

# PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

## PPI Pay Surge

Concerns about PPI posts being undervalued and underpaid were countered by the recent appearance of an advert in the 'Executive/Senior' section of The Guardian's recruitment pages.

A joint post of Assistant Director for Patient & Public Involvement has been advertised as an integrated post by Newham PCT and Newham Healthcare Trust.

The seniority of the post comes as a great encouragement to those who argue that PPI must take on a more high profile role. The salary £45,000-49,000 pa is thought to be one the highest so far paid for a post with sole responsibility for PPI.

Jane Connor, Head of Improving Health Partnerships at Newham PCT suggested that local benchmarks are having an influence on salary levels. She said "I think it is that other PCT's in East London have gone in at a similar kind of level. This is actually the first joint post in Newham. From the point of view of patients and the public, they don't care where the boundaries are. This is the start of a more outward facing approach to involvement".

She stresses that it's not just about salary levels. "This post is Assistant Director level because it demonstrates how seriously we take it. We want to push patient and public involvement. This is partly driven by Primary Care patient survey results, which are appalling".

Setting out an agenda for this new high powered post, she said "Often, people are not satisfied with services and don't feel that they are being treated with dignity. We must raise standards around communication and patient experience which are not good enough. This is really challenging".

In defence of the relatively high salary she said "Some people may feel that it is a lot of money. It is an important and challenging post. We are not necessarily looking for a NHS or clinical track record it's about finding someone with the ability to change organisations".

"It's not just about salary levels...We want to push patient and public involvement"

### PPI Pay League

Chief Executive CPPIH	£95 - £100,000 pa
Asst Director PPI	to £49,000 pa
PPI Manager	£25-35,000 pa
PALS Officer	£15-25,000 pa
Chair CPPIH	£25,000 - £30,000 pa (3 day week)
Forum Support Worker	£18-25,000 pa
Patient Forum Member	Expenses only

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Patient Advice and Liaison Services were the vanguard for PPI, aimed at helping patients with problems on the spot. How are they faring and developing?

#### Patients Forums

Reports from around the country on progress, successes and challenges.

CPPIH Commissioner Ian Hayes looks at early successes and identifies some signs for the way forward.

#### Laying the Foundations

NHS Foundation Trusts are charged with having thousands of members and boards of governors to oversee the trust's development and delivery. Brenda McCrory from Queen Victoria Hospital in East Grinstead explains how this trust intends to build on its 60 year PPI heritage as it faces a move towards a mutual future as an NHS Foundation Trust.

#### Case Studies

Being a lone PPI Manager. This case study describes some simple steps to major progress.

Reaching the hearts that others do not reach. Two common challenges for PPI are addressed here. How to get local people active and how to engage disadvantaged groups.

#### Network Series

This month we find out what makes the North West Community Involvement Network so successful.

# Kwik Fit

This summer, if you go to Trader Vick's Hawaiian style cocktail bar in London's Park Lane Hilton, you will notice that one waitress looks different. Whereas the others have an Oceanic island look, this one is distinctly European.

In fact she is French. As we chatted she struggled and grimaced to think of the word which explained why many years ago she had spent a week in a damp northern town.

I could not believe my luck. I'd been waiting more than twenty years for an opportunity to use this word. I savoured the opportunity for a little longer. I allowed her to grimace some more and to scratch her head. Then I said it. "Jumelee" I said "twin towns". There I had done it.

The expression of relief and delight on her face made me believe that the word jumelee had some kind of magical quality. It's a word I notice every time I enter a town like Portsmouth jumelee with Duisburg, or Darlington jumelee with Amiens or poor old Lincoln tonguetwistingly jumelee'd with Neustadt an der Weinstrasse.

It first came to my attention over two decades ago when I was merrily jumeleeeing for a fortnight in Clermont Ferrand, where it became etched in my memory. Who would have thought that I would have to wait so long to use it?

On that little trip to our twin town I was struck

by another word. Michelin. I was amazed that this famous brand name was French first of all. Then when I heard the way that they pronounce it I was dumbstruck. They say "Meeshlan".

For the past couple of months this little piece of knowledge about the word Meeshlan has caused me no end of frustration. There has been a radio advertising campaign in our area promoting a restaurant where their chef has won two Michelin Stars. Every time the voice over man pronounces Michelin as "Mitchulin" I shudder and shout Meeshlan to the radio.

If you think about it, it's obvious why he does it. I thought back to those TV adverts involving the Michelin Man. We have been conditioned over many years to say "Mitchulin". Then something struck me. There is no such thing as an advert for tyres on TV anymore. In the seventies and eighties they were all over the place. Now, nobody bothers to do it.

It's because, the tyre fitting industry has consolidated into large groupings like Kwik Fit. Tyre manufacturers don't have to put so much effort in getting us as individuals to go out and ask for their tyres. If they can get the big groups to take them, they will do the work for them.

Last month I enjoyed a cup of coffee with Dr Peter Barrett, Chair of the Independent Reconfiguration Panel. He made the point that as services change we need to make sure that we

do proper consultation.

It would be easy to do a Michelin and abdicate our responsibilities to big groups when consulting about health services, on the basis that if they are happy, everything must be OK, and we can save ourselves a lot of time effort and money.

Health services are not disposable like tyres. They are very personal and individual and we need to ensure that we listen to all the stakeholders properly. It's encouraging that the Independent Reconfiguration Panel is providing advice on good practice in consultation; it's just a pity that so few people even know that it exists.

Michelin Man might not need an advertising campaign anymore, but the valuable services of the Independent Reconfiguration Panel need to be known about.

Service reconfigurations can create a heady brew, people can become drunk with power. Proper consultation will create a rich cocktail of opinion and views.

Talking of cocktails, next time you are in Trader Vick's ask for the Vodka Jumelee. It's a new concoction and it will never get a 'Mitchulin Star'.

## EDITORIAL ADVISORY BOARD

### Chris Dabbs

Chris has worked in patient and public involvement at local and national levels since 1990. He is a Fellow of the School for Social Entrepreneurs, and chairs Passionately Curious Ltd., a social business that is a forum support organisation for PPI forums. Chris is an Associate of both the NHS Modernisation Agency and the Engaging Communities Learning Network of NatPaCT (National Primary and Care Trust Development Programme).

### 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.

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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.

### Publisher/Editor

Malcolm McClean  
3000 Manchester Business Park  
Aviator Way, Manchester M22 5TG  
m.mcclean@bearhunt.org.uk  
Tel: 0161 266 1977

### Editors

Sarah Bashford - Managing Editor  
s.bashford@bearhunt.org.uk  
Tel: 0161 266 1978  
Chris Dabbs - Features Editor  
c.dabbs@bearhunt.org.uk

### Publication Coordinator

Shirley Naden-Lamb  
Tel: 0161 266 1000

### Production and Design

Spirit Design  
www.spirit-design.co.uk  
patrhodes@spirit-design.co.uk  
Tel: 0161 430 7771

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# News from Patients forums

## Health forums – new baby celebrates success in Shaping Health

**The new health 'baby' - a network of 571 independent forums supported by the Commission for Patient and Public Involvement in Health - is celebrating its first six months of life, with a nationwide series of successes.**

This unique organisation has already drawn almost 5,000 people from all walks of life into forum membership, to become the public voice in health in their towns and cities. Many of them are "first time" volunteers in the health arena and come from traditionally hard-to-reach groups such as black and minority ethnic people, disabled, and young adults.

Giving up several hours each week, forum members are already energetically making a difference in health care, changing the way health service decisions are made.

The forum network, set up by the Commission on December 1, 2003, is helping save a diabetic clinic from closure affecting more than 600 patients in the North West; in the East Midlands, forums are helping to improve communications with young diabetes patients, who forget their medication as they wish to have a good night out – and end up in casualty as a result. Another forum is helping to improve ambulance journeys for patients.

In the West Midlands, Coventry Patient and Public Involvement in Health forums are working with local groups to make sure that the needs of the Chinese community are understood by the NHS.

Meanwhile, in Yorkshire, forums worked with a local wheelchair user group to 'road test' a journey around hospital buildings to assess potential problems for people with disabilities.

In Lincolnshire, forum members won a stay of execution for a planned closure of a local rural health centre, after quizzing local residents; a nearby forum is also investigating patients' access to out of hours GP services, and is to test them in a survey.

Fellow members in Medway swung into action when they discovered that two branch surgeries were facing closure without anyone asking the public. They persuaded the GPs to consult patients. In Dorset, members of one forum called on 23 GPs to discuss plans to

review local physiotherapy services.

Older men's health checks are coming under the spotlight in the South East, and in Oxford, the Patient and Public Involvement in Health forum successfully fought plans to close a mental health centre.

