

# PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

## True Costs of Public Participation

Is it possible to assess costs and benefits of different participatory approaches? Edward Andersson has been finding out.



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## The Rules

Isn't it great to watch your children growing up? You've nurtured them from birth; watched them develop and grow; and struggled as they became assertive enough to begin to challenge your established conventions and rules.

One thing that I have always tried to teach my kids is the importance of questioning the 'rules', and this has sometimes made life difficult for me. It has though, also made me notice some new insight or new perspective that my set of rules would have denied me.

A series of episodes this week has reinforced in me my determination to challenge rules and accept that doing so creates some risks. Yet without risk how will we ever find anything new?

When my daughter explained that she is due for two weeks work experience, I made a suggestion. Instead of counting paperclips in some plumbing merchant's office, I suggested that she should come and work with me. It would be unpredictable, we would be travelling a lot, meeting a wide range of interesting people, working on projects and as if that was not enough I had scheduled a trip to Grimsby.

She was over the moon. Perhaps Grimsby is more exciting than I had imagined. So, I completed the forms and sent them back to the school. We talked excitedly about how we might

arrange to visit a fish processing factory whilst in Grimsby. I hear that fish skin can be made into a strong material and Birds Eye are just throwing it away.

Then the rules kicked in. I received a call from the school. They asked me where my office was. I said it is virtual. It is wherever I am at the time. "Is it insured?" they asked. Of course not I told them. "Then your daughter can't come with you it's too much of a risk". So I can raise her from birth, take her all over the world on holidays and watch her fall from trees, but taking her to Grimsby it seems is so dangerous that the school can't condone it. They are asking me to take out insurance, which I am refusing to do. If something bad were to happen what would I do - sue myself? I would be both defendant and prosecution.

Here is a case where the rules just don't fit the situation, yet everyone is gripped by such fear, they are unable to see the stupidity of their own rules.

In the same week I spent time visiting sports projects all over the country. Sport England has spent £1.2 billion over the past ten years trying to get people more active - and activity rates have actually gone down. So I am helping them to think differently and have had to spend a lot of time in my car. I was determined that during this week travelling I would make an effort

to keep active. I was turned away from four gyms. The reason? I had not undertaken their induction programme and it was too much of a risk to let me in. I explained that I have been going to a gym every day for the past ten years. This would not do. The rules forbade it. One receptionist took great delight in telling me that even if I were Arnold Swartzenneger I would not be coming into her gym.

The rules are stifling us and squeezing the life out of our society. In Chris Dabb's letter to Mr's Buggins (back page) this month I was pleased to see that he is addressing the importance of PPI in challenging the established rules and conventions which surround health care.

He says we should value the mavericks and the 'weirdo's' much more than we do. These are the people who challenge rules and ask how we can do things better or different.

As PPI becomes an established activity we have to be so careful that it does not become another rule bound culture trapped amidst preconceived notions of how things ought to be.

When we are asked to think radically we are sometimes asked to think 'outside the box'. Chris Dabbs wants to ask the question "What box?"

It's great that PPI is maturing, but lets not get boxed in by the 'rules'.

## 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.

### Nick Bosanquet

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.

### Zenna Atkins

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

for Peace, a member of CAN, an Ernst and Young Entrepreneur of the Year, founder of PCSP, founder of YSHIP, now First Base, a founder member of the Work Life Balance Trust and a mother of two.

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

Malcolm is currently Chief Executive of Addenbrookes NHS Trust. Previously he was Chief Executive of the Norfolk and Norwich University Hospital NHS Trust and, prior to that, Chief Executive of the Royal Liverpool University Hospital, Liverpool Health Authority and Crewe Health Authority. Malcolm has held a number of other positions in the NHS spanning some 29 years and was awarded a CBE in the Queens 2002 Honours list.

### David Gilbert

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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# News items

## White paper focuses on bringing health closer to people

**A raft of new plans are outlined in 'Our Health, our care, our say: a new direction for community services' - the Government's White Paper on improving community health and care services.**

The White Paper aims to provide people more choice and say over the care they receive in the community, and much closer working and coordination between health and social care. This will include improved access to GPs by increasing the choice of practices for everyone and extending opening hours; more support for people with long term conditions; local partnerships between Local Authorities and PCTs to produce joint teams and common assessments; and a new generation of community hospitals and health centres that provide health and care services in the heart of the community.

New measures outlined in 'Our health, our care, our say' include:

- Shifting expenditure from spending on hospitals to spending on care closer to home and on preventative services
- New responsibilities placed on local councils and the NHS to work together to provide joined up care plans for those who need them.
- Bringing some specialties out of the hospital nearer to people including dermatology, ENT, orthopaedics and gynaecology
- Introducing a new generation of community hospitals that will provide diagnostics, minor surgery, outpatient facilities and access to social services in one location.
- Pilot a new NHS "Life Check" to assess people's lifestyle risks, the right steps to take and provide referrals to specialists if needed.
- Give patients a guarantee of registration onto a GP practice list in their locality and simplifying the system for doing this
- Introducing incentives to GP practices to offer opening times that respond to the needs of patients in their area
- Increasing the quantity and quality of primary care in under served, deprived areas through nationally supported procurement of new capacity with contracts awarded by PCTs
- Supporting people to self care by trebling the investment in the Expert Patient Programme
- Developing an "information prescription" for people with long term health and social care needs and for their carers, investing in professional education and skills development
- Providing a Personal Health and Social Care Plan as part of an integrated health and social care record
- More support for carers including improved emergency respite arrangements and the establishment of a national helpline for carers.
- Extension of direct payments and piloting of Individual Budgets for social care

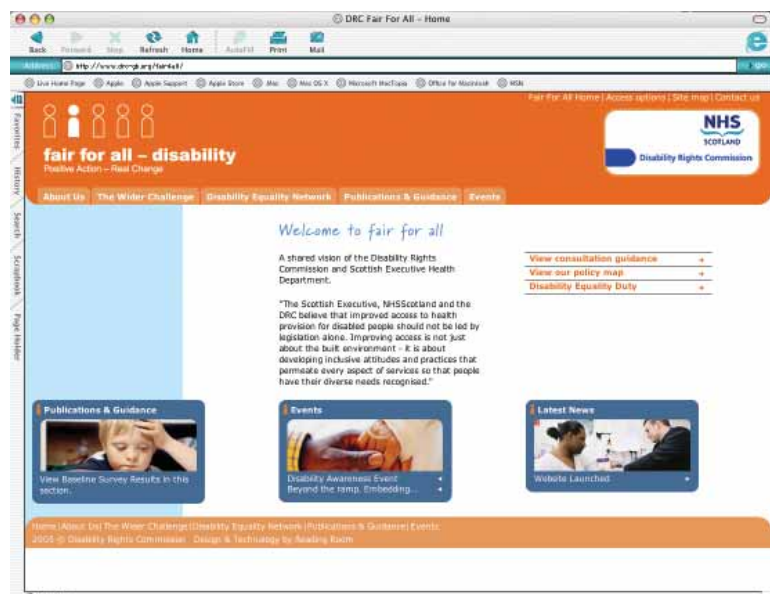
## New website on 'Fair for all - Disability'

**A new website 'Fair for all - Disability' has been launched by the Scottish Executive Health Department, and the Disability Rights Commission.**

Fair For All - Disability initiative aims to show health practitioners and managers how to go beyond compliance with the law but to achieve the best practice that promotes the rights, independence, choice and inclusion of disabled people as health service users and members of the community.

This fully accessible website provides accurate, up to date information offering an outline of the work Fair For All - Disability is doing, information on key activities, publications and events

**Please visit [www.fairforalldisability.org](http://www.fairforalldisability.org)**



# News items

## Patient and consumer organizations welcome outcome of World Health Organization first Patients for Patient Safety workshop

**Patient and consumer organizations joined together on 8 February to welcome the publication of the London Declaration from Patients for Patient Safety following the World Health Organization's (WHO) first Patients for Patient Safety workshop last year. The International Alliance of Patients' Organizations (IAPO) and Consumers Advancing Patient Safety (CAPS) commended the WHO on incorporating the patients' voice in a meaningful way into the WHO World Alliance for Patient Safety and congratulated Patients for Patient Safety on its achievements to date. Patients for Patient Safety is one of six action areas of the WHO World Alliance for Patient Safety.**

"Patients must be at the centre of our quest to improve patient safety" said Sir Liam Donaldson, Chair of the World Alliance for Patient Safety. "When things go wrong, they and their families suffer from any harm caused. Patients for Patient Safety is designed to ensure that patients and their families are a central part of international efforts to improve patient safety through this WHO Alliance"

The groundbreaking Patients for Patient

Safety workshop was held in London, 27-30 November 2005 running in parallel to the EU Summit on Patient Safety, organized by the UK Government in its role of Presidency of the EU during 2005. Following a competitive application process, 24 patient and consumer advocates – patient safety champions - were selected together representing 21 countries across developed, transitional and developing countries, providing a truly global voice.

