

# PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

## Teething Troubles

### CPPIH Chief promises tough action to iron out Patient Forum concerns

**The Commission for Patient and Public Involvement in Health (CPPIH) remained upbeat and positive this month when faced with a raft of criticism, as concern about the arrangements for running PPI forums begins to bite.**

In an exclusive interview with PPI Monitor, the Chief Executive of CPPIH, Laura McMurtrie said "You have to remember that there are over 1000 people involved in forums. Most people are extremely excited about the prospect of being involved and want to make a difference".

The difficulties recruiting members to forums has always been an issue, and it appears that this has not gone away. Some forums report member 'drop out' even though they have only been in existence since the start of this year. According to McMurtrie "The national turnover rate is running at about 10%. It's difficult because of the nature of forums to do comparisons with other organisations, but from what we can gather, this does not seem to be too bad".

Further concerns are being raised about the arrangements for running the forums. One forum chair told PPI Monitor "many of the problems stem from the appointment of voluntary organisations as Forum Support Organisations, many of which have not got the skills or organisation to do the job".

In response McMurtrie disagreed saying that "Some parts are working better than others and as the weeks go by, the difficulties are becoming fewer and fewer".

The CPPIH is just completing its first round of performance management reviews and McMurtrie issued a warning "we will be very tough with people who do not perform. Contracts can be removed from people".

In a hard hitting assessment of forum arrangements, one forum chair was critical of the process for member appointments, adding "Unlike the NHS itself, forum chairs are not allowed to participate in the interview process for new members, making it impossible to ensure an appropriate skill mix".

According to the source, completing the forum membership is proving problematic "forum membership is not up to speed, and there is no information about when forums will be completed. With members expenses often paid late and a small number of members it is proving difficult to establish special interest groups".

It is clear that the CPPIH has a statutory responsibility to appoint forum members and McMurtrie stressed "we have targets for forum characteristics and a duty to reflect diversity. This becomes difficult when you involve forum members in the appointments process. Forum members may become involved in the future when they can develop more experience about recruiting for diversity".

Rumours of a shake up of the arrangements for PPI were firmly rebutted by McMurtrie, saying "The Department of Health is subject to a major review, which includes all arms lengths bodies and we are just one of these".

A series of 32 workshops with forum representatives is being facilitated by CPPIH to iron out some of the issues raised since their formation and to consider future issues. Feedback from these is expected in June.

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### PPI Tools.

See how Photography can help to elicit the views of the more marginalised members of your local community.

Learn how using diaries can be a useful tool for involving patients and the public in health issues.

### Case Studies.

CPPIH Regional Manager for the North East, Sally Young highlights the practical achievements so far of Patients Forums in this area.

PPI Forum Co-ordinator, Tim Hatton presents a wealth of ideas for others as he presents the story of the first six months working for an FSO.

### This months **Cup of Coffee**

Interview takes a close look at the work of Pals at Oxleas NHS Trust.

### Networks.

PPI Monitor starts a short series of features on the help and support available from Networks for all those working in PPI. This month we begin with Engaging Communities Learning Network (ECLN).

### Window on Wales.

PPI Monitor takes a look at the different approach to PPI in Wales.

And much more.....

# Plague Dogs

It's amazing how much rubbish you can accumulate in your garage. After two years in my 'new' home, I decided that it was time to make room for the car and clear out the junk.

In amongst the piles of old photos, broken MFI furniture and rusty Black & Decker's, there lay a sad, crumpled and dusty pair of Hush Puppies.

You must remember Hush Puppies. We've all had a pair at some time in our lives. This was an iconic brand which almost died. In 1994 sales had plummeted to only 30,000 pairs worldwide. When the President of the firm accepted a fashion award in 1996, the brand was selling nearly two million pairs, yet he had to admit that the company had very little to do with the resurgence of interest. The brand had reached a kind of 'tipping point' where the idea just took off through the power of connectors, mavens and salespeople.

Malcolm Gladwell's best seller *The Tipping Point* – How little things can make a big difference details the Hush Puppies story and describes it as a word of mouth epidemic. Epidemics rely on three basic principles – one, contagiousness; two, the fact that little causes can have big effects; and three, that change happens not gradually but at one dramatic moment. The name given to that one dramatic moment when everything can change all at once is the Tipping Point.