Forum members, concerned over changes within the chemotherapy unit in South Tees, insisted on a detailed report from the consultant.

In London, the regional team is working with Barts and the London Trust to support its development of a Children and Young person's forum.

In the South West, Patient and Public Involvement in Health mental health forum members are meeting this month in a joint working group to tackle issues over potential cuts in services threatened because of a multi-million pound deficit.

Chair of the Commission Sharon Grant said: "It is highly encouraging that after only six months, the forums are already making their presence felt. The NHS has lacked real independent user involvement for far too long, and we are seeing here the determination of ordinary people to check and challenge decision makers in health. In the so-called age of apathy, it is a real lesson in how people's desire to make a difference

**Giving up several hours each week, forum members are already energetically making a difference in health care, changing the way health service decisions are made.**



can be set free - if they are given the information, support and powers to do so."

"These are our first steps, but the message is clear – there's a new voice in health which will be hard to ignore, and patient power is here to stay."

Laura McMurtrie, Chief Executive of the Commission for Patient and Public Involvement in Health, said: "I have been all over England in recent weeks, and it is clear that people want to take part, and see this work as important.

"This system is breaking new ground in public engagement and we are learning all the time. But there is no doubt that involving patients and healthcare users in shaping services is the way forward."

People who join forums have an exciting opportunity to speak out for themselves and their communities, over a range of health issues from mental health to emergency services.

Over a 16-week period in autumn 2003, the Commission set up a network of almost 5,000 volunteers with support teams to run the 571 independent forums around the country. It is the first system of its kind in Europe.

All over the country, forums are meeting hospital and health service chiefs, and getting the inside track on what is going on – armed with real powers to make sure their views and concerns are heard.

Details of the CPPIH's work and how to get involved can be found on the Commission's website, [www.cppi.org](http://www.cppi.org), or contact the National Call Centre team on 0845 120 7111.

# Patient and public involvement in health

**A frequent challenge to PPI has been the lack of good evidence to back it up. A new publication is changing that. Its compiler, Christine Farrell, explains.**

Evidence for patient and public involvement is now available in a new publication from the Department of Health, *Patient and Public Involvement in Health: the evidence for policy implementation*. Produced in an accessible format, the report is aimed at people working in the NHS, and at patient, voluntary and community groups. The evidence has been gathered from 12 recent research studies, whose aims and methods are briefly described.

The studies covered a range of patient groups such as:

- children and young people
- people with communication difficulties
- users of cancer services
- family planning service users.

The topics covered included:

- shared decision-making
- the role information sources play in patient decision-making
- methods of user involvement
- ways of developing public involvement in primary care.

## Patient and public involvement.

The evidence overwhelmingly demonstrates that patient involvement increases patient satisfaction and is found to be rewarding by some health professionals. It also identifies ways in which the organisation of clinics and consultations can be improved to meet patients' needs.

The involvement of members of the public and their representatives does influence the planning and development of services and increases the confidence, understanding and skills of those who participate.

## The outcomes of involvement.

Needless to say, there are many complex issues and processes to be considered during the development of patient and public interactions in health care. Changing the culture of the NHS so that it welcomes the

It really did change my whole outlook on nursing. Coming back on to the ward, my attitude and my practice completely changed. From that point on, I was the person who was always saying 'Why are we doing this? Have we asked the patients what they want?'

*Ward sister who involved children and young people in planning services.*

involvement of all stakeholders is a difficult and time-consuming task. Nevertheless, the evidence from the research identifies many positive outcomes for patients, the public and staff. For patients, these include:

- increased confidence and a reduction in anxiety and fear
- greater control over their own lives and conditions
- greater knowledge and understanding of their own condition(s)
- increased trust in health providers
- more appropriate use of services
- increased capacity to seek information from external sources and to make decisions about non-medical treatments.

For members of the public who had been involved with service planning, the benefits were:

- an increase in confidence, understanding and skills
- the satisfaction of being able to contribute to local service developments
- the satisfaction of improving local services
- less health inequality
- health improvement.

For health professionals, positive outcomes included:

- a more equal partnership between professional and patient

- better management of the consultation process
- improved understanding of patients' health problems
- increased patient compliance
- greater trust with patients
- patient satisfaction.

## Good practice.

As well as providing evidence, the report also provides practical examples of good practice in the involvement of patients and the public. These include:

- a check list, derived from patient and staff interviews, of ways of improving communication with people who have communication difficulties
- a 'script' to help health professionals involve their patients
- guidelines for working with children and young people to involve them in service planning and an analysis of the dynamics of parent-child interaction with staff when treatment options are being discussed
- examples of workshops for GPs to help them involve patients
- validated training for GPs to help them develop their shared decision-making skills and ways of explaining the relative risks of treatment options
- examples for primary care trusts of collaboration with local voluntary organisations
- a cycle of user involvement that evaluates services and feeds back to users.

Many more examples of good practice are contained in the individual research reports. Both these and the full report can be accessed through the web site at <http://www.healthinpartnership.org>.

**Christine Farrell**

Freelance Specialist in Patient and Public Involvement.

Hard copies of *Patient and Public Involvement in Health: the evidence for policy implementation* (ref. 40119) by phoning 08701 555 455 or by email at [doh@prolog.uk.com](mailto:doh@prolog.uk.com)

# PPI MONITOR

## ANNUAL CONFERENCE

11th November 2004 • Manchester



### Confidence, Connection and Contribution

At last Patient & Public Involvement (PPI) is coming of age. It is seen as a key component in the White Paper on Public Health. According to Derek Wanless who authored two reports leading up to the White Paper, the level of public engagement will be the key determinant of the nation's health and the quality of services provided.

Yet those working in PPI face a range of challenges. Many are in the process of building confidence, both in the process, and amongst patients and the public; Others are striving to build connection between people, agencies, ideas and services; whilst all of us want to get to grips with how we can make PPI even more effective in making a massive sustained contribution to health.

These are the themes of this year's **PPI Monitor Annual Conference – Confidence, Connection and Contribution.**

This is a not to be missed event for anyone determined to take ever more heightened action to make PPI central to health. It is not just another conference. We are aiming to inspire you, motivate you, provide you with new insights and connect you to a nationwide PPI community.

Importantly, you will be able to network with PPI people from all walks of life, from all over the country. If you are serious about taking massive and sustained action to make PPI central to health – you will use the inspiration from this day for a long time to come.

Put this in your diary now and watch for further details. If you want to take advantage of the **special discount 30%** for **PPI Monitor** subscribers then you can pre-register using the form below.

**Yes I am interested in attending the PPI Monitor annual conference in November. Please send me a full conference programme.**

Name & job title: \_\_\_\_\_

Organisation & address: \_\_\_\_\_

Postcode: \_\_\_\_\_

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**Malcolm McClean,**

Bearhunt, Suite 108, 3000 Manchester Business Park,

Aviator Way, Manchester M22 5TG • Or fax it back to 0161 266 1403 • Tel: 0161 266 1977 • Email: m.mcclean@bearhunt.org.uk

## Case Studies

### Case study

# Learning from the Guinea Pigs

**Queen Victoria Hospital embraced PPI over 60 years ago. Brenda McCrory explains how her Trust intends to build upon this heritage as it faces a move to a mutual future as an NHS foundation trust.**

The life of the Queen Victoria Hospital, a cottage hospital in East Grinstead, West Sussex, changed forever in 1940, as the pioneering plastic surgeon Sir Archibald McIndoe began rebuilding the lives of badly burned airmen. McIndoe healed their wounds but he also embraced the holistic ethos of healing their lives through a patient and public involvement programme that could only leave others standing back in admiration.

The surgeon persuaded the town to take these terribly disfigured war heroes to their hearts and befriend them. He organised a social life for these young men and persuaded the rich and famous to help out either both with financial contribution to the hospital and in more tangible ways such as entertaining the "Guinea Pigs" – the name the men gave themselves – in their homes.

Consultation on all aspects of their care was a McIndoe trademark. He went to lengths to explain the frequent and often painful operations the men faced. He would even negotiate the times of operations so they could have an evening at the pub behind the hospital, which was subsequently renamed the Guinea Pig, and be responsible for returning at the appointed time.

Present-day developments in medicine have seen a greater level of specialisation with doctors and nurses becoming experts in their particular field. Centres of excellence where hospitals serve large geographical populations are therefore being developed. There is a body of evidence that specialist units achieve better clinical outcomes. The Queen Victoria Hospital has been a centre of excellence since the 1940s and retaining this service, during times of radical

change, has been driven by the support of patients and the local population.

The ethos of the Queen Victoria Hospital remains pioneering, to be at the forefront of everything it does. The involvement of patients and the public involvement has always been a natural element in its service provision, and increasing this is a huge opportunity. As the Hospital strides towards NHS foundation trust status – one of the first 24 in the country – the involvement of patients and the public therefore remains high on the list of priorities.