The key outcome of the workshop was the publication of the London Declaration through which the patient safety champions expressed their vision for safer health care systems worldwide and highlighted concrete areas where patients and consumers – and the organizations that represent them - can work in partnership with health providers to make a significant contribution to the improvement of patient safety.

"We learned from the 24 thoughtful patient safety champions that challenges in delivering safe, compassionate health care cut across all geographic, ethnic and socio-economic boundaries," said Susan E. Sheridan, MIM, MBA, CAPS Co-Founder and President and Lead of Patients for Patient Safety. "The

London Declaration will be the soul of the work of the World Alliance."

IAPO and CAPS congratulated the workshop participants for their incredible focus and skill in defining and developing the role of patients and consumers in the WHO's World Alliance for Patient Safety. In addition to the concrete outcomes, the workshop was also an important signal of highlighted the importance of the patient voice in health policy-making.

IAPO and CAPS have announced their support for the London Declaration with its commitment to harness the expertise, knowledge and motivation of consumers and patients to work through partnerships to improve patient safety for all patients. IAPO Chair, Albert van der Zeijden, commented, "This Declaration demonstrates the strong commitment of consumers and patients, and the organizations that represent them, to contribute their knowledge and expertise to improve patient safety in a structured and effective way."

## Help for DoH Study

The White Paper Better Information, Better Choices, Better Health proposed the development of a national Information Accreditation Scheme to give members of the public "a clear set of quality criteria covering currency of information, its reliability, user involvement in development, and accessibility". In developing the business case for the scheme, the Department of Health has asked the Picker Institute to carry out a study to determine the current quality of health and social care information to enable an assessment of the costs and added value of accrediting information providers.

Picker is producing an estimate of the

number and types of information providers offering information on four specific diseases or conditions:

- chronic obstructive pulmonary disease (COPD)
- arthritis
- healthy eating to prevent or reduce obesity
- measles, mumps and rubella vaccination (MMR).

The institute is aiming to obtain copies of relevant information materials (or website links) in order to find out more about how they were developed (by surveying

information providers) and assessing them against a quality checklist.

They are interested in information developed specifically for patients or members of the public by UK-based commercial organisations, voluntary groups, NHS and other healthcare providers, professional or government organisations.

If you know of any information materials on any of the four topics listed above (leaflets, audio, video or websites), then they would like to hear from you, or if you have any comments on this area of research contact [Danielle.swain@pickereurope.ac.uk](mailto:Danielle.swain@pickereurope.ac.uk) or on 01865 208100

# A Tool for Leaders

Fabienne Jacquet explains how Diabetes UK's latest toolkit can help empower people within black and minority ethnic communities.

**Diabetes occurs when the amount of glucose (sugar) in the blood is too high. Normally, a hormone called insulin controls the amount of glucose in our blood. With diabetes the body either doesn't produce any or enough insulin, or the insulin it does produce doesn't work properly.**

There are two types of diabetes. Type 1 diabetes is usually diagnosed in people under 40 and is treated with insulin injections, diet and exercise. Type 2 diabetes usually appears in people over the age of 40, though often appears after the age of 25 in South Asian and African-Caribbean people. It can be treated with diet and exercise alone although it can also often require tablets and sometimes, insulin injections as well.

Diabetes can be managed by achieving blood glucose and blood pressure levels as near to normal as possible. This, together with a healthy lifestyle, will help protect against the long-term complications of the condition which include heart disease, stroke, kidney disease, blindness and amputation.

Diabetes is a serious problem amongst black and minority ethnic communities. The prevalence of Type 2 diabetes is up to six times higher in Asian people and it also tends to develop around five years sooner. 20% of the South Asian community and 17% of the African-Caribbean community has Type 2 diabetes, in contrast to 3% of the general population. Diabetes affects two million people in the United Kingdom and another million are estimated to have the condition but are not yet diagnosed.

In spite of those alarming figures, awareness levels of how to manage the condition remain low amongst black and minority ethnic communities.

To tackle this, at the end of 2005, Diabetes UK launched an awareness raising toolkit to help community and religious leaders, and health care professionals, organise awareness days about diabetes and the work of Diabetes UK.

The toolkit aims to equip community and religious leaders with the ability to organise awareness days for anyone affected by

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diabetes including, people with the condition, their family and carers. The awareness days provide information in a culturally sensitive way that enables people to understand diabetes and help educate and empower community members.

The Toolkit was launched in London and the West Midlands as a pilot programme. To date, 119 people have requested it and 50 people have organised events using its recommendations.

Jenne Dixit, Equality and Diversity Advisor at Diabetes UK, said, "Diabetes UK developed the toolkit to empower local communities and give them better access to information in a culturally sensitive way. We know that people who are of South Asian descent have a higher risk of developing Type 2 diabetes, so it is important that all is done to reach those communities. Local community and religious leaders are in a position of trust and can help communicate Diabetes UK's awareness messages".

The toolkit will soon be available on the Diabetes UK website downloadable in PDF format free of charge. Diabetes UK is also planning to develop a CD-rom this year to complement the Toolkit - which will also be available from the Diabetes UK website together with a good practice section for all to download and use.

Dr. Harshad Mistri of the Confederation of Indian Organisations uses the toolkit to organise regular awareness events for the

South Asian community. He believes it has been extremely useful in reaching South Asian communities. Dr. Mistri said, "One of the main advantages of the tool is that all the information about diabetes is shown and organised in a very visual way and as many of the people we try to reach do not speak English too well, using the tool is still effective in communicating clearly and easily."

Dr. Mistri conducts regular evaluation of his events and those attending have confirmed that they enjoyed having the opportunity to talk to a member of their community, who could for instance help them understand medical terms by translating them into their own language.

Dr. Mistri's awareness events have proved extremely popular and have attracted interest from the BBC, Radio 4 and from major newspapers such as The Guardian.

To raise awareness of diabetes in minority ethnic groups, Diabetes UK has also produced information leaflets on a variety of topics relating to diabetes in various ethnic languages including Hindi, Urdu, Punjabi, Bengali, Gujarati and Chinese. The free information sheets can be found on the website ([www.diabetes.org.uk](http://www.diabetes.org.uk)) or ordered from Diabetes UK.

In addition, Diabetes UK has produced an information video 'Understanding and Managing Diabetes in the South Asian Communities' available in VHS and DVD format as well as an audio tape 'So you think you know about Diabetes?' which is available in Bengali, Hindi and English.

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For further information and support on any aspect of managing diabetes or to order free fact sheets contact the Diabetes UK Careline on 0845 120 2960. A translation service is also offered on this number. The line is open Monday to Friday between 9.00 a.m. and 5.00 p.m.

## True Costs of Public Participation

Is it possible to assess costs and benefits of different participatory approaches? Edward Andersson has been finding out.

### Participants – economic man or social animal?

There are conflicting views of what motivates participants to engage and also on the correct way to avoid engagement fatigue. Are participants primarily in it for personal gains and benefits, or are they motivated by a will to work for the greater good of the community? The answer to this is critical to the way in which we should encourage increased participation: should we appeal to their self-interest or their conscience? The truth is that the answer depends on the context; in some cases participants will respond well to material incentives and in other cases they will be at best pointless and at worst harmful to the success of the project.

### What we know we don't know

While we know very little about the economics of public participation in general, the sad truth is that we know even less about the specific costs and benefits of the participants. In many ways, this is a remarkable situation; the motives of the people who are supposed to be at the centre of engagement are still somewhat of a mystery to practitioners and researchers. The reporting and thinking is often centred on the interests and outlook of the delivering bodies, a situation increasingly seen to cause problems.

### Why does it matter?

It is often assumed that hidden in the teeming masses of the public is a huge untapped drive to get involved; all an organisation has to do is to organise the events and the participants will come. The growing signs of 'engagement fatigue' go some way to dispelling this myth. In fact the will (and time) available among members of the public to get involved is limited and we need to get a clearer understanding of their priorities in order to target engagement better and make the best use of the time they are willing to give us.

I believe it is possible to talk about two

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different perspectives on why people participate. One perspective focuses primarily on the material incentives whereas the other emphasises altruistic motives for participation. These two models are obviously generalisations and are in practice participants are often driven by both.

### What's in it for me?

The materialist view assumes that participants are primarily guided by material incentives. They balance the gains and losses of participation, either to themselves or their close friends and family, and base their decision on whether or not to participate on this assessment. If this is what motivates participants increasing the direct benefits of participation and reducing the costs is the route to increasing the levels of participation.