The involvement of patients and the public in health needs to become more like a social

epidemic. A world that follows the rules of epidemics is a very different place from the world we think we live in now.

The Hush Puppies epidemic came about because certain types of people interacted with others in particular ways – that is, the connectors, mavens and salespeople.

Connectors know lots of people. That's not the same as having lots of friends. We often know much of the same information as our close friends. New information is more likely to come from acquaintances. So the best connectors have lots of acquaintances through which they pass information.

Whereas connectors are great carriers of information, they alone do not create a social epidemic. There are people that we rely on to connect us to new information. These are called mavens. It comes from the Yiddish and it means one who accumulates knowledge. Often these people are obsessive about a particular theme and when they speak they carry a high degree of credibility.

Mavens are highly credible, but for an idea to really take off, it needs a persuader or salesperson. These are people who have a particular gift for resonating passion when they are committed to an idea.

These social epidemics occur when there is a high degree of interaction between particular types of people with a strong idea. This process is not linear. It is not structural. It is not formal.

There seems to be a belief that the creation of a Commission, structures, rules and procedures will somehow create that frisson of excitement that will have us all jumping up and down wanting to be involved in health issues. The word on the streets suggests that this is not happening.

We need to think about how to create a social epidemic, using the power of mavens, connectors and salespeople. This is more about judgement than science; it is more about passion than procedures; and it is more about relationships than routines. It requires some thought, some experimentation and some risk. Yet without a fresh approach, the average person will continue to be unaware of PPI, and many of those that know of it will find it as appealing as a plague dog. Rather than a PPI plague dog we want a PPI Hush Puppy.

When I looked at my pristine, empty garage I asked myself why I had been clinging to all of this 'stuff'. It felt comfortable, it was what I knew, it anchored me to the past. Ditching it made me feel anxious. Having gritted my teeth and confined much of my past to a skip I feel fresh, liberated and filled with optimism (incidentally, I also made £225 at auction). It has taken two years to take the plunge. The structures and approaches to PPI forums smack too much of the past. Let's hope that the CPPIH don't wait two years to clear out their clutter.

## 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.

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

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

### David Gilbert

David Gilbert is Senior Advisor Patient and Community Engagement at the NHSU. He was Head of Patient and Public Involvement at the Commission for Health Improvement (CHI). He has worked at the Consumers Association, Kings Fund and Office for Public Management (OPM). He was a Community Health Council member, Chair of MIND in Barnet and user of mental health services. He led the national consultation on the NHS Plan, development of the public and patient involvement strategy in Wales. David's passions are Samuel and Adam (4 year and 4 week old sons respectively), poetry, and (depressingly) Leeds United.

### Publisher/Editor

Malcolm McClean  
Bearhunt, Suite 108  
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 Dabs - Features Editor  
c.dabs@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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# Patient Experience

## Results from a programme of consultation to develop a patient experience statement: final report

The Department of Health is currently developing a 'Patient Experience Statement' that encapsulates how patients would like to experience the NHS, with a focus on emotional responses rather than physical aspects of care. This report brings together findings from consultation with the public, patients and health professionals.

### 1.1 Current emotional experience

Patients and public emphasized that their experience of the NHS tends to occur at times when they are at their most vulnerable and emotional, which heightens the intensity of their emotions, and particularly their negative feelings

- They continually referred to feeling emotional generally
- And there was a strong feeling that these emotional needs were not always met by the NHS

Opinions and experiences differed hugely across the participants; however it is possible to draw out some consistent themes in terms of typical positive and negative feelings. Most commonly identified negative feelings were confusion, disappointment, annoyance and frustration

- Underlying causes were poor communication, long waiting times, condescending staff attitudes and feeling lost in the system

Many patients felt isolated, overwhelmed by the experience and treated like a number instead of an individual. There were numerous mentions of feeling scared, afraid or anxious. These feelings were often attributed to their situation and medical condition but some felt that they were exacerbated by their NHS care (particularly in secondary care)

Many participants also identified positive feelings: feeling cared for, listened to and reassured

- There was a greater incidence of this among participants from the rural, more affluent areas and those in receipt of maternity care

### 1.2 The ideal emotional experience

Differences across the groups and locations largely disappeared in discussion of the ideal patient experience at an emotional level

- There was a very strong convergence of opinion about what would constitute the ideal with patients wanting to feel reassured, confident, cared for, informed, safe and relaxed