There is little doubt that the Trust is indebted to the 12,000 people who have already registered as NHS Foundation Trust members, but the reason behind the support lies in the McIndoe days when a culture of involvement was engendered throughout the hospital and the local community. They supported each other, the hospital staff and the townspeople. Recognising the strength of just such a relationship the Trust staff have worked hard to ensure it is retained.

But respect and support must be earned, and the Trust cannot afford to rest on its laurels. To retain its pioneering reputation, it must be innovative in involving its members – who are champions of the Trust – in its work and in its future.

The members will be an asset, and plans are being developed to help their understanding of the clinical services provided and of the pioneering work that will retain the Hospital's status. If they are successfully involved and their understanding increased they will be invaluable in acting as our ambassadors and as our earpieces in the community. This in turn will give us the ability to really understand people's expectations and needs and thus give them a greater voice.

At a more formal level, 24 public governors will make up the majority on the Board of Governors of the Foundation Trust. Public involvement has been warmly encouraged, particularly among patient support groups who are among our most ardent admirers.

The biggest challenge will be to manage the expectations of the Governors and to ensure that communication channels are as long as they are wide for them to achieve a real understanding of where we are going and why. Equally, as the Trust looks to its Governors and members to understand complex issues, it is poised and ready to listen and to take on their views.

In a move which for us resembles not leaving anything to chance, the past year has also seen the establishment of PPI forums, consisting of local volunteers with an interest in health issues. They form another group with its ear to the ground to ensure that NHS trusts are responsive to local voices.

All these people have roles to play. The Trust must be innovative in using its skills and in treating them as equal partners and involving them at all levels.

PPI is not simply asking for patient and public views – it has a wider remit. It is about partnership working with the local community, the local authority, the voluntary sector and other organisations, as well as patients, their carers and the public. It also about demonstrating how we listen to others, supply good quality information, and are passionate about inviting patients to help strengthen accountability as equal partners. NHS foundation trusts need patients, carers and the public telling their stories in order to learn, to develop and to make positive changes.

Sir Archibald McIndoe personified the principle rule in healthcare – People are our Priority – the Queen Victoria Hospital has never lost sight of this.

**Brenda McCrory**

PPI and PALS Coordinator

Queen Victoria NHS Hospital Trust

tel.: 01342 414200

email: [brenda.mccrory@qvh.nhs.uk](mailto:brenda.mccrory@qvh.nhs.uk)

## Case Studies

### Case study

# Keep it simple

**Jemma Gilbert describes a project which shows that effective PPI does not need to be complex or expensive – simplicity and enthusiasm are more critical.**

Being a lone PPI Manager is difficult: with responsibility for challenging individual behaviours and changing traditional working practices, the road to success can seem like a never-ending climb. It's so easy to be focused on the end goal and frustrated by the lack of pace that often we miss the small revolutions taking place in every corner – brave individuals willing to give public involvement a go.

Glittering but complex case studies can often frighten a PPI beginner away. So here is one of those small but revolutionary moments, a project of which we are extremely proud of at Sutton and Merton PCT.

In just six months, Sue Buckhurst, our Head of Speech and Language Therapies and a PPI novice, had canvassed the views of service users, built relationships with parents, discovered what changes they wanted and begun to make their wishes a reality. All this whilst managing busy speech and language therapy services. The beauty is the demonstration that an individual's enthusiasm and willingness to listen is sometimes more important than experience. There was no grand budget; there was no complex 'science bit'. The main ingredient was someone willing to have a go, an added pinch of PPI Manager support ... oh, and liberal splashes of post-it notes!

**So how did Sue do it? Take heart and read on ...**

There were two key steps. The first was relatively standard in PPI terms: a simple satisfaction survey for parents whose children were receiving paediatric speech and language therapy services. This was achieved by looking at other examples of satisfaction surveys and following online advice about length and format. The real beauty of this was that it generated an

engaged body of parents, who realised that their views mattered. A number indicated their interest in attending a participation group to discuss their experiences in more depth. With this simple first step we had got some information on what people thought about the service and also had some willing future participants in the bag!

This brings us to the slightly more creative and adventurous second step: a parent participation group centred on a pathway-mapping exercise. The great thing about this exercise was transferring the familiar method of pathway mapping into the 'foreign' public participation group environment to make things less intimidating. Almost every local NHS organisation will have someone, probably part of a modernisation team, who has that infectious passion for mapping with brown paper, post-it notes and sticky tape. All you need to do is set them to PPI purposes.

Parents were invited to attend a participation group for 2½ hours in the morning, with a crèche in the room next door for their children. They were asked:

- to recount their 'physical journey' through the service
- to describe 'good' and 'not so good' aspects of the service
- to comment specifically on aspects relating to information, choice, waiting, quality and safety
- to map their 'emotional journey' against their 'physical journey', and finally
- to describe what their 'perfect journey' in a perfect NHS would be.

By hosting a participation group, we had created a new forum for debate with parents and formed new relationships with our service users. Examples of things we learned were that parents:

- appreciated the recently reorganised service with reduced waiting times
- wanted more contact with other parents who were 'in the same boat' and were

willing to volunteer themselves for a 'parent contacts sheet'

- disagreed on whether an early diagnosis for their child was a relief or a potential unhelpful label
- would have appreciated some specific information packs at the start of their journey and were happy to help design these
- praised the team providing the services for their caring and personal approach

Since holding the participation group, the findings have been discussed with the wider speech and language therapies team to decide what changes could be made in the short or long term. Some of these have already been made and we have continued to update and engage with the service users. The next challenge is to encourage more comments from dads and attempt involvement with the children who use the service to ensure that we are as child-friendly as possible.

So, if you're looking for success, the key factors were: keeping things as simple as possible; using a method we've used before; and having a brave beginner who is committed, understanding and listens to the experiences that service users have had – warts and all.

And remember, PPI Managers, today you may feel like you're throwing seeds on rocky ground but keep an eye out and you will see some promising sprouts.

This is just one of many successful PPI projects that Sutton and Merton PCT has achieved in the last two years. I want to thank all my colleagues for bravely pioneering work in this area.

**Jemma Gilbert**

Community Engagement Manager  
Sutton and Merton Primary Care Trust  
tel.: 020 8251 1129  
email: Jemma.Gilbert@smcpt.nhs.uk

## Case Studies

### Case study

# Clinical thinking

**A major challenge for PPI is involving lay people in clinical issues. Emma Challans describes how patients are being engaged in the clinical audit process in Sheffield.**

## Why create a clinical audit patient panel?

Sheffield South West PCT had a clinical governance review by the Commission for Health Improvement (CHI) in June 2003. One area highlighted for improvement was involving patients in how primary care services are delivered. This particular aspect seems to appear frequently in clinical governance reviews for all trusts.

Clinical audit is at the heart of clinical governance, which seeks to ensure that services are delivered in the most effective way. Components such as risk management, training and development, clinical audit and effectiveness all complement each other. Clinical audit establishes whether the care delivered is to the recommended evidence-based guidelines and, if not, highlights possible reasons why.

How do we know we are delivering the best care to a patient? We have evidence-based NICE technology appraisals and clinical guidelines as well as National Service Frameworks, but do we really know what patients want or expect from a service? If we are to improve services and ensure that patients feel that they have ownership of their care, what do we have to do to ensure that patients are at the centre of the organisation and that they can be heard through active involvement?

Clinical audit assists and develops services in improving patient care. It therefore appeared only logical to create a Clinical Audit Patient Panel (CAPP).

## What have we done so far?

Very few audits had previously involved patients and most of these had had only token patient input. The new Panel has been set up to advise, support and improve clinical audit activity within the Trust. It will enable service users' and carers' perspectives to be included in evaluating quality and to identify opportunities for improvement. Members can be actively involved in all phases of a project from initiation to completion.

A poster was developed informing patients and carers that the Trust wanted to set up a CAPP. This was disseminated widely through the Trust's Evidence-Based

Practice Group and sent to every GP practice, optometrist, dentist, community pharmacist, service base and to local community and voluntary groups. The development of the CAPP was publicised to other staff through Practice Learning Initiative events and wherever there was an appropriate opportunity. It was key to make everyone aware of the Panel so that staff notified each other and were in a position to pass the information on to patients. The Sheffield Podiatry Service actively involves patients and has done so for a number of years; their experience and knowledge was useful when setting up the Panel. Close links were also maintained with the PALS Manager.

A number of patients and carers made enquiries about the Panel via telephone and email. 11 people of different ages and backgrounds expressed an interest in the Panel. Each person was sent a CAPP application form requesting basic information such as their name, occupation, experience of health care, hobbies and interests and how they felt they would be able to contribute to the Panel. All the forms were completed and returned.