The most clear cut materialist perspective is

found in mainstream economics. Neoclassical economics assume that people act rationally and that they consider their own interests as the basis for decisions. This notion of the "economic man" has been criticised for making unrealistic assumptions, such as perfect information, discounting of future costs and benefits, and no consideration of the impact of social norms on people's behaviour.

### For the greater good

On the other hand, altruistic motives are not based on personal gain, but rather the feeling of doing 'what is right'; often the goal is collective rather than individual benefits. Social norms and social capital play a part in encouraging this behaviour. If altruistic motives are what is driving participation, it would seem less important to focus on increasing personal benefits, but rather focussing on the benefits to groups and society at large. Communicating the beneficial outcomes of participation in a clear and effective way could also play a part, as well as efforts to create a culture of participation where it is seen as "the right thing to do".

In fact, some research has shown that where people are primarily motivated by altruism, the introduction of material incentives (like monetary compensation) can actually decrease the level of participation. It seems that people think in different frames of mind depending on whether they are thinking about their own interests or the greater good. Bringing money into the picture seems to put people into a different set of mind and to put them off doing things voluntarily.

### Methods to encourage participation

Both altruistic and materialistic encouragements have been used to increase participation in the UK over recent years. Efforts to make participation more accessible (reducing costs) are increasingly being used, such as scheduling meetings at better times, providing child care, and reimbursing costs for transport and other expenses. It is also increasingly common to pay compensation

for the time that participants put into the process (increasing the direct benefits).

On the other hand, we have initiatives encouraging altruistic behaviour. The citizen curricula and last year's 'Year of the Volunteer' programme aim to create and develop a culture of public participation in society. These initiatives do not promise to deliver benefits to the individual but rather appeal to their will to do good.

## What our research found

Case studies carried out by Involve to explore the perceptions of the costs and benefits of participation have highlighted a number of different situations with relevance to this debate.

One of our case studies was a primary care trust (PCT) in north-east England that ran a health support service in collaboration with a major health charity. This service relied on volunteer participants for its day-to-day functioning. When asked about their motivations for taking part the participants cited motives like "doing the right thing" and "giving something back to the community". When asked about financial compensation (beyond the PCT providing free transport), the interviewees felt that they were happy not to receive any, indicating strong altruistic motives. The participants in this case mostly were retired and it could be argued that their time had lower opportunity costs.

In the case of a large carers' involvement project run by a county council in southern England, participants were able to claim for expenses related to their attendance. Many participants did not claim, and while this might be attributed to poor information or complicated claims forms, it is equally possible that there were altruistic factors in play. The council's offer to pay costs may have been sufficient for many people as a gesture of respect and appreciation for their time and effort, without the participants actually having to take the council up on the offer.

We also looked at a case where a charity ran a long-term engagement process in Wales aiming to support children and their families to break cycles of deprivation and ill-health. Because the project relied on the long-term involvement of the participants, and because of past experience of participants being

'mined for information' by organisations, the charity went to great lengths to ensure that participants were adequately compensated for their involvement. The policy was that in cases where participants had a stake in the outcome of an activity, the main thing was to ensure that their direct costs were paid for, while in cases where there were no direct benefits to the participants themselves (like when external researchers wanted to carry out interviews), direct compensation of some kind was in order.

## The way forward

There appears to be a difference between costs and benefits. For costs, it is fairly straightforward: reducing the costs to participants can have a real impact on the ability of people to take part. This could mean reducing costs, for example by shifting around the timings of meetings or providing free crèche facilities, and it can also mean compensating for incurred costs, like travel or accommodation costs. These methods

would enable those who are willing to attend but find the costs prohibitive. However, it is unlikely that reducing costs would encourage those who have little natural inclination to participate to attend.

For benefits, it is slightly different: increasing the levels of benefits can have a real impact on the willingness of participants to take part. In cases where the main benefit experienced by the participants is the opportunity to make a difference to others or similar altruistic motives it may be counterproductive to introduce financial incentives. In the case of the volunteer-run health advice service, paying participants a wage for their time might undermine the feelings of doing good that drove participants to take part. In short, putting a price on people's participation can be a risky strategy.

On the other hand, in situations where the participants have little to gain from the participation, monetary compensation can be a fair way of making sure that there is something in it for the participants.

## Conclusion

This is an area that we really need to learn more about. The scale and number of public participation events (in the health sector and elsewhere) looks set to increase even further in the coming years. While the 'supply' of engagement events is rising the 'demand' for them may well drop due to engagement fatigue. We all need to wise up to the fact that the time and energy that participants put into participating is a valuable and finite resource. Not just because participation can deliver improved services, wider support for decisions and reduced conflict, but also because it is time that participants might otherwise have spent with their families and friends. It is our responsibility to ensure that we do not waste it.

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The materialist view assumes that participants are primarily guided by material incentives. They balance the gains and losses of participation, either to themselves or their close friends and family, and base their decision on whether or not to participate on this assessment.

# Welcome to L2Ozone!

**Marketing is a key skill, but one often overlooked in engaging communities in health. Jackie Rankin offers a successful example from Merseyside.**

The L2Ozone is a partnership of statutory, voluntary and community organisations in South Sefton, Merseyside, whose vision was to:

- Bring small organisations and local community members into the arena to work more closely with large statutory agencies
- Give providers – including volunteers in community and voluntary organisations – the skills to market their services effectively

This vision embraces the principles outlined in the Choosing Health White Paper - Working together, Enabling Informed Choice and Personalising Services.

The sector has grasped the opportunity and more than 30 organisations, including the residents and tenants association, are involved in the Zone network.

## The Issues

Fewer than 30% of adults in South Sefton (of which Linacre ward is part) reach the recommended 30 minutes a day, 5 times a week, physical activity target and almost 11% do not exercise at all.<sup>1</sup> Yet seven out of ten people said they would be more active if they knew what was available locally.<sup>2</sup>

Small organisations had little or no marketing budgets, yet lacked the skills to do it themselves, leading to a sense of frustration and isolation that people did not know what was available on their doorsteps.

Residents and Tenants Association Chair Barbara Hardwick: "It was so frustrating – people were saying there was nothing for them to do in the area but everything they were asking for was already being offered. The problem was that small organisations don't always promote their services well. The L2Ozone has gone a long way in solving that problem."

## How It Was Done

In 2003 May Logan Centre (a healthy living centre, managed by Liverpool Housing Trust), supported by Sefton Leisure Services and South Sefton Primary Care Trust, bid for and secured New Opportunities Funding

(now Big Lottery Fund) to support an initial social marketing skill development programme.

Consultants trained some 20 organisations in the key skills needed for creative and effective design and promotion of services to key target groups. A marketing plan was devised and implemented. The plan is now in its third year with training updated as new organisations come on board.

An evaluation of the marketing skills/network programme by Liverpool John Moores University states that "Most respondents indicated that there is now an increase in the use of services provided by their various agencies and this is attributed to the partnership working".

Project Co-ordinator Chris McBrien feels the ongoing professional support from journalist Jackie Rankin, who was involved in the original training, has been a vital element in sustaining the project. "We have the basic skills to promote ourselves but we don't always make it a priority. Jackie has supported partners on the ground and ensured promotion is kept high on everyone's agenda. Without that input things might be different."

Jackie Rankin co-ordinates the pivotal "product" of the Zone, a tabloid style newspaper that has proven an effective social marketing tool. Lively features on partner organisations use photographs of people – for instance a "vox pop" on the food in the community café, featured local people in taster sessions. This type of article both involves local people in publicising services and in a small area people are recognised, serving to personalise those services and make them fit with residents own lifestyles. To ensure they are available, the Peel and Knowsley Tenants group deliver all residents the newspapers to 1500 homes, while a further 1500 are available for free collection from into venues in L2O.

In a survey of 140 people, six out of ten said

they were familiar with the Zone newspaper. One fifth of respondents had used a new service in L2O as a result of reading the newspaper.

A vibrant network enables ongoing joint working and continued skill development. Around 20 organisations meet regularly for an information exchange and can reach each other through an exclusive database. But the real energy is in the informal partnerships that have produced events like Get Going Bootle, an annual physical activity based event attended by 350 people

Christine McBrien reflects that "This project has built the capacity of people who are delivering services on the ground to provide real informed choice."

**Jackie Rankin**

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For further information on any element of the L2Ozone or a copy of the JMU report, please contact Christine McBrien on 0151 922 8588 or email cmcbrien@lht.co.uk

## References.

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## It's a Mystery

**How can genuine patient feedback be obtained about services? Jean Mead describes an approach in Wales using mystery patients.**

The Mystery Patient Project has been established through the development of a local partnership approach to public and patient involvement by three local health boards (Conwy, Denbighshire and Flintshire), the Clwyd Community Health Council (CHC) and the Conwy and Denbighshire NHS Trust.

