsequently through acevo's "Surer Funding" Commission acevo set out a new economic model to ensure that charities and the voluntary sector would enter into contracts for service delivery that provide high quality services for value for money. The tide has now moved to not be a question of "if" the government is going to do it but "when and how".
2. A key strand of the Government's programme of public service reform has been to open up public service markets to the private and the third sectors. The Government's Manifesto aims to deliver, "services free to all, personal to each... and driving innovation through diversity of provision and power in the hands of the patient, the parent and the citizen."
3. The Labour Party Manifesto recognises that the third sector, incorporating Britain's charities and not-for-profit organisations, "has shown itself to be innovative, efficient and effective," and argues that "its potential for service delivery should be considered on equal terms." It goes on to outline the specific areas in which the third sector could make a particularly significant contribution: employment training, children's services, correctional services, health services and education.
4. acevo is the only association for third sector chief executives in the UK with over 2000 members. The third sector now employs the full-time equivalent of 1.5 million staff, and has a turnover of £46 billion.

# Health scrutiny

**Health overview and scrutiny committees (OSCs) and PPI forums are “a vital part of the future direction of the NHS”, and health OSCs have been “beacons in helping shape services locally”, said Health Minister Rosie Winterton on 19 September at an event about health scrutiny and PPI supported by the Centre for Public Scrutiny (CfPS). ‘People power’ features heavily in current government policy (most recently highlighted by the current ‘Your Health, Your Care, Your Say’ consultation), but it is still refreshing to hear a Minister express such strong praise about scrutiny. She stayed past her allotted time to gather further thoughts from the audience of scrutineers and PPI forum members. What has brought about this positive momentum?**

Quite simply, health scrutiny is proving increasingly effective and increasingly influential. There is no need to take Rosie Winterton’s word for it: CfPS is publishing in October the outcomes of the first phase of evaluative research into the effectiveness of health OSCs, led by the University of Manchester under commission from the Centre’s Health Scrutiny Support Programme (HSSP). The results also provide a refreshing and sometimes surprising insight into OSC’s contribution to PPI and improved service delivery.

Importantly, initial fears that health scrutiny would destabilise or damage relationships between local authorities and the NHS have been allayed. 60% of local authorities and 40% of NHS bodies who responded to a survey said that relationships had actually improved. Many organisations expressed intent to build partnerships through health scrutiny that would extend beyond specific scrutiny reviews – showing how the process can be a springboard for enhanced relationships in a wider context. Moreover, NHS bodies are responding to scrutiny recommendations: 40% have changed policies, procedures or services as a result of reviews and often thought relationship-building with OSCs could help build public confidence in their proposals. This doubtless backs up Rosie Winterton’s claim that “partnership working will be key to providing high quality services.”

This constructive, collaborative approach could perhaps result from health scrutiny’s increasing focus on broader, cross-cutting public health issues that concern both local

authorities and health bodies, rather than earlier trends that favoured scrutiny of specific NHS organisations. The research showed that just over half of health OSCs had conducted cross-cutting reviews into topics such as obesity, teenage pregnancy, diabetes or healthy lifestyles and that 19% had conducted reviews of public health or health inequality topics such as health improvement or access to services. Significantly, health OSCs are increasingly looking at how local authorities can contribute to improved public health. For example, Bexley has looked at impact analysis for tackling health inequalities, Cornwall has at community action on diabetes, Northamptonshire at urban regeneration to stimulate physical activity and Stockport at targeted interventions around obesity. The Minister highlighted local authorities as the natural leaders of such cross-cutting discussions, given the role of elected council members in promoting constituents’ economic, environmental and social well-being.

Of course, both the Minister and CfPS acknowledge that challenges remain around achieving successful PPI through OSCs and PPI forums.

Firstly, the research has highlighted as a key challenge activities around ‘substantial developments and variations’ (SDVs) to health services. Over three-quarters of OSCs had been asked to consider SDVs as part of statutory NHS consultation, which places further demands on limited health scrutiny resources and has the potential to divert OSCs from other cross-cutting reviews.

Secondly, there are differing challenges around resources for OSCs and the NHS. Although less of an issue than at the start of health scrutiny, some health OSCs continue to feel they lack sufficient funding, time, staff or training to adequately support health scrutiny. Health bodies more frequently want clearer guidance or training on the role and purpose of scrutiny reviews. Both OSCs and the NHS commented that engaging with patient and public representative groups can be more time consuming and complicated than anticipated and often struggle to resource this relationship-building process. Extending this discussion about resources, Rosie Winterton cited the NHS Plan’s intention that PPI should be properly supported and expressed the hope that

the review of CPPIH would result in more resources for frontline PPI.

Thirdly, the research also highlighted some instances where the relative roles and responsibilities between OSCs and other PPI structures (including PPI forums) needed clarifying. Rosie Winterton called for this relationship to develop in a way that reflects the complementary roles of OSCs and PPI forums, but within well-defined boundaries. She posed questions about how joint working can be most effective, asking whether PPI forum members could be co-opted onto OSCs without compromising their independence, and whether streamlining PPI forums to local authority boundaries would be appropriate or whether alternative configurations would be more favourable to service improvement?