The majority of patients were not experienced in what clinical audit was; they had a general idea but did not fully understand the concept and details behind it. A training and information event was held to ensure that Panel members got a good understanding of clinical audit so that they could actively contribute.

It is essential that all Panel members have a basic knowledge and understanding of clinical audit. We have therefore given introductory training on how and why audits are done and what they can achieve if carried out properly. Panel members were informed and continually reminded of their responsibilities regarding confidentiality and, if enrolling to be part of the Panel, each person signed a confidentiality agreement. Once members have received training and signed to be part of the Panel, they are then available to the Trust to assist in developing and improving services through clinical audit and questionnaires.

Seven people were able to attend the afternoon training event; another session is being held for the other four people who could not do so. A brief introductory presentation was delivered and participants were given a clinical audit guide based on that for staff, but specifically adapted for patients. The event was relaxed and this created opportunities for people to ask questions and learn more about how they could help the Trust. We could also

discover if patients had any doubts, fears or concerns about being involved in the Panel.

Concerns are often raised by both sides regarding patient involvement. A patient may feel that their views are not taken seriously, they will look foolish, won't understand issues or that what they say or do may affect their future care. Staff may feel that they are being criticised, involvement undermines their role, a relationship with a patient will be affected or that it may result in loss of patient confidence. This has been addressed by ensuring that patients will not be working with their own GP practice, dentist, etc.

## General

When involving patients it must be clear from the very start why a person is involved and how they are expected to assist the service.

Involving patients is key to developing services. They can tell us a range of things: how to communicate, how we make them feel, how convenient the service is, how we can respect them and their culture, whether we involve them in decisions and whether they trust us. When designing a patient questionnaire to find out how well patients think the service is doing, are we asking them the right questions or things that are of no importance to them? Is what they feel is actually most relevant ever asked? Would it be better for a member of staff to go through a questionnaire with a patient or for another lay person to go through it with them? Recent projects indicate that a person is more likely to tell another patient something that they would never mention to their health care provider.

Four patients have signed the confidentiality agreement to be part of the Panel so far and three have declined. We will continue to advertise the Panel throughout the PCT area, and hopefully more interest will be received.

Involving patients in clinical audit will help the Trust take forward patient-driven services. We have taken the first steps in giving patients a real opportunity to help us effectively rather than what has previously often been a mere token.

**Emma Challans**

Clinical Effectiveness Facilitator  
Sheffield South West PCT

Emma.Challans@sheffieldsw-pct.nhs.uk

Tel: 0114 271 1151

## Case Studies

### Case study

# Reaching the hearts that others don't reach

**Two common challenges for PPI are how to get local people active and how to engage disadvantaged groups. As Rutuja Kulkarni explains, in Slough they develop their own health activists.**

## Introduction

Mortality from heart disease is high in Slough and higher in certain parts of the population, such as the South Asian community. In 1999, Slough PCT secured funding from the Department of Health's Coronary Heart Disease Health Improvement Reward Scheme to raise awareness of heart health, invest in local people and facilitate better access.

The Health Activists project targeting specific areas with minority ethnic and deprived populations was set up in partnership with local further and higher education providers to deliver accredited training to local communities and professionals. The project meets the national and local priority set on heart disease reduction through the National Service Framework (NSF). It also allows the PCT to work with local communities on inequalities, whilst building local commitment on improving health.

## Methods

A 12-week Open College Network course has qualified 30 health activists. Participants have included people from within the community as well as organisations like Age Concern, nursery schools, neighbourhood wardens, interpreters and day centres. Training has covered health, health promotion, communicating to promote health, working with groups, mapping the local community, heart disease, risk factors and protective factors. 21 professionals in different sectors have attended heart awareness seminars with similar content. Health activists running sessions in the community are paid by

the PCT on a sessional basis and sessions are evaluated along the lines of knowledge gained, intention to change and enjoyment. Mainstream support for the project has been secured through the PCT Local Development Plan.

## Results

Over 99 sessions have been run in the community to date and 1,559 people have accessed healthy hearts information. Evaluation of training and sessions shows enjoyment, changes in knowledge, attitude, confidence and behaviour. Comments made have included "best for ages to help the communities of Slough", "hope my group has as much fun learning about heart disease as I did", "I feel like a kid again playing ball in the park", "I learnt how to cook curry differently", "I will walk to relieve stress", "my son doesn't have McDonald's everyday now!", "didn't realise there was so much salt in processed food". Continued training and development of health activists has covered diabetes, blood pressure monitoring, oral health, nutrition in schools, social networks and flu immunisation.

## Developments

The PCT has successfully attracted New Opportunities Fund (NOF) money to develop health activists in other areas (mental health, older people, children and young people and learning disabilities). A Project Manager has been appointed and will be working with the various partnership boards to develop the health activists to support these streams of work.

## Discussion

A number of factors have contributed to the success of this project. National focus on public health, community involvement, health promotion, health improvement and local results – reaching 1% of Slough's population within a year with positive outcomes – have all made a case for health activists in Slough.

## Case Study

Shahbano Razvi is a health activist (HA) and also works as an interpreter on a part-time basis for Slough PCT with the Community Nursing team. In her role as a HA she has worked with the women's group of Parvaaz, a voluntary group supporting parents and carers of people with disabilities. 10-15 people regularly attend the women's group and sessions covered have included heart disease and risk factors.

Healthy eating and physical activity were the risk factors looked at in more detail, as they were considered to be more within the control of individuals and communities. The group had lively discussions on the balance of good health and food groups, portion sizes, hidden sugars, weight management and physical activity. As well as the discussions, the group regularly went for walks lead by Shahbano and took part in swimming sessions over the course of 10 weeks. Setting up the swimming resulted in the local leisure centre offering women-only hours on various days for all activities. Many of the women have continued with their swimming and there plans to train some of them as lifeguards.

**For details please contact Shahbano on 01753 635533.**

### Rutuja Kulkarni

Health Promotion Programmes Manager  
Public Health Directorate  
Slough teaching Primary Care Trust  
Telephone: 01753 635182 or 07876 562539  
rutuja.kulkarni@berkshire.nhs.uk

## Case Studies

### PALS and PPI - a Country-Wide View?

**The new systems of patient and public involvement (PPI) are 'settling down', and across the country, the NHS is learning how to involve people in its every day work. Patient Advice and Liaison Services (PALS) are now set up and functioning well in trusts all over England. They are playing an important role in delivering successful PPI initiatives in local communities.**

Supported nationally by the National PALS Development Group (NPDG) and the National PPI Leads Network, both PALS and PPI are operating on several levels to improve NHS services for patients.

But what is the difference between the work of PALS and that of PPI – and how do they fit together? The answers to these questions vary from place to place. This is not because of a lack of consistency, but because there is a huge emphasis on making services as local as they can be. To do this, NHS organisations need to know the population they serve: they need to listen and respond to local needs and wants.

The national consensus regarding PALS and PPI is therefore very hard to gauge! PPI has a very wide range, and could be considered the 'umbrella' that will enable NHS organisations to involve and consult patients and the public in its work. PALS is one of the 'functions' that helps to achieve effective PPI, because the very nature of the service brings us into contact with patients every day – and we find out people's thoughts on all sorts of things.

To give an idea of how PALS and PPI look together in different places, a couple of very different trusts have offered an insight into their inner workings ...

### Case study

#### Worthing and Southlands Hospitals NHS Trust

The Patient Advice and Liaison Service at Worthing and Southlands Hospitals NHS Trust was a pathfinder service, and has been in place since November 2001. It is single-handed with just a PALS Manager. From the outset, it was seen as a service that links to the public and patient involvement (PPI) agenda, rather than being directly involved, although the lines are fairly blurred at times.

As the service has developed over the past 2\_ years, it has become integrated with clinical governance, and all reports go to the Trust Board via the Clinical Governance Committee.

There is also a Clinical Governance Sub-Group that consists of the PALS Manager, the Complaints and Claims Manager, the Risk Manager, the Clinical Risk Manager, the Audit Manager and a Training Department Manager. This group collects all trends and issues raised through these multiple avenues, and combines them into an action plan to identify improvement and training opportunities, and record what is being done to improve patient care. In turn, this feeds back into the Clinical Governance Committee.

More recently developed is a Patient Experience Group. This involves as many representatives of staff who may hear of issues from patients as possible – for example, chaplains, medical secretaries, volunteers and the Chief Executive's PA, to name a few. The proposal is to identify how often the same issues arise and thereby 'back up' the need for change with specific facts. It is anticipated that this will probably include some individual issues. This is a new group however, and will develop over time as learning increases.