The project invites patients who are being treated by the Conwy and Denbighshire NHS Trust for a heart condition or receiving orthopaedic treatment to give their views on the quality of trust services. The project asks what patients visiting clinics or hospital think of the cardiac or orthopaedic services and support services, like x-ray and physiotherapy. We are also asking mums-to-be to give their views on services throughout pregnancy and afterwards.

Patients within Conwy, Denbighshire and Flintshire who will be accessing the services in the three selected departments will all have an opportunity to become "Mystery Patients". They will be given an information leaflet containing an application form at point of contact with their GP, or they will be sent a leaflet with their initial appointment letter from the hospital.

Clwyd Community Health Council will lead the project and work in partnership with the Trust and Local Health Boards. Patients who would like to become "Mystery Patients" contact the CHC which will then send out an information pack containing a number of questionnaires and reply paid envelopes. A questionnaire will be completed and returned to the CHC each time the patient has contact with a service within the Trust. The questionnaires will allow patients to comment on the services they receive. The questions will ask about waiting times for appointments, any delays when attending for appointments and whether explanations were given, attitude of staff, overall standard of communication, the hospital environment and hospital catering.

The aim of the Mystery Patient project is to evaluate, from the patients' perspective, their experiences of the healthcare services they receive from point of referral through to discharge.

The questionnaires will be mainly in a tick

box format and patients will tick the box that most closely matches their experiences and views.

Trust staff are aware that the project is running, but will not know which patients are "Mystery Patients". The success of the project depends on staff being unaware who the Mystery Patients are so that they provide their usual standard of care. Only Clwyd CHC will have the patient details and completed forms and they will ensure that the patient's identity is kept a 'mystery' throughout. Patients are assured that the questionnaire is totally anonymous and that the responses that they give are treated in the strictest confidence.

A publicity campaign is being used to encourage patients to participate in the project. As well as the leaflet outlining the project being sent out to patients at the earliest opportunity, publicity is reinforced by posters and leaflets in GP surgeries and hospital clinics and by articles on local radio and in the local press.

The project will run for approximately two years and at the end Clwyd CHC will publish a report based on patient feedback from the questionnaires. All patients who take part in the project will be sent a copy of the report and it will also be published on the CHC website. The information obtained will help identify strengths within health care as well as areas that need more development and to learn from the patient's experience in considering service improvement. By getting feedback from the public, the Conwy

and Denbighshire NHS Trust can make real improvements to services that will make the patient's experience that much better.

The Mystery Patient Project was officially launched on 13 December, 2005, by Dr. Brian Gibbons, Minister for Health and Social Services in the Welsh Assembly Government. Since the launch, there has been a considerable amount of interest shown, both by the public and also by other hospital staff who have seen details of the launch on the BBC News website.

**Jean Mead**

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from left to right: Dr. Brian Gibbons, Minister for Health and Social Services, Welsh Assembly Government; Vicky Russell, Patient Experience Officer, Conwy and Denbighshire NHS Trust; Gail Roberts, Chief Officer, Clwyd Community Health Council; Hilary Stevens, Chairman, Conwy and Denbighshire NHS Trust.

### Mystery Patient

**Referred for orthopaedic treatment?**

**Referred for heart treatment?**

**Having a baby?**

**Could you be a MYSTERY PATIENT?**

**What is it?**

The project invites real patients who are being treated by the Conwy & Denbighshire NHS Trust for a heart condition, orthopaedic treatment or because they are having a baby, to give their views on the quality of hospital services. Any patient who lives in the counties of Conwy, Denbighshire and Flintshire who is being referred to one of the 3 specialities will be able to be a Mystery Patient.

**What would I have to do?**

The project is being managed by Clwyd Community Health Council who are the independent watchdogs who represent the interests of the public in the NHS. All the information that you give them will be strictly confidential, as the success of the project depends on NHS staff being unaware that you are a Mystery Patient. The Community Health Council will send you a pack of questionnaires. Each time you visit for an appointment, treatment or admission you would fill in a questionnaire and return it to the Community Health Council in a pre paid envelope.

**What happens then?**

At the end of the project, which will run for two years, the Community Health Council will publish a report based on patient feedback from the questionnaires. The Conwy & Denbighshire NHS Trust will then be able to use the information from the report to make real improvements to their service and to make the patient's experience better.

**Interested?**

For further information or a pack, please contact  
**Clwyd Community Health Council**  
on 0845 2267292  
or email admin@clwydchc.org.uk

# NEDs and PPI: what can we learn

## What can PPI learn from non-executive directors? Tim Gilling has been listening to an expert.

My July 2005 contribution to PPI Monitor highlighted the distinct but interlinked contributions that various non-executives make to the PPI framework – including members of PPI forums, overview and scrutiny committees, NHS foundation trust members and non-executives on health boards. The first three of these PPI players are creatures of the 21st century – relatively new features on the PPI landscape. Non-Executive Directors (NEDs) have, however, been used for decades across the public sector to bring an element of ‘representation’ and independent challenge to service design, delivery and accountability. But even if the PPI landscape is now also populated by more explicit and widespread mechanisms for public input, there is still much to be learned from the experience of NEDs in health and elsewhere.

The Centre for Public Scrutiny (CfPS) Annual Lecture 2006 was delivered on 24 January by recent Public Appointments Commissioner Baroness Rennie Fritchie, who discussed ‘the Role of the Non-Executive Director’. She began by reflecting on the evolution of public sector boards over the last few decades. Boards had always had non-executive ‘lay people at their heart’, she said, but there was a significant step change in the early 1990s, on the introduction of the purchaser / provider split in the NHS and the subsequent proliferation of new arms-length bodies. These needed new boards, and the trend was away from large ‘representative’ boards, predominantly peopled by non-executives, and towards a more ‘commercial’ model, where smaller, streamlined boards included executive input like their counterparts in the private sector. This businesslike approach may sometimes have brought clarity, purpose and direction to board activities – but Baroness Fritchie remains unconvinced that it is fit for purpose in the public sector. After all, private sector boards are accountable almost solely to shareholders whereas public sector boards must master much wider responsibilities: to its sponsor department and minister, to the wider policy agenda and to the public it is ultimately serving.

So how do we establish a fit-for-purpose model for public sector non-executives? Baroness Fritchie outlined a series of major requirements for boards, each of which has resonance with other non-executive members of the PPI landscape and may help us consider coherently the shape of future public governance systems in health.

### Knowledge and Information

“Board members themselves need the knowledge and expertise which will best meet the demands facing the organisation; and up-to-date information about the

organisation itself; external and key strategic issues; key targets, goals and timescales; and lines of accountability.”

Baroness Fritchie emphasised the need for NEDs to know what the key strategic issues are and be sufficiently equipped to deal with them. She asked: “How many Board meetings have you been to where you whiz through the most challenging items on the agenda because the people around the table don’t know enough about the issue to ask good questions?”

She added that getting the level of detail right was problematic, as NEDs should have sufficient knowledge of workings of the organisation to be answerable for its actions, but an ability to stand back from the day-to-day management and be able to retain an objective view, informed by the workings of the wider sector. She suggested NEDs adopt a flexible approach, keeping strategic as much as possible but adapting their behaviour according to the issue and desired outcome: “Boards need to learn to fly at 30,000 feet, to have the biggest overarching picture, to know when to drop down to 20,000 feet, 10,000 feet, and where to land and walk about.”

### Clarity

“There needs to be clarity about who the key stakeholders are and the requirements and relationships that are in place to hold the Board accountable.”

The most problematic element here, Baroness Fritchie suggested, is the “network of scrutineers and regulators” to which each Board is in return accountable: “the Minister, Parliament, senior officials, auditors, regulators, citizens” among a raft of named bodies for each sector. She agreed with the conclusion of the CfPS Scrutiny Map publication, which calls for greater coherence within this scrutiny landscape. She emphasised the need within governance for a ‘whole systems’ approach which examines the purpose and value of various components, how do they relate one to the other, how they improve accountability to local people and policy delivery.

My July 2005 contribution to PPI Monitor highlighted the distinct but interlinked contributions that various non-executives make to the PPI framework – including members of PPI forums, overview and scrutiny committees, NHS foundation trust members and non-executives on health boards.

## Power

"An effective board needs the authority to: act as a governing body; make key decisions; see that senior management is accepting and implementing its decisions."

Baroness Fritchie added to this principle: "We need to precisely know, discuss, debate and agree reasonable ways of developing the reserved powers of the board." There should be clear terms of reference around the extent of a board's powers to avoid public misunderstanding when things go wrong. She offered a few suggestions for empowering a board even if its role is limited. First, there should be better mechanisms through which people from within an organisation can bring issues to the attention of the board: for example better 'safe systems' or feedback loops for reporting legitimate concerns to the board. Second, renaming NEDs as 'Independent Directors' may be a better definition of board members' powers, stressing the positive aspect of this role rather than emphasising its 'non-executive' nature.