Many of these ideal emotions are inter-linked and it is difficult to disentangle them in order to rank them by importance

- However, the notion of reassurance was key – being reassured that they were safe and 'in good hands'
- Also central to an ideal experience was the personal touch; feeling that they were important and 'special'

Staff descriptions of the ideal for patients were very similar to those described by patients themselves

- They indicate that, in many cases, they are aware of how patients are feeling but are constrained by time, resources and the culture of the NHS itself to engender a more positive emotional experience
- Staff concur that the emotional experience is important and should not be neglected

All participants were asked for suggestions on how the ideal may be achieved. Many were cynical about this and felt that it was unlikely but gave numerous practical suggestions on the way forward.

- These centred on how patients are communicated with (in terms of both quality and quantity of information) and changes to the environment (particularly waiting rooms).

Specific suggestions are outlined in Section 6

### 1.3 Response to the draft statement

The response to the draft statement from the public is largely favourable

- It is easily understood, with both the language and sentiment resonating well



with everyone (regardless of age, gender, socio-economic group)

The overriding message is seen as being positive, engaging and inclusive

- It tackles issues that are felt to be important and which are not felt to be current priorities for the NHS

Recommendations focus on fairly minor amendments, such as specific wording or tonal changes

- As some of the male participants were less comfortable with the emphasis on emotions, a more explicit reference to high quality physical care may give the statement as a whole more credibility

The staff were much more critical of the statement, although it is likely that their response is coloured by their perception of new initiative overload in the NHS

- They criticised the statement for being 'spin' or part of an expensive communications campaign
- They were concerned that the statement would raise patient expectation and that they (and the NHS as a whole) would not be able to deliver

Clearly, the dissemination and the positioning of the statement to staff will need to be handled carefully by the DH.

EMAIL: [enquiries@opinionleader.co.uk](mailto:enquiries@opinionleader.co.uk)  
 WEBSITE: <http://www.dh.gov.uk/assetRoom/t/04/07/60/93/04076093.pdf>  
 AUTHORS: Opinion Leader Research

# Click here for better health

**Millions of patients are set to become health experts at the click of a mouse, as comprehensive health information from the British Medical Journal (BMJ) has been launched on NHS Direct Online.**

The Department of Health has been working with the BMJ to make available BMJ Best Treatments, which provides information on the most common health conditions including explanations of the pros and cons of elective surgery procedures, details of other treatments available, and advice on pre-and post-operative care. It also offers information on the choice of possible treatments for 60 chronic conditions, ranking them according to effectiveness and highlighting the risks and benefits of each.

Best Treatments will equip the public with evidence-based information on common surgical procedures, put into language and formats which are accessible, clear and jargon-free. To date this information has only been available to US patients.

This new resource provides patients with the same evidence based information as their doctors, which will support them to make informed choices about their healthcare.

Minister of State for Health Rosie Winterton said:

"We are committed to patients and doctors having access to the same high quality, evidence-based information to support shared decision-making. That's why we're expanding the range of information available to patients and the public by making Best Treatments available on the NHS Direct Online website.

"We are working to provide a modern, flexible NHS that fits around patients' needs and meets their expectations. We know that patients would like more information to support them in making decisions about their healthcare. This is an important step in providing patients with the resources they need to make informed choices."

# Health information delivered to your door

**Millions of people are set to become healthcare experts in their own home, thanks to a new health guide based on NHS Direct information in Thomson Local telephone directories that are being delivered across England.**

Thomson Local directories now include easy to use, step by step healthcare advice and information covering over 25 of the most common adult and child health problems with advice on how to treat symptoms at home where appropriate.

It also contains Department of Health campaign messages such as tobacco education, immunisation and Get the Right Treatment, a campaign that informs people about the range of healthcare options available and how to use local services appropriately.

This unique partnership between NHS Direct, the Department of Health and Thomson Local telephone directories means that the 64 page self-help guide, will be distributed to over 18 million households in England over the next year.

Minister of State for Health Rosie Winterton said:

"This guide will equip people with the information they need to make healthcare decisions. There are now more healthcare options available than ever before, and by making the right choice at the right time, people will get the fastest, best possible treatment. For example, pharmacists are easily accessible and offer a range of services in addition to advising patients.

"Almost 90% of respondents to the Choice Consultation Survey told us