To support PALS as a single-handed service, we have also developed PALS Champions. The Champions are representatives from every ward and department – including non-clinical areas. They play a key part in ensuring that PALS is visible across the Trust. They:

- spread information about PALS and what it can do
- are the focus in their area for resolving issues
- signpost to the PALS Manager

The Champions meet monthly and bring issues to a 'round table' discussion. These are recorded into an action plan for future improvements.

The Trust has recently formulated a PPI policy and Steering Group, and the PALS Manager is part of this – although it is early days as yet.

**Helen Peirce**

PALS Manager

tel.: 01903 205111

email: Helen.Peirce@wash.nhs.uk

## Case Studies

### Case study

## North Staffordshire Combined Healthcare NHS Trust

North Staffordshire Combined Healthcare describes itself as a “complex care trust”, providing services to people experiencing mental distress or illness, people with a cognitive impairment, and older people with complex physical health needs. Around 120 care teams operate in, or from, 50 different locations within Stoke-on-Trent, Newcastle-under-Lyme and the Staffordshire Moorlands.

Given the diversity of client needs and the geographical spread of our services, we are developing a model for PALS based on the ethos that “We are all PALS”. Providing ‘on-the-spot’ help is something we can all do; it is not restricted to a few dedicated PALS workers. Nine times out of ten there is sufficient experience and knowledge within teams to address issues and requests as part of day-to-day client care.

We also recognise, however, that sometimes people prefer to talk to staff who are separate from the people providing care. So, we offer the choice between talking to someone ‘on the spot’ and contacting our PALS office by freephone or freepost.

The Trust also recognises the need to develop PALS as a way of working – an ethos that builds on existing good practice within a new framework that adds value to the ways in which we listen and respond to what people are telling us or asking of us.

Therefore, an approach has been cultivated that develops ‘PALS Leads’ within each care team. These are experienced staff who initially undertake one day’s training and then provide leadership within their team for PALS. Over one hundred members of staff have had the training so far.

The Trust has developed a policy called Listening and Responding, which is about PALS, formal complaints and how they interface. In addition to this, there is a developing PALS Practice Guide, which is published, along with the policy, on the Trust’s web site <http://www.nsch-tr.wmids.nhs.uk> The Guide provides an overview of PALS and our approach to it, alongside good practice guidance on the production of client information, links to accredited health web sites, further information on patient and public involvement, and so on.

One of the ways in which we are linking PALS to the wider PPI agenda is by inviting people to express an interest in service development. This is done by writing to PALS clients who have expressly agreed to receive correspondence from the PALS Office. In addition to asking for clients’ views on PALS, which they can feed back anonymously, we ask if they want to find out more about how they can get involved. Clients who identify themselves in this way receive further information about opportunities for getting involved and the support and training that the Trust can offer them.

**John Larkham**

Head of PALS

tel.: 01782 275171

email: [johnr.larkham@nsch-tr.wmids.nhs.uk](mailto:johnr.larkham@nsch-tr.wmids.nhs.uk)

## Resources

### National PALS Development Group -

[http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/PatientAdviceAndLiaisonServices/PatientAdviceAndLiaisonServicesArticle/fs/en?CONTENT\\_ID=4081000&chk=8y3gOD](http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/PatientAdviceAndLiaisonServices/PatientAdviceAndLiaisonServicesArticle/fs/en?CONTENT_ID=4081000&chk=8y3gOD)

### PALS Post newsletter -

<http://www.hfht.org/chiq/PALS%20Newsletter.htm>

### National PALS Directory -

<http://www.hfht.org/chiq/services.htm>

### PALS information and resources -

<http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/PatientAdviceAndLiaisonServices/fs/en>

### PALS portal, National electronic Library for Health -

<http://www.nelh.nhs.uk/pals/>

These are just two examples of how PALS are developing locally effective ways of linking the feedback they get about patients experience into the wider PPI agenda. Using patients’ experiences to enrich the learning within the NHS is building all the time – both PALS and PPI are intrinsic to this process.

**Kathleen Sheehan**

PALS / Communications Officer

Sedgefield Primary Care Trust.

tel: 0191 301 3820

[Kathleen.Sheehan@sedgefieldpct.nhs.uk](mailto:Kathleen.Sheehan@sedgefieldpct.nhs.uk)

# No muzak or nice distractions

**What role can the arts play in PPI? Brian Chapman argues that they are essential for us all, not least for people who are disempowered by illness.**

“The arts have a powerful, mysterious and healing impact on humanity. The arts are not only needed; they are the foundation for our survival and growth as a species. Art is perhaps humanity’s most essential, most universal language. It is not a frill but a necessary part of communication.”

(Eisner, 1987 - researcher and writer on cognition, Stanford University, USA).

“Survival and growth as a species ... essential” – powerful stuff, but we know it is true. The arts address deep-rooted issues about life and inform how we (re)construct our world. When we bring the arts and design into healthcare settings (places of birth, life and death), fundamental questions arise around quality of experience and healing processes. Questions also surface about artists, their role, professionalism, impact and value for money.

Are the arts sanitised and institutionalised in healthcare? Are they used to gloss over poor buildings and inadequate services? Are they painted in ‘the colour of mediocre’ to please the punters? Is there a risk of much sought-after research creating mass-produced models of ‘what is good art for hospitals’ or ‘what works in this setting’ to the detriment of more risk-taking exploration?

There are no easy answers. The point is that the questions are being asked! Artists are finally being taken seriously within what has been a scientifically dominated and – dare I say – clinically dogmatic, blinkered healthcare system

So how do we embed the arts within healthcare systems and militate against tired notions of arts being a ‘frill’ or low priority in relation to clinical medicine?

LIME, the Manchester-based arts in health development team, has sought to weave together arts, health and social agendas for many years. Having spent nearly 30 years as an artist in this field, I am beginning to see increasing opportunities for artists and positive changes within health, arts and cultural policy at all levels. I also observe a sustainable impact on healthcare culture.

LIME’s practice has developed and changed over time, but has always been rooted in consultation and participation. Emphasis is now on embedding ‘good practice’. The seeding process is established and some of the questions are being addressed.

For example, an integrated arts programme in the Moorside mental health unit in Trafford has enabled a ‘Gold Standard Practice Development Unit (PDU) Accreditation’ for delivery of care to patients. The focus of the art programme was to convert an activity room into a user-led café and cultural centre. Artists worked on the wards with the patients and staff teams. David Bartholomew, the PDU Manager, says:

“A direct consequence of LIME running this project has been the development of a unique collaboration between service users, staff and the College and all have been recognised as stakeholders in the Unit environment. Given this, LIME has been influential in the cultural and attitudinal change within the service that embraces users, and their carers in the development of services ... Perhaps the most significant aspect of the input LIME has given is being instrumental in changing the perception of an inpatient admission. Whilst in the past, inpatient admission is viewed as a negative experience, the approach adopted for the café and arts project was very much to focus on an individual’s strengths and abilities and to nurture these in a positive manner to enable individuals to develop new skills, and qualifications.”

Similarly, both Bolton Mental Health and Social Care Services and the South Manchester University Hospitals NHS Trust have won national awards through work with LIME. Artists working in a range of media have played a key role in multi-professional working, increased patient involvement

Some interesting political developments have occurred in recent years. Government policy is influencing both arts and health to be increasingly inclusive, participatory and agenda-crossing. Meanwhile, artists, service users and healthcare workers are singing to the same tune, influencing notions of holistic and creative healthcare from the bottom up through imaginative alternatives.

and significant changes in practice. Critical is embedding good relationships between project managers, artists and the trusts at all levels.

This work gathers together professional, local authorities and cultural industries, education and healthcare communities to share practice and learn from each other. It draws down arts, health and social policy driven funding. It is not about prettying places up, providing muzak and nice distractions, or buying art to enhance spaces. It’s about creating new stakeholders and facilitating decision-making, learning and new connections. It’s about fashioning opportunities for artists to share with people excluded or disadvantaged through illness their creative language and artistic medium, whilst also creating alternative avenues for the arts.

**Brian Chapman**

Director  
LIME.

tel.: 0161 256 4389

email: lime@ic24.net

For more information visit

<http://www.limeart.org/>

# A CUP OF COFFEE WITH...

David Taylor, Head of Regeneration, University Hospital Birmingham NHS Foundation Trust.

## Each month PPI Monitor enjoys a cup of coffee with a leading figure in the world of PPI

**The regeneration of Birmingham's Bull Ring shopping area has been a major success for the city. Regeneration is now on the agenda of Birmingham's biggest NHS Trust.**

David Taylor is a regeneration man, who has been brought in to help the University Hospital NHS Trust, to transform the lives of its local people, by using its enormous spending power to regenerate its most deprived neighbourhoods.