## Motivation

"The appropriate incentives must be in place to align the Directors' interests with those individuals, groups and communities they represent – their stakeholders."

Baroness Fritchie emphasised that 'incentives' – financial or otherwise – have strong implications on the quality of board appointments. "Remuneration is a diversity issue, and favours older, retired professionals who can afford to contribute to public service, and good for them, but it's not inclusive." Truly diverse and representative boards can only be achieved if appropriate and consistent incentives are in place, rather than the current "patchwork quilt" of policies, whereby some NEDs are paid, some unpaid, some get pension contributions whereas others only get discretionary expenses.

The motivation to 'represent' may also be impacted by the appointment process itself. Especially, there was discussion around whether 'representation' through the ballot box – for example by local councillors – was more effective than that provided by non-executives attracted or motivated by other means. Baroness Fritchie emphasised that the priority should be finding board members with the knowledge, experience and passion

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to fulfil the role, and that election was not necessarily the only effective mechanism. She did, however, warn that some non-executives' motivations are unsuitably narrow for board work, and could lead to skewed provision satisfying only a narrow interest group.

## Time

"To work effectively, Directors need time to read, understand and absorb relevant documents and papers and sufficiently well organised periods of time to work together as a group."

Baroness Fritchie said that time was another important factor in securing proficient and consistent engagement with board activities. She added that 'time' should not be spent purely in board meetings: activity and accountability between meetings is also important. "As a previous Board Chair, I used

to go round the table and ask, particularly the non-executive independent directors, what have you done on behalf of this Board since we last met?" This, she continued, helped to determine which members only came to Board meetings and which took an ongoing interest in the issues, walked the patch, asked questions of people to inform their board work.

## What does this tell us about PPI?

The challenges faced by NEDs will certainly be familiar with all participants in the current PPI landscape. Local authority health scrutineers, PPI forum members and NHS foundation trust governors all have to rapidly assimilate information on constantly evolving health policy and practice. They have to know the strategic issues, ask challenging questions and coordinate closely with other scrutineers, ensuring their activity achieves the best outcome for public health. They need to perform a 'community leadership' role whilst considering the wider health landscape. They need to look for strategic levers by which they can feed into decision-making processes on behalf of the public they represent.

Baroness Fritchie says "we are getting more demanding of our non-executives in the areas of time, expertise and accountability": and CfPS salutes those of you performing these demanding roles in the PPI landscape. As our Chair, Dr. Tony Wright MP, concluded at January's lecture: "Such systems can only improve if you join up with other people sitting on similar bodies, become part of a network and learn from each other." As the Centre enters its fourth year, we invite you to join further debate through our networks, publications, online services and research.

**Tim Gilling**

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For further details of the Centre for Public Scrutiny's activities, and its Annual Conference on 28 June, contact Alex Hardy at [alex.hardy@cfps.org.uk](mailto:alex.hardy@cfps.org.uk) or 020 7296 6211.

## Future Services - a platform for

There is a new consumer blueprint for responsive public services, as Amanda Cumberland explains.

**The Future Services initiative was established by the Confederation of British Industry (CBI), National Consumer Council (NCC), and National Council for Voluntary Organisations (NCVO) in June 2004 as a platform to stimulate debate about how our public services can be shaped by the people and communities that use them. The initiative brought together three national representative organisations whose work had revealed the continued absence of the user voice at the heart of the public service reform debate. We decided we could build a stronger platform by working together to channel ideas to service leaders and policy makers.**

In March 2005, we held a one-day deliberative citizens' forum, with 100 people from the Nottingham area, to explore what people think of their public services, how services could be made more responsive and how individual service users could get involved.

Participants were given the opportunity to discuss their views on public services and to develop their own ideas for how service design and delivery could be improved. Throughout the day, small group discussion was interspersed with sessions led by expert witnesses, who provided the participants with the evidence and knowledge they needed to fully consider the issues and make decisions. The forum was a great success, with participants presenting their ideas to John Reid, then Secretary of State for Health.

The event had a real energy, and participants were extremely positive about their experience of getting involved in this way. One woman described how she never realised that she could have so much power, simply by having a voice.

The consumer blueprint that resulted from this major public consultation exercise provides an excellent insight into people's priorities, frustrations, hopes and motivations for public service reform. People most value the human touch – empathy, compassion and warmth. Government tends to focus on efficiency and hard targets, which are important but not sufficient – they also need to capture a softer side.

People are passionate about public services. They care about them deeply, and often talk about positive experiences using words like wonderful, brilliant, and excellent. Despite this, there is a popular narrative that public services are failing. People think that public services are not getting things right in their delivery, communication, and engagement with users. They talk about feeling cheated, ignored, and made to feel small. Why is this?

The NCC believes that it is because people have low expectations of public services, and see them as institutionalised, bureaucratic, and lacking modernity. Most people believe that businesses are much better at being responsive to people's needs because they appear to be willing to listen to what

customers want, and deliver changes in response to these demands.

People also feel alienated by public services, and feel that they lack control over how they are delivered. When people have tried to get involved, they think that they are unheard and often feel unable to change anything. There is a strong perception that there is little openness or accountability in public services, leading to a sense of detachment between services and users.

What this demonstrates is a perception gap between what is actually happening in public services, and how people feel about using those services. Positive personal experiences tend to be seen as lucky flukes, or only applicable to specific pockets of service delivery. People feel lucky when things turn out well, but they don't want others to have to rely on luck. They want everyone to have the assurance of a good service.

The good news is that the evidence is out there on how to build better public services, and close the perception gap between objective improvements and subjective experience. Real change is possible, and the starting point is to listen to what people want and how they experience services. People using services are the real experts in what it is like to experience that service, and what could be done to improve that experience.

Engaging with consumers, and helping them develop their own solutions is fundamentally what lies at the heart of a patient-led NHS. We know that involvement is vital for building better, more responsive services that leave people both objectively and subjectively more satisfied. It helps to create services that are designed and delivered around the needs of users, and that are more open and accountable to the people they serve.

Involvement plays a crucial role in making sure that services really meet people's needs, and empowering service users. Giving service users a voice is a critical tool in enabling managers, providers, commissioners and regulators to balance the conflicts that arise from the allocation of limited resources, and from competing interests. It is crucial that service users have the chance to speak

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## involvement

and be heard at all stages of service design and commissioning, not just at the point of delivery.

It is this approach of bringing people together to allow them to contribute to the design and delivery of services that is reaping real benefits for public services and their consumers. Bringing the right people together, giving them authority, the information they need, and an environment conducive to deliberation can really transform the decision-making process, and put service users at the heart of public services.

The kind of deliberative approach used in the Future Services project has been successful in other areas. Citizens' juries – which engage a small group of citizens in discussions on a key question relating to a policy or service issue – have been used successfully both nationally and locally, to influence issues ranging from genetically modified food to transport policy.

This type of approach is also being used by the Department of Health in their current consultation on healthcare outside hospitals – an imaginative step forward from the traditional consultation mechanisms.

And the appetite for involvement is there. One of the key wishes from our forum participants was for early and meaningful involvement. They wanted a greater say over how services are run, and how resources are allocated. They wanted to help to set standards for local services, and have some say in removing providers that come below a certain standard. And other case studies show that listening to the voice of consumers is not just part of the accountability of public services, it is also a way to improve them. For example, some local authorities have started to ask residents their views on council spending, even choosing from different levels of taxation and spending. 45% of residents cast a vote, compared to 26% in the previous local election. And by using imaginative ways to get local people involved, Crime Concern has cut crime in five neighbourhoods in Birmingham at twice the rate of other areas in the city and saved £10.70 of public money for every £1 invested.

But involvement doesn't have to be on the grand scale of a citizens' jury to be successful. When we speak to consumers about what marks out the best public services they talk about compassion, warmth, the

People feel alienated by public services, and feel that they lack control over how they are delivered.

human touch, respect. They ask these to be demonstrated through even simple basic things as someone phoning back when they say they will, and getting a smile from the receptionist. Get the little things right and it sends a signal that this organisation respects and values the people who use it. And it prepares the ground for effective involvement by creating an environment of respect and trust. The blueprint from our citizens' forum was very simple, and reflected the need to get seemingly simple things right.

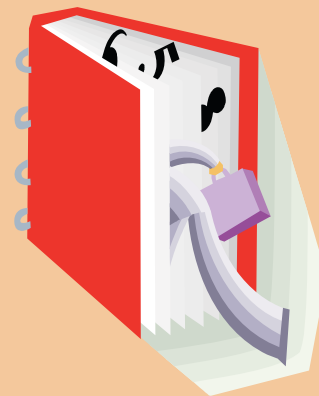
People asked for accessible services that are easy for people to use. They asked for public services to be honest and open with them at all stages of service delivery, and for communication to be regular, easy and straightforward. They asked for involvement early enough in the process for their input to have real effect. And they asked for feedback on what has happened as a result of their involvement.