CfPS is endeavouring to tackle these issues and support PPI through its Health Scrutiny Support Programme (HSSP) and wider activities. We have already published guidance on how health scrutiny committees and PPI forums can work together more effectively and will shortly be publishing a guide on SDVs. We are urging local authorities and NHS bodies to work together towards common local definitions for SDVs, and are asking whether it might be feasible for NHS bodies to publish a ‘forward plan’ of service developments, similar to that produced regularly by council executives in relation to ‘key decisions’, to enable more strategic scrutiny by OSCs and PPI forums.

A final thought from Rosie Winterton’s speech reflects the goal CfPS is striving for – “an NHS that is part of the community rather than detached from it.” On the back of the positive momentum currently surrounding scrutiny, we would like to congratulate all involved in PPI on progress to date. I also hope we can all seize this opportunity to work together and steer services towards being genuinely guided by patient and public concerns. Please contact us if you have any thoughts on how this can be achieved.

**Tim Gilling**

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The evaluative research into the effectiveness of health scrutiny will be released in early October. Please visit [www.cfps.org.uk/health](http://www.cfps.org.uk/health) for further details.

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## Last Word from Chris Dabbs



### Dear Mrs. Buggins,

**Imagine the situation. It is 2015; you are buying fuel for your hybrid car. Having filled up, you hand over your £100 and your personal carbon ID card. 50 carbon credits are taken from your carbon account. This saves buying them at the counter, which at market rates would set you back another £25.**

It might sound far-fetched, but this scenario is now being seriously considered to help improve energy use and reduce pollution. It is thought that it would contribute to bringing our emissions down by at least 60% by 2050.

Everyone would get a free allocation of carbon credits to pay for electricity, gas and petrol. Low consumers could sell surplus credits on the carbon market, while high consumers would have to buy. Everyday decision-making would have to take account of the cost of carbon, prompting changes in behaviour. Energy efficiency should improve alongside the demand for and development of low carbon technologies.

At present, the only high-profile answers to ever-growing demand for health and social care seem to be pouring increasing amounts of money into the NHS, GPs charging patients, or instituting some form of delay to manage the demand. I wonder if an approach equivalent to carbon credits might not only better manage services, but also put more control and choice directly in people's hands.

Everyone would be given a personal health allowance – a free basic allocation of health credits, on top of which those with either disabilities or long-term conditions would get appropriate allowances. The system might require all providers – statutory, private or social – to charge the credits, thus making access to services more equitable for all, and providing a partial counterbalance to inequality in incomes.

Those whose use of services was relatively low could sell their surplus credits on the health market, while high users would have to buy. Decision-making about health and well-being would have to take account of the cost of services. Behaviour would change. People who would otherwise use services for trivial issues might see a greater value in self-care and self-management. There would be a greater value placed on health-improving services (as already happens in insurance-based health care systems), including non-health care solutions, such as improved diets. Personal and collective responsibilities for the use of health and social services would be better balanced.

For commissioners and providers of services, greater responsibility would be shared with consumers – who (with the credits acting as economic incentives) might also be seen and treated more favourably as responsible citizens. Demand would be likely to be more stable and predictable, but supply would have to become more responsive, as the range of direct choices for citizens would more closely match their requirements.

Would there be issues and concerns about such as system? Of course. But the present health and social care system, with ever-increasing pressure on professionals and ever-growing thirst for resources, is unsustainable. Maybe at least part of the solution may lie in people's own hands, if we dare to give them real resources?

Keep well

**Chris**

*Chris chairs Passionately Curious Ltd, a social business that is working with diverse citizens and communities.*

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# EVENTS CALENDAR

## Making a Difference to Your Patient's Experience

**Monday 5th December,  
Manchester & London**

09.00 - 16.30

Price: £195 + VAT

Contact: Miguel Ramskill

Telephone: 01952 201338

E-Mail: [train@sti-uk.com](mailto:train@sti-uk.com)

Fax: 01952 293717

### Summary:

This new one-day course is intended for PALS Coordinators and PALS Champions. It is an opportunity to look at your service through your patient's eyes with the aim of improving their experience.

## Effective Patient and Public Involvement Conference

Practical strategies to put patients at the centre of NHS Services

**3rd November 2005, 27 Sussex Place,  
London NW1**

Health Service Journal presents this timely one-day conference specifically designed to highlight and demonstrate how to overcome the challenges of effectively creating open and patient-centred services.

Developed through research with some of the industry's most respected health service professionals this is the ultimate forum to address issues of concern for all those involved with PPI.

### Contact Details

Email: [hsjc.onferences@emap.com](mailto:hsjc.onferences@emap.com)

Tel: 0845 056 8299

## Equality & Diversity: Excellence through inclusion

**Monday 31st October London**

Leading edge practice from within and outside the NHS will be showcased to demonstrate how this contributes to improved patient care.

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