One wonders how a local government regeneration professional ended up working in a hospital. The answer is rather simple according to Taylor "I applied for the job after seeing an advert".

Of course though, this was an unusual advert. There are very few trusts in the country with such a post. He says "It was down to the vision of Chair and Chief Executive, that the NHS should become far more prominent in regeneration and play a major role to reduce disadvantage".

It was the blend of experience of the Trust Chair, as a politician on Birmingham City Council and as a practicing dentist, which made him realise that there were ways that a trust could affect prosperity and tackle disadvantage.

I wondered if Taylor had asked himself how he ended up working in a hospital. "About one hundred times" he says. "This job offered real potential. Not many people switch from local government to the NHS. The vision persuaded me that there was real potential and an immense challenge".

It's easy to grasp the principle that health is related to wealth, and that trusts could do more to contribute to local prosperity. But what exactly does a Director of Regeneration do?

"Let me give you some examples" he says.

"Take training. We've tried hard to take advantage of the fact that we are the second biggest employer in Birmingham, expanding by 500 jobs a year. We

I wondered if Taylor had asked himself how he ended up working in a hospital. "About one hundred times" he says. "This job offered real potential. Not many people switch from local government to the NHS. The vision persuaded me that there was real potential and an immense challenge".

hadn't done anything to get local people into jobs, and we have all sorts of jobs – technicians, porters, gardeners, not just clinical posts".

His experience of funding came in useful "We bid for European Social Fund monies so that we could train unemployed people and give them a chance. We will have trained 400 by April, and the success rate of people going to 'positive destinations' is 60%. A high proportion are from black and minority ethnic groups which are underrepresented in the Trust".

The success in putting local people back to work has led to other trusts in the city joining in to work in partnership on the programme.

He says that there has been little resistance within the Trust to the idea of being involved in regeneration work "You take people with you – if you are a busy sister you have to realise that working with a trainee won't take you away from patient care. People are very enthusiastic having worked with trainees and often want another one".

The Trust's current scheme promises to do

even more for the local economy "We are moving towards the concept of a learning hub as we build a £521 million hospital with a private sector partner. We will employ 2000 construction workers. In the past these would often have been 'bussed in'. We will work with the Learning & Skills Council to target certain areas – becoming a learning hub for the whole community. We estimate this will put £4 million into the local economy, plus £5 million in training, with 2-3000 people benefiting from the scheme, including some of the worst –off people".

So that's what Head of Regeneration does. He says "A lot of my work is networking. Often other people have the ideas. People in the Trust

have the best ideas but don't know how to make them happen".

As a newcomer to the NHS, he gives his tips for engaging people: -

- Get involved
- Listen
- Don't dismiss people
- Often people have good ideas but don't know how to make them happen
- Find the link
- Be genuinely keen to see projects succeed

With a buying power of £100 million of goods and services, the trust now sources 30% from the West Midlands and wants to make it higher.

David Taylor is masterminding a new plan to create a kind of 'silicon valley' for medical technology around the hospital, creating even more jobs.

Perhaps more trusts will tread the path of Birmingham and appoint a regeneration professional, using its wealth to contribute to health.

# Positive signs at the crossroads

Only just six months old, the existence of PPI forums is being challenged in some quarters. CPPIH Commissioner Ian Hayes looks at early successes and identifies some signs for the way forward.

**Once again, it seems England's formal system for public involvement in the Health Service is at a crossroads. The independent structure enacted in January 2003 has only been operational since last December but it's already been called into question by the national review of "arm's length bodies." Crossroads are dangerous places and, while it's too early to talk about souls being sold to the devil, we must have concerns that PPI may take a wrong turn.**

After years of controversial gestation and after replacing a system which – despite its failings – had served us well, the new structure is in its infancy. To consider changing it already betrays a lack of commitment and foresight.

I'm no apologist for bureaucracy. I always believe that public involvement is a major force against red tape, and I'd fully accept that the system of non-departmental public bodies (NDPBs) reviewing the Health Service is labyrinthine. My simple view of involvement is that it starts when a patient says, "explain that to me, doctor, so I can decide what I want." Complexity risks alienating the very people we seek to involve but the key elements of the system are so important to the future of PPI that we must support them.

Most important are the independent PPI forums, made up of volunteers, rooted in their communities and working in partnership with commissioners and providers of health services. They need time to develop, to change cultures and to demonstrate their ability to improve our experience of health services at individual, local and national levels. They need the support and resources required to fulfil their promise.

A real danger exists that failing to support the PPI forums will call into question the entire movement towards PPI in health. We may lose the first generation of volunteers and a once in a lifetime opportunity to place the consumer at the centre of decision-making in health.

The immediate risk is that the PPI forums will be paralysed by the "change blight" which so frequently afflicts the NHS at just the time when they are beginning to show signs of success. I've always had three concerns when thinking about whether forums would succeed:

- they wouldn't represent or engage with their communities
- they wouldn't be able to work with the complex structures surrounding them
- they'd get stuck with traditional "patient" areas like signage and patient information and fail to get involved with complex structural issues.

I thought overcoming these risks would

A real danger exists that failing to support the PPI forums will call into question the entire movement towards PPI in health.

We may lose the first generation of volunteers and a once in a lifetime opportunity to place the consumer at the centre of decision-making in health.

take both time and greater investment than would be available, but there are already positive signs. The progress is variable but an unscientific, and entirely partial, review of activity in my own area in the South-West shows signs that each of these problems can be overcome.

PPI forums in the Bristol area have been working to ensure they involve groups we've previously failed to involve by the simple expedient of going out to meet them. Signs that forums have a good understanding of this key role include a partnership between the United Bristol Healthcare Trust Forum and local black and minority ethnic groups to run an event during National Carers' Week. This understanding of the need to seek out the views of those least likely to be engaged is also evidenced by the North Devon Forum which is actively looking for ways to seek the views of isolated farming communities and the small black and minority ethnic groups in the area.

PPI Forums are also showing positive signs of an ability to seek out ways of working within the complex organisational structures that make up their local health economy. The carers' event in Bristol has been a case in point. It's rapidly expanded and now includes another two forums, two PCTs and the local social services department. These are encouraging signs that the forums will be able to fulfil their task.

Even more reassuring to me are signs of an ability and willingness to reach across the divide that often exists between health and social services. I've always been cynical about "joint planning" and its successors. It's always seemed less a seamless interface and more a black hole into which good intentions disappear. One of the first regional events held by CPPIH in the South-West was a conference bringing together forum members, PPI leads and representatives from overview and scrutiny committees (OSCs). To see a reduction in that cynicism, agreement of common agendas and some concrete "to

# Reader's Letter

do lists" was a tribute to the presence of the forum members.

Finally, there are real signs that the ability to work with the complex structures will mean that PPI forums will be able to engage with the big strategic issues facing health care. Services in Bath have long suffered from huge financial deficits, underperformance, problems with waiting lists and rapid turnover of senior managers. This is just the kind of intractable structural problem you might expect to be beyond the capacity of new forums made up of untrained lay members, but work has already begun.

The chief executives of four local trusts have briefed 30 members from seven PPI forums. They looked at plans to address capacity and service issues while dealing with the financial deficit. This will require complex service changes including bed reductions, changes to community-based care, closure of some services and the development of new treatment centres. This early ability to get involved in "the big picture" is yet another positive sign that forums will fulfil their promise. Moreover, the willingness of the managers charged with resolving the problems to involve the forums illustrates the value being placed on the expertise of patients and public. It's also another illustration of the ability to work with complexity – the work plan under development will require six forums, four trusts and a number of PCTs to work together. Links have already been established with the local OSC.

It's anecdotal, and I'm a partial observer, but these are clear signs that PPI forums are already working. I'm sure there are examples where forums haven't got to grips with the task but right now I'm going to unashamedly concentrate on the successes. These show the way forward and point up the need to give support, resources and – most importantly – time to ensure the promise of a system built on constructive engagement is fulfilled.

If we are at a crossroads then let's make sure that the PPI forums are fully consulted on the way forward. It would show very little respect or commitment for PPI if the system was changed without consultation with its real owners – the patients and public.

**Ian Hayes**

CPPIH Commissioner  
Tel.: 0121-222 4535  
Email [ian.hayes@cppih.org](mailto:ian.hayes@cppih.org)

## Teething Troubles - cover article in PPI Monitor (May 2004)

I'm writing in reply to the quoted comments from a PPI Forum Chair in the above article.

My main concern is that, as a Forum Support Organisation (and a voluntary sector organisation) we are finding the ease at which others allocate blame for issues within the PPI Forum project to FSOs very frustrating and unfounded.

It may be that in one specific forum, in one specific area, there has been a lack of professionalism shown. However, that is not and should not be taken as a reflection of the quality of delivery across the country.