At NCC, we believe in putting people at the heart of public services. Involvement mechanisms like this that go beyond the traditional tick-box consultation, and involve people early on in the decision-making process, are helping to make that vision a reality.

### Amanda Cumberland

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Future services: a consumer blueprint for responsive public services, with DVD available from the CBI or at [www.ncc.org.uk/publicservices/futureservices](http://www.ncc.org.uk/publicservices/futureservices)



## Contribute to PPI Monitor!

Do you want to write an article for PPI Monitor?

Everyone involved in public and patient involvement has a story to tell, and we would like you to tell us yours.

Have you approached your own PPI in a new and innovative way?

Do you have something to share with other readers about solving problems and moving forward?

Will one of your case studies help someone else?

Share your challenges and successes with other readers.

Talk to Malcolm on  
01625 584448  
or email on  
[m.mcclean@bearhunt.org.uk](mailto:m.mcclean@bearhunt.org.uk)

# New website set to revolutioni

## PALS Online aims to raise public and professional awareness of Patient Advice and Liaison Services.

**According to new research\*, only 50% of GPs and 51.6% of the general public know about the NHS Patient Advice and Liaison Services (PALS). Mary Adams, Chair of the National PALS Development Group (NPDG), explains: "Our research has shown that although PALS have existed for three years, not enough people know about them yet. Many, including GPs, just don't know that each NHS trust provides a service for patients, families and carers where they can sort out problems, and get support and advice about the NHS. We need to raise awareness of PALS and increase understanding of the services on offer. PALS Online is an important step in establishing PALS in the national consciousness."**

According to NPDG-commissioned research:

- 80% of GPs think that less than 10% of the general public know about PALS
- 85% of the GPs who know about PALS think they provide information on and explanations of NHS complaints procedures and how to get in contact with someone who can help
- but only 23% of GPs know that PALS can provide assistance with mobility services
- the public associates PALS more readily with information provision: over 44% know that PALS provide information about the NHS and health-related matters

PALS Online aims to unite PALS across the country, explain the key functions of PALS to the public and through an online directory enable patients to contact their local service.

### Improved services

PALS Online is also designed to improve service provision. Mary Adams has plans for the site: "We will shortly be adding a training module which will enhance the professional development of PALS workers. As a result, we hope to see an improved service for patients and a greater take-up of PALS."

PALS have offered the same services nationwide since April 2002, when all NHS trusts were required to set one up, but the way the service is delivered varies. In response to PALS workers' requests, PALS

Online will include a dedicated members' area where they will be able to see what others are doing around the country and share best practice and ideas.

All PALS have been asked to submit their contact details to the site so they can be easily approached by patients and carers. A news section will keep PALS workers up to date with the latest PALS developments and an online resource centre will enable PALS workers all over the country to contribute content and share documents, experiences and opinions.

### Increased knowledge

The site has been developed by NPDG, which represents PALS within each of the 28 strategic health authority (SHA) areas. Project Manager, John Larkham – seconded to NPDG from North Staffordshire Combined

Healthcare NHS Trust – has worked closely with NPDG members to ensure that PALS workers have had input into the development of the site from the beginning.

He says: "A task group of the NPDG started working on the website two years ago and we consulted widely with PALS workers in early 2004. The initial functions of the site reflect their priorities and we have secured further development funding that will see additional features in the early New Year."

"As a result, we hope healthcare professionals and others working with patients and carers will be encouraged to use PALS Online. Professionals will be able to keep abreast of what PALS are doing and how they are making a difference locally, both for their own knowledge and to communicate with their patients."

### What is PALS?

PALS provide information about the NHS and other health-related enquiries; they help resolve concerns or problems when using the NHS and provide information about the NHS complaints procedure and how to get independent help when pursuing a complaint.

PALS play a vital role as catalysts for change and improvement in the NHS by feeding concerns and problems back to managers who design and manage the services. They can also work across boundaries between healthcare and social services, for example when arranging care for the elderly, or arranging healthcare for prisoners. PALS act as the customer service desk of the NHS; they will help anyone who has a concern about their NHS treatment.

Anyone interested in finding out more about their local PALS should visit [www.pals.nhs.uk](http://www.pals.nhs.uk)

\* TNS conducted an internet survey for PALS amongst 200 GPs from 15 to 19 September, 2005. NEMS Market Research conducted an omnibus survey for PALS from 13 to 18 September, 2005.

According to new research\*, only 50% of GPs and 51.6% of the general public know about the NHS Patient Advice and Liaison Services (PALS).

## Use PALS

**An elderly carer new to the area welcomed the help of PALS to find the best local healthcare for his wife.**

Noel Ward and his wife moved in spring 2005 from their house in Devon to a ground floor flat in St. Albans, Hertfordshire. Mrs Ward suffered from major respiratory and related problems and was on oxygen 24 hours a day. The new flat made day to day life far easier and meant they were close to their two sons and their families. However, they were virtually complete strangers to the area.

Mr. and Mrs. Ward registered with the local GP. Since regular home visits were a priority, they sought advice as to whether a larger GP practice might be better. They did receive a recommendation for such a GP practice but realised it might be difficult to register with it because it was obviously so popular.

Noel's eldest son works for the NHS and he suggested a call to the local PALS. Noel explains, "I'd never heard of PALS and didn't know such a service existed until my son recommended them. Wendy Henrys, the PALS worker, was very helpful and rang back after an hour to say that the practice would be delighted for us to register as patients. They were excellent and visited my wife until her recent death."

Noel continues, "Wendy at our local PALS was very efficient. I would certainly recommend PALS to anyone who has concerns about their healthcare. I have received excellent service - invaluable to anyone not familiar with the area".

**Harry Cayton and Mary Adams launched PALS Online on 19 October 2005.**

Harry Cayton, Department of Health's national director for patients and the public, said "I welcome PALS Online both as a channel for making PALS more accessible to patients and as a means of developing the way PALS work together across the country."

## PALS Online aims to unite PALS across the country.

\* TNS conducted an internet survey for PALS amongst 200 GPs from 15 to 19 September, 2005. NEMS Market Research conducted an omnibus survey for PALS from 13 to 18 September, 2005.

# A Good Choice for Mental Health

**Choice could have a greater effect in mental health services than in most other fields, yet it has been little discussed. Jennifer Rankin outlines an approach using personal recovery budgets that offers citizens real control and responsiveness.**

There have been many impressive promises made about choice in the NHS. We regularly hear that choice will make the Health Service more effective, more equitable and better attuned to the needs of patients. At the forefront of the Government's reform agenda is the policy of giving patients a choice of providers. By the end of this year, all patients who need elective surgery will be able to choose between four or five different providers, something which is set to be increased to an unlimited choice by 2008.

But to date we have heard considerably less about what choice means in relation to other areas of health care, including mental health. Mental health problems affect at least one in six people in the general population, as well as a high proportion of people who experience multiple disadvantages.

At a basic level, choice means the power to make decisions. But this deceptively simple concept represents a significant departure in the sphere of mental health. Common to all kinds of mental health treatment has been a system lacking both the resource capacity and flexibility to provide a personal service that engages the individual in their own recovery. For people with severe mental health problems, there is a history of poor

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practice which has denied people choice in very basic ways.

A recent report by the Institute for Public Policy Research (IPPR) suggests that choice could be an important force for change in mental health services. This account was less concerned with a consumer model of

choice, where people could choose different providers. Instead, it was more focused on a 'citizen' model of choice where people with mental health problems could be empowered through their health care and have more choice and control over treatments. People who use mental health services are more concerned over access to services and having control over their treatment, rather than 'consumer choices' between providers.

There are clear parallels here with people with physical disabilities. In the early 1990s the disability rights movement embraced 'consumer choice' because the slogan made it harder for governments to dismiss their views. The language and logic of consumerism helped to secure direct payments – individual budgets for people to buy their own services. Yet, there was also a sense that consumerism was an inadequate platform for other ambitions. Choice was bound up in a much wider agenda of being treated with dignity, respect and included in society. These findings have similar resonance for mental health. In one sense, choice is a means to an end, where the goal is a more responsive service. But choice is also an end in itself.

Extending choice for people with mental health problems has not been a priority for the reform of mental health services. In part this is probably because the service lacks capacity and the resources to offer people choices. One survey of 250 GPs in 2004 found that eight out of ten over-prescribed antidepressants due to a perceived lack of



alternative options. Another survey by Mind in 2002 found that although only one in five people went to their GP expecting to ask for antidepressants, 98 % of people left with a prescription for them. For many people, psychological treatments are hard to access, let alone have a degree of choice over. In other respects, choice and control go against the grain of daily practice of some services, such as inpatient wards. The Mental Health Taskforce appointed by the Department of Health concluded that on inpatient wards people have been routinely denied very basic choices, about eating, drinking and daily routine.