I moved to the voluntary sector some 6 years ago having had both private and statutory sector experience. I find the level of professionalism, comparable and often better than other sectors and can say with confidence that it is also reflected in the FSO delivery I am aware of. I don't mind taking responsibility for some issues, we all do things wrong. But to allocate most of the issues with this project to FSO organisations just because they happen to be from the voluntary sector is frankly, naive, damaging and offensive.

**Richard Jackson**

Leeds FSO Contract Manager  
Voluntary Action-Leeds  
Stringer House, 34 Lupton Street  
Hunslet, Leeds LS10 2QW  
T: 0113 297 7923 F: 0113 297 7921  
E: [richard.jackson@val.org.uk](mailto:richard.jackson@val.org.uk)  
[www.val.org.uk](http://www.val.org.uk)

If you would like to comment on any article in PPI Monitor or if you have a view to express relating to PPI then please email: [s.bashford@bearhunt.org.uk](mailto:s.bashford@bearhunt.org.uk)

## News briefs

### New disability rights

From October 2004, all service providers will have to consider changes to physical features or premises to overcome barriers to access for disabled people. The Disability Rights Commission says "Patient choice means providing health services that meet individual needs and preferences." Further information can be found on the Disability Rights Commission's website at <http://www.drc.org.uk/open4all/>

### NHS complaints handling

On July 1st, the Healthcare Commission took over responsibility for investigating NHS complaints that have not been satisfactorily resolved at a local level.

Consultation on our proposed complaints handling process ended in April and an analysis of the feedback, together with our response, was published last month. The Healthcare Commission aims to be independent, fair, consistent and timely in handling second stage complaints and will be communicating with NHS professionals, complaints and PALS staff, key stakeholders and patient groups to explain the new process.

There is a detailed paper at <http://www.healthcarecommission.org.uk/assetRoot/04/00/19/35/04001935.doc>

# The time of their lives

Dementia and hope may be considered incompatible. Yet we must not be seduced by the doom and gloom of the medical model into seeing everything in terms of loss, says John Killick.



Claire Craig is an occupational therapist in Yorkshire. One day a lady with whom she had been sharing an arts activity said to her: "We have been on a wonderful journey, you and I. What fun we've had, laughing and singing. Holding a rainbow in our hands."<sup>1</sup>

The rainbow seems a suitable metaphor for dementia. The dark clouds are there, causing the rain, but the sun brings strong rays which transform the scene with colour. Yet, like the rainbow, the moments of illumination are often fleeting, and to be valued for their intensity in the Now.

My work at the Dementia Services Development Centre at the University of Stirling is all about positives: bringing opportunities to people with dementia to take part in artistic activity. The overriding aim is communication. Why such an emphasis? Because many people have problems in this area. Where verbal language becomes difficult then the non-verbal must step in to fill the gap. The arts offer a number of non-verbal languages for our use: dance, mime, music, painting, sculpture, photography and various crafts. We are failing those in our care if we do not offer these opportunities.

There is another reason why the arts have a special role for those with the condition. Dementia seems to attack the reasoning part of the brain: the capacity to make and retain connections between events, information and ideas. But it does not prevent people from having feelings: the ability to feel and express emotion seems to be left largely intact, indeed may even be enhanced. So many people with dementia are experiencing difficulties with memory, leading to confusion, and feeling emotion strongly, leading to distress. We have to find ways of transforming the negative feelings into positive ones. A similar process, I suggest, applies to memory. Many memories, particularly ones from the recent past, seem inaccessible, but experiences which are

associated with strong feelings seem to be more robust. The arts make special use of this kind of memory.

But where emotion is concerned some would go even further. These are the words of Faith Gibson, Emeritus Professor of Social Work at the University of Ulster: "Dementia strips people down to the essence of their being and frees them to be in more direct touch with their emotions. They communicate with greater authenticity than our customary conventional reliance on controlled emotional expression."<sup>2</sup>

There is evidence that some people with dementia can maintain an interest in artistic expression after the condition develops and others can discover new and hitherto unrealised potential in particular art-forms. A very exciting piece of research by Bruce Miller in California is exploring this phenomenon.<sup>3</sup>

Christophe Grillet is a man in his seventies living in Cambridge who had a very successful career as an architect, but since the onset of dementia has taken up sculpture as an expressive medium. He loves going to a stone-carving studio an artist friend runs and here he has found a way of pouring his strong feelings into this new creative activity. His wife Kate said, "he needs the possibility of being able to be overwhelmed by what he is doing." At other times, Christophe seems listless and bored, but on the days when he goes to the studio he is alert and involved. Sometimes he gets upset because he cannot fully realise his conception, or because of what his subject reminds him of, but he is always deeply engaged by the activity. The resulting sculptures are powerful and influenced by classical and primitive models. A number of the pieces have figures or faces carved on each side, and there has been a gradual movement from the three-dimensional towards more relief work. Christophe has shared a three-person show at

Oxford Dementia Centre, and two works have been bought for the Iris Murdoch Building at the University of Stirling.

Of course, not everyone is going to embark upon a full-scale artistic career post-diagnosis. But in the projects we have funded from Stirling a common characteristic has been the number of people who have taken naturally to new forms of artistic expression, and the high quality of what they have produced. The enthusiasm and concentration shown suggest that, as experienced in the moment, they are indeed having 'the times of their lives', and also challenging our understanding of what dementia as a condition means.

**John Killick**

Research Fellow

Dementia Services Development Centre

University of Stirling

email: e.j.killick@stir.ac.uk

Tel: 01786 467740

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# Making public services personal

**At the beginning of 2003 the National Consumer Council set up an Independent Policy Commission on Public Services to examine contemporary consumer expectations of public services, how these were being met and the nature of conflict between consumer and citizen interest.**

When we reported in April 2004, we concluded that consumer expectations of public services are currently moving quickly ahead of what services in general are providing. The society in which our public services now operate is vastly different to the post-war society for which much of the Welfare State was designed. Traditional structures, such as the way families are organised, have changed. Contemporary society has broken away from previous centres of authority and is defined by much greater social pluralism and diversity of race and culture. The paternalistic delivery of public services, characterised by the 'doctor knows best' relationship between professionals and users, is increasingly challenged in an era of increased individualism where vastly improved information flows fuel the emergence of informed and assertive users of public services.

Yet much of the public service infrastructure remains monolithic, and does not compare well with the standard of services consumers receive elsewhere. Public services need to respond to current demands and be proactive in anticipating future demand if they are to embrace the scale and pace of social change and manage its consequences. If they do not, there is a danger that confidence in public services will decline further and government will find it harder to justify a continued commitment to collective provision through taxation. However, if public services are able to orient themselves to respond to consumer and stakeholder needs as well as acting within the public interest, confidence in them and commitment to them will be restored.

The Commission believe that choice should be introduced as the best way of ensuring responsiveness to consumers. Choice can include economic choices - where money follows users' choices - and non-economic choices - where financial payment is not involved but includes options such as administrative choices and service options. It can also include choice over different types

of service, over different providers and can entail giving users direct budgetary control. We recognise that there are limits on choice as a result of budget limitations or where individual choice conflicts with the wider public interest.

In addition to choice, the expression of voice is critical to empowering users. This covers a spectrum from complaint and redress to full stakeholder dialogue, which the Commission holds to be a critical tool in enabling managers, providers and regulators to balance the conflicts that arise from the allocation of limited resources, and from differing interests. This voice must be heard at the point at which services are commissioned, regulated, inspected and monitored and not just at the point of supply.

When considering an individual's direct influence over public services, the notion of 'citizenship' is problematic when engagement and trust in the electoral process is declining. Voting rights confer very limited influence over the direct provision of services. Alternative ways of ensuring voices are heard are required. Participation in decision-making and deliberation between different interests offers focused and practical ways to ensure the wider public interest is balanced with the needs of individuals.

There is also the possibility that some who use the term 'citizen interest' do so to avoid coming to terms with the potentially conflicting needs of different communities of interest. If public services are to respond to the plurality and diversity of consumer demand, the catch-all, monolithic term 'citizen' is unhelpful. We believe it is more helpful to think about the individual as a consumer, as a member of a wider group of stakeholders and as concerned with the wider public interest.

The Commission examined and tested a set of values that need to underpin modern public services and act as a guide against which different needs can be traded-off, weighted and prioritised. Public values evolve through constant dialogue between the public and the state, but they must also be promoted and embedded through every bit of public service provision'

- Flexibility and Responsiveness
- Fairness and Equity
- Openness and Honesty

- Efficiency and Effectiveness
- Responsibility and Accountability

Alongside these values, consumers pointed to an additional element not captured here that we consider fundamental. Consumers prize an empathetic relationship with professionals who take responsibility for the services they provide. While it may not be possible to legislate for empathy, the Commission believe that if the structures are right, services are values driven, decisions informed by dialogue and professional mindsets can be transformed, empathy will be enhanced. But this will also require competence framework for professionals that embed the kind of relationship-building skills that support consumer choice, into accepted standards of technical competence. Professionals also need to be appraised and rewarded for empowering consumers.