Lack of choice in treatment is somewhat paradoxical, because there has never been so much evidence on the many potential treatments and interventions that improve the symptoms of mental health problems. The National Institute for Health and Clinical Excellence (NICE) publishes detailed clinical guidelines covering a range of treatment options. NICE guidelines also highlight the importance of patient input into decisions on medication. However, this ideal lags behind the reality of everyday practice. Surveys of patients have shown that many receive fairly superficial guidance about their medication, with limited information about side effects or alternatives to medication.

So how might greater choice be introduced for people with mental health problems? The NHS has often proved fairly unresponsive to people's demands for different kinds of services, notably talking treatments. Introducing greater individual budget holding, through direct payments or specific vouchers for talking therapies could help to remedy this. If people were given their own personal recovery budget they could choose their own treatment. This would also help correct a theoretical anomaly where people (at least, those who are eligible for community care) have choice in social care, but not in health care. The report recommended testing this approach through pilots.

A personal recovery budget is in essence a direct payment for mental health. However, if it is to work, the current direct payments system will require some adaptation. Currently, only people who are eligible for community care can receive direct payments, a relatively small group that does not

exactly correspond to people who need to access mental health services. In addition, modification of the provisions on direct payments will be required to enable their use in integrated social care and health settings. If choice is to be a reality, there needs to be an increase in the capacity of what the NHS offers people with mental health problems, such as psychological therapies.

Greater choice brings with it other difficult issues. In particular, there is an open question as to how far people are responsible for the consequences of a poor choice, which has implications for the individual and overall level of resources available for others. One way to guard against poor choices is to ensure that people are appropriately supported in making choices. Here, there

Lack of choice in treatment is somewhat paradoxical, because there has never been so much evidence on the many potential treatments and interventions that improve the symptoms of mental health problems.

would be an important role for independent advocates, as well as the professionals who are able to provide information in a clear, jargon-free way to support people in making choices.

However, any policy to extend choice and enable greater control will only succeed if it is supported by wider cultural changes within health and social services. Baroness Neuberger's book *The Moral State We're In* is one of several recent accounts that suggest there is a lack of kindness within services. Ensuring that services are personal and responsive to people is as much about ensuring people are treated with dignity, kindness and respect, as it is about formal mechanisms, such as user representation on the trust board or individual budgets. On this score, the 'personalisation' agenda offers an important new way of looking at public services. Personalisation is about recognising that the individual brings something to the improvement of their own health. It re-orientates the role of professionals from offering 'top down' prescriptions to applying their specific knowledge in a collaborative way with the individual.

In 2003, the Secretary of State for Health characterised the new approach to health services in the phrase "Trust me, I'm a patient". Ultimately, this approach heralds a step change in mental health policy. Choice and control holds out the prospect of more effective, more efficient services that are aligned to the interventions that work best for individuals. Choice is also an end in itself, and could help to reinforce other agendas, on rights and social inclusion.

**Jennifer Rankin**

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A Good Choice for Mental Health is available on the IPPR website at [www.ippr.org](http://www.ippr.org). It is part of a series of working papers in the project, *Mental Health in the Mainstream*. The final report, published in June 2005, sets out recommendations for Government to improve services for people with mental health problems and to promote better mental health.

# Just Imagine!

**Jan Wallcraft asks - can you imagine how mental health research might be if every aspect of it was strongly influenced by people who have directly experienced mental health services?**

- If service users become part of agenda setting, how might research priorities change?
- How would the attitudes of researchers change towards the people in their studies?
- How would the success of a particular treatment or service be measured?
- What would service users want to set as ethical standards for research?

Service User Research Group in England (SURGE) has produced guidance for involvement in every aspect of mental health research carried out under the auspices of the national Mental Health Research Network.

I will introduce the key aspects of SURGE's guidance paper with reference to my own involvement with service user leadership in research.

I became a service user in the 1970s. Fortunately, after a couple of admissions I managed to stay away from further treatment. However, the experience of a breakdown and psychiatric intervention is not easily forgotten, and I still had a lot of problems. I wanted to understand more about what had happened to me.

Research is important to service users because it is the basis for progress in medical science, and our present Government has placed particular emphasis on evidence-based practice in medicine. They established the National Institute for Clinical Excellence (NICE), to provide guidance on available research evidence, and the Mental Health Research Network (and other health research networks) to support and co-ordinate high quality research. However, without service user involvement in research, the basic assumptions, values and research methods will be unchanged, and the same types of treatments would be reproduced endlessly, with only minor modifications and reforms.

So, what difference can we hope for from greater service user involvement in research?

For research to get ethical approval and funding, it must be shown to be worth doing, and not to pose unnecessary risk of harm to the

research participants. However, service users, if asked, might have different views on what types of research are of greatest benefit or harm, and might want to see different research methods used, and to find ways in which research can bring practical benefits to service users taking part, such as empowerment, skill-sharing, action learning, service users helping to disseminate results, etc.

The Guidance paper aims:

- to provide an introduction to service user involvement in Mental Health Research
- to ask WHY this is valuable and vital to the high quality research in mental health
- to promote some changes in our thinking and develop sound principles for involvement
- to offer a brief toolkit of HOW to work collaboratively

The SURGE Guidance covers all stages of the research process from decisions about what to research, through choice of methods, how to measure research outcomes, understanding research findings, sharing information and putting research conclusions into practice. It argues for key principles of clarity and transparency, diversity, respect, flexibility and accessibility of research, and honesty about where power lies so that service users can make informed choices.

The SURGE Guidance states that service users can and should be involved at each of these stages, and argues that their involvement will benefit the quality of research, and its acceptability to the wider public.

## Setting priorities

An example of service users identifying research priorities is the project currently being run by the Sainsbury Centre on behalf of the Department of Health. As a first stage, over 3000 survey forms have been sent out widely to service users and families/carers to ask them their priorities for future research in mental health. Service user researchers will also be carrying out one-to-one interviews and focus groups with groups of service users such as asylum seekers who are less likely to fill in questionnaires. The results will influence the future of Government funding for mental health research.

## Capacity building and support

An example of capacity building is given by

the SURE (Service User Research Enterprise) project at the Institute of Psychiatry (IoP). The service user researchers at SURE are providing training and support for a group of local service users to enable them to become involved in research run by the IoP.

## Involvement in commissioning research

An example of involvement in commissioning research is at the National Programme on Forensic Mental Health Research and Development, where service users are on the advisory committee, and are paid to review research proposals. The programme has developed a user involvement induction pack, and service user peer review forms to help the involvement work well.

Finally, it is worth a brief exploration of the vexed question of service user-controlled research. Turner and Beresford (2005) make a difference between service user-controlled research and 'user-led' research, which they see as an ambiguous term, referring to research that might not be genuinely controlled by service users. They make a clear distinction between user controlled research and research involving service users.

The development of increased capacity and confidence among service user researchers, will, I hope, ultimately lead to more genuinely service user-controlled research, and on the way to this, we can make a real difference to the type and quality of mainstream large scale mental health research through information gathering, training and networking, and through supporting service users who want to be involved with the MHRN.

**Dr. Jan Wallcraft**

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To download the SURGE Good Practice Guidance, go to [www.mhrn.info/surge.html](http://www.mhrn.info/surge.html)

Reference: User Controlled Research report summary, M. Turner and P. Beresford, Involve, 2005. from: [www.invo.org.uk](http://www.invo.org.uk), or [www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)

For more information on research groups please go to [www.ukmhrn.info](http://www.ukmhrn.info)

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## Last Word from Chris Dabbs



### Dear Mrs. Buggins,

**I have been working with an architect who claims not to design buildings. He says that he "saw the light" when he realised that what he should do is to design environments for people.**

There is now a small but growing number of psychologists and psychiatrists who, after spending years seeking to treat mental illness, have concluded that what they should do is to promote mental health and happiness.

Copernicus looked at the Sun and the planets and challenged the orthodoxy – and the whole way that people perceived their world – when he came out and said that the Earth went around the Sun and not vice versa.

Many people in most organisations, when challenged to think radically, try to think "out of the box". I want to ask, "What box?" We often impose our own limitations before we even start.

It is only a small number of people who, at the start, are willing (or able?) to really think differently, and to see things in a new way. When they do, they are generally rebuffed, ignored or ridiculed. Yet it is from them that the greatest advances are usually made.

If you keep on doing what you've always done, you'll keep on getting what you've always got. Taking a new perspective on anything inevitably opens up new answers to questions and issues. As Albert Einstein said, "The significant problems we face cannot be solved at the same level of thinking we were at when we created them."