The new demands that consumers are placing on public services have consequences for all parts of the service delivery chain, and indeed for consumers themselves. More choice means greater sharing of responsibility and a more mature attitude to risk. In order to get it right, purchasers, commissioners, providers, professionals and regulators will need to embed the values, develop new and better practice that is truly responsive to consumer needs and open up their governance structures to stakeholder representation. These are big challenges for public services. The changes required are a journey in which the commissioners and providers of services have to make some rapid progress to catch up with already changed consumer expectation. The good news is that during the course of the Commission's work we discovered some truly inspiring examples of what is being done by some and could be done by many.

**Sue Slipman**

Chair, NCC independent Commission on Public Services

1 The Commission conducted an extensive two-stage investigation into these values, deliberating them with a wide demographic and geographical cross section of consumers and with stakeholders from 180 different organisations in four different service areas.

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Making Public Services Personal: A New Compact for Public Services: The independent Policy Commission on Public Services report to the National Consumer Council, NCC April 2004. [http://www.ncc.org.uk/pubs/pdf/poicy\\_commission.pdf](http://www.ncc.org.uk/pubs/pdf/poicy_commission.pdf)

# Keeping it simple

**Fresh air and enthusiasm. That's what makes the North West Community Involvement Network so successful according to its coordinators, Cath Sisson and Kim Lowden.**

The Network has over 350 members across the North West. It was started three years ago and is going from strength to strength. Kim originally recognised the need for individuals working in community engagement to share what they were doing. At that time, people with responsibility for community engagement and patient and public involvement often felt quite isolated within their organisations. We sent out a flyer to each primary care group, health authority and community health council in the North West and asked if anyone would like to join us. We held an event and found people who were keen to get ideas and inspiration to tackle an increasingly complex PPI agenda. Since then we have met regularly.

People struggle with community engagement - particularly excluded groups, but there is some brilliant work happening in the North West. The Network helps us share. We have found it useful for simple things like how to do a baseline assessment. We didn't have to reinvent the wheel. One of the secrets of our success is that the Network is very informal. Members drive the agenda and decide what issues to discuss at each of our networking days. They help us to find speakers who interest or inspire them and attend whichever event is useful to them.

The Network has set up an e-group to enable members to communicate with each other, share best practice, find others with similar interests or ask for help in problem solving. Currently, a lot of members work for NHS organisations, but increasing numbers are joining NWCIN from the new PPI Forum Support Organisations. A significant number also work for voluntary sector agencies. We originally thought that our e-group and Internet discussion forum would provide the mechanism for people to find new ideas and share concerns. We were wrong; the web discussion forum ([www.nhsia.nhs.uk/nwcin](http://www.nhsia.nhs.uk/nwcin)) has proved less successful. It appears that people were, and still are, too busy to 'surf'. Members value, however, the e-group as a means of sharing information. We have found that the regular events provide a safe forum for individuals to explore what

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they don't know in a non-threatening environment.

We try to be professional but in an informal way. As NWCIN does not have a hierarchical structure, we can do that. None of us would claim to be experts as the field is evolving all the time. We have built up quite a lot of trust, which enables members to admit when they are struggling with something and not be afraid to ask others for help. There is always someone who can find a way to sort things. The downside is that some people come to events expecting chalk and talk, our emphasis is much more interactive. You have to be prepared to share - that does not suit everyone.

The Network has always operated with minimal resources. Early on, Hazel Blears (who was then a junior Health Minister) gave us a small amount of funding to get started. The NHS Information Authority helped us set up a website and e-group. Recently, we have got some support from the three North West

workforce development confederations. We have resisted making any charges for events, as that might be a barrier to the people who would benefit most. We run on a shoestring - less than £5000 a year. That covers at least four network events every year and a bit of secretarial support. We are very reliant on members to make things happen - although our organisations are very supportive. People are very generous - speakers give time freely - organisations offer venues and the members do a lot of the legwork. The events include speakers and workshops on whatever is current in community engagement and the PPI agenda. As most of us have a special interest in the involvement of traditionally excluded groups, we spend a fair amount of time looking at initiatives that are successful in that area. We also like to use the events to keep up to date with latest policy initiatives.

One of our members, Eejay Whitehead of St. Helens PCT, has reflected that you would easily pay £400 for a conference programme in London which NWCIN does for free. We have found the Network very useful for finding other organisations to share projects. Burnley Pendle and Rossendale PCT, for example, was keen to do a project involving very elderly people as peer interviewers. Through the Network, two other PCTs were identified who shared the initiative. It was very successful as it reduced costs and produced some leading edge work. This wouldn't have been possible without the Network.

What have we learned? It is important to keep things simple - you need to be free to explore the latest issues. We are not tied down by rigid rules and constitutions. We have a simple terms of reference, agreed by Network members. We are all busy so don't have time for bureaucracy. It's amazing what you can do with a small group of enthusiasts.

**Kim Lowden**

Head of Patient and Public Involvement,  
Knowsley PCT

**Cath Sisson**

Public Involvement Manager, Burnley Pendle  
and Rossendale PCT  
01282 610335 or  
[cath.sisson@bprpct.nhs.uk](mailto:cath.sisson@bprpct.nhs.uk)

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## Last Word from Chris Dabbs



### Dear Mrs. Buggins,

**Here's a thing – what is it that Coca-Cola sell? A dark, sweet, fizzy drink? That is only what is on the shelves. No, what Coca-Cola sell is happiness and warm feelings. And see how Lucozade has been transformed from what you imbibed when ill to a sports energy drink. The focus is not the product, but the consumer.**

Social marketing is starting to raise its profile – at least for public health. This is not about clever advertising, though, but rather using the range of PR and marketing techniques – including community engagement and leadership – for social benefit. It is about listening to people's priorities and attitudes, and then responding to them.

How can Nike and Reebok sell so many shoes at such high prices? They engage the trendsetters – often young people on the streets of poor or "black" areas. Marketing identifies key target groups and then explores their perspectives, culture, role models and language. Some brands actively recruit opinion leaders. Red Bull has sponsored influential students at universities as "grassroots" product champions.

Emotional engagement is essential for a lasting impact. Humour and music, in particular, are used. These can establish a deep relationship between people and brand. Target groups can gain a sense of community through "in jokes", role models or cultural references only they recognise. Using their media of choice also helps.

Effective marketing is not only clear about its message, but remains ready and able to respond swiftly to events, which might be unexpected opportunities or deliberately provoked news stories or controversy. This requires ready availability of savvy people comfortable with the media.

Sure, these mega-corporations have huge marketing budgets. Yet the NHS will soon be spending over £100 billion per year and has over one million potential messengers – disparagingly called "human resources" (yes,

NHS staff). It also has millions of satisfied "customers" and one of the best-loved brands in Britain.

Health-related social marketing can be successful. In Africa, radio soap operas raise awareness about HIV. In Australia, the "slip, slap, slop" campaign changed behaviour to reduce skin cancer. Its developer, Simon Chapman, also subverted commercial marketing through the "Bugger Up" campaign – for example, insertion of drooping fags transformed macho cigarette adverts into messages about reduced virility.

Social marketing can not only influence people's attitudes and behaviour for better health, but also improve their use of health care. In Liverpool, they have improved take-up of breast and cervical screening through "hairdressers for health" and department stores tagging knickers.

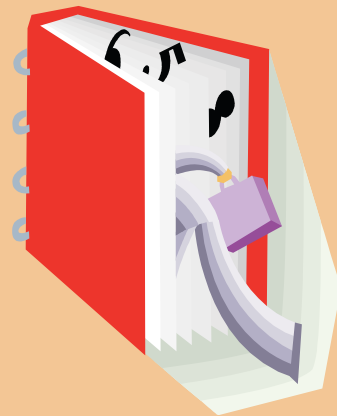
Everyone engaged in PPI now has a major opportunity, especially alongside talented communications colleagues. Both health care and public health practitioners will be interested in the potential impacts of social marketing. Such an opportunity to persuade the NHS "mainstream" of the relevance of PPI!

PPI people – whether professional or unpaid – have most of the skills and knowledge already – networks with local leaders and communities, sensitivity to local issues and concerns, and the explicit role to listen and engage with patients and the public. Maybe Coca-Cola and McDonald's could have competition soon?

keep well

**Chris**

Chris chairs Passionately Curious Ltd, a social business that is a local network provider for PPI Forums.



## 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?

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Share your challenges and successes with other readers.

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