All of these lessons are equally applicable to patient and public involvement in health. For example, why is it that PPI often accepts – consciously or unconsciously

– a medical model of the world in which doctors have most of the answers, and the key response is treatment and medication? If anyone thinks it does not, let us ask how often PPI genuinely challenges this way of thinking, and why lay people are most often described as "patients" – that is, defined first and foremost by their condition, or their subservient relationship to clinicians.

Similarly, now that PPI is part of the mainstream of the NHS, limits, rules and ways of doing things have arrived and largely been accepted. Yet are we really saying that having PALS, forums, councils, committees, etc. is the limit of our expectations or ingenuity? Why should lay people not have much more direct say in things than this?

Perhaps we should value much more the mavericks and "weirdos" in our midst. While most people should get on with straightforward delivery of activities and services, this small group of people offer a future in which things can be different and better. They do not follow where the path leads; they go instead where there is no path and leave a trail.

However crazy original ideas may first sound, let us give them serious consideration – after all, as the musician Jeffrey Lewis opined, "It's the ones who've cracked that the light shines through" – and we need all the light that we can get.

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

The Patients  
Association Summit  
– cleaner hospitals  
– safer healthcare

London on 24-25 May 2006.

The theme for this year reflects the wider scope needed to tackle patient health and safety head on, building on the high profile The Patients Association has achieved with the clean hospitals debate and this time bringing in all aspects of patient safety and cleanliness.

For details contact  
The Patients Association.

### Involve Learning Programme – From Paper to Practice

A series of regional events capturing new developments in participation and translating them into practical options.

Cardiff – 7th March 2006  
Manchester – 23rd March 2006  
Edinburgh – 28th March 2006  
London – 30th March 2006

Details: [learning@involving.org](mailto:learning@involving.org) or  
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controlled by service users. They make a clear distinction between user controlled research and research involving service users.

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Reference: User Controlled Research report summary, M. Turner and P.Beresford, Involve, 2005. from: [www.invo.org.uk](http://www.invo.org.uk), or [www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)

For more information on research groups and how to join or start one, please go to [www.ukmhrn.info](http://www.ukmhrn.info)

# Capital Projects

Angela Barnard reports on how 11 projects in London helped to identify good practice for service user and carer involvement in research.

The PC11 Project was an evaluation of the impact of consumer involvement in 11 research projects known collectively as the London Primary Care Studies Programme. The Programme was commissioned by the London Research and Development Directorate in 2001 and was part of a capacity development programme to increase service user/carer involvement in primary care research. All 11 studies were required to include service users/carers and the Directorate also commissioned training and support for everyone involved. The PC11 Project also considered the impact of this and any other training that took place among the 11 studies.

Based in locations across Greater London, the studies covered a wide range of subjects. These included:

- orthodontics
- learning disabilities
- child health surveillance
- communication difficulties
- mental health
- (screening for) tuberculosis
- falling
- self management
- unmet health needs

Service users/carers of different ages and backgrounds were involved at varying stages in the studies in a wide range of ways and the 11 studies lasted for different lengths of time, from 12 months to three years.

Based at the Peninsula Medical School, the PC11 evaluation team was a group of academics, researchers, representatives from Folk.us\* and a service user. Our evaluation addressed three main research questions:

- To gain an in depth understanding of the experience of consumer involvement and the effect of this on the quality of individual projects. We considered this both in terms of the research process and the research outcomes.
- To assess the impact of the training on consumer involvement.

Based at the Peninsula Medical School, the PC11 evaluation team was a group of academics, researchers, representatives from Folk.us\* and a service user.

- To dovetail our previous experience with lessons learnt from this project, in considering methods and criteria for evaluating the impact of user involvement.

We collected both quantitative and qualitative data from researchers, service users, carers and other participants involved in the design and delivery of the 11 studies. Not surprisingly, much of what we discovered echoed issues that are common to the wider realm of patient and public involvement and this article looks at some of them.

On our project questionnaire, we asked people involved in the studies to describe their role. There were four choices: researcher, service user, carer and other. We received 61 responses and among them 20 people ticked two labels and one person ticked three. Ten of those who ticked two

labels described themselves as both a service user and a researcher. This was the first indication we had that the way in which people perceive themselves and the way they are perceived by others may not be the same and when we interviewed some of these people to discuss their experiences in more detail, we found this to be an important issue.

We interviewed people who were 'researchers' with academic qualifications and, in some cases, holding permanent posts in academic departments. However, they also identified themselves to our project as 'service users' as this was a significant element of their background and was important to them within the context of their participation in the study. It was noteworthy that not all these people were comfortable sharing their 'service user' background with their academic colleagues.

We also interviewed people involved in these studies who had little or no previous experience of research, who might typically be perceived as 'service users'. However, they were undertaking a range of research activities within the studies and therefore felt it was legitimate to also describe themselves as 'researchers'. Unlike the previous group, none of these expressed any reservation about referring to themselves in this dual way.

In a different context, these two roles could be 'clinician' and 'service user' and the same individual values would apply. What makes this significant is that the individuals concerned perceive these dual descriptions as entirely legitimate and integral. Seen in this way, they are a strong indicator that the rigid, single labels so often used are not a true reflection of our own or others personal values and, as such, are not helpful to integrated working.

The other realm in which we found enablers and barriers to this integrated style of working was the manner in which studies were run and, correspondingly, the quality of the experiences participants reported. We

\* Folk.us is a Department of Health funded initiative, which was established to facilitate and promote meaningful and effective service user, patient and carer involvement, in all types of research relating to health and social care in North and East Devon.

found that the 11 studies broadly fell into two groups in which people described

- i) mainly positive experiences and
- ii) a mixture of positive and negative experiences.

These are general patterns within the two groups of studies which do not suggest that everyone in each of the groups shared the same experiences.

The studies in group i) tended to treat service users/carers like partners, but among the projects in group ii) some of the service users/carers felt remote from senior researchers and clinicians and did not always feel able to contribute.

Some characteristics among the studies that achieved a partnership style were; varied and effective methods of communication (e.g. regular one-to-one telephone contact, use of easy-to-understand language); respect for the knowledge and insights of service users/carers; and a strong personal commitment from everybody concerned to use involvement to improve both research and service delivery.

Among the studies that did not achieve this type of partnership, people identified the continued use of 'jargon' by researchers and clinicians, and a small number (one or two) of 'representatives' on steering/advisory committees. These messages were very strong and were reflected in the main themes we identified in the data we collected from across the groups of individuals involved.

Overall, we found that there were identifiable, positive outcomes of integrated working which are summarised as:

- changes to research questions were made because service users/carers were able to say what the important questions were for improving services
- new or revised questionnaires, interview designs etc. (research tools) were created by service users/carers
- service users/carers found new ways of collecting data and were able to include many more people to provide data
- service users'/carers' explanations of data related directly to how people experience the delivery of services
- service users/carers used their own

We collected both quantitative and qualitative data from researchers, service users, carers and other participants involved in the design and delivery of the 11 studies.

networks to tell other people about their findings

- service users/carers were successful in finding ways to change services, based on the research findings, and in measuring those changes
- their involvement increased the number of service users/carers in research

Most of the people we received responses from considered that the involvement of service users/carers in the studies had been beneficial. The service users/carers described a variety of personal benefits and positive experiences. Researchers also described how they had benefited from and learned from service users/carers. Most people agreed that the studies themselves had been carried out more successfully and had better outcomes because of the service users/carers involved.

Our evaluation found that the training and support commissioned by the funders had been useful to many. However, many more people said that the training and learning that went on within the individual studies was more useful to them than the commissioned training.

Our report makes a range of recommendations about involving members of the wider community in research, some of which are for changes in policy and some are what we call 'good practice', which could take place without any policy change. They are aimed at

- researchers and academics
- commissioners/funders
- ethics and governance bodies
- potential collaborators (service users, carers, community groups, etc.)

Many of our findings and recommendations are similar to those of other projects in related areas of service user/carer involvement in research. Despite the emphasis on user/carer involvement in policy since 1999, research on and evaluation of this topic are still new to many and there is much more work to do. We also believe that there is much more that commissioners, funders, researchers and academics can do to increase the volume and improve the quality of service user/carer and other potential partners' involvement in research.

As a personal reflection, I would add that my own participation in the PC11 Project was both significant and extremely rewarding. As well as the knowledge and experience I was able to draw on from my service use background, I was also able to use many of my 'transferable skills' such as project management, financial monitoring, event organising, report writing, interviewing skills and many others. Unqualified? Lacking in expertise? I don't think so, and I'm sure there are plenty more where I came from!

**Angela Barnard**

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Copies of the PC11 Report and PC11 Report Summary are available from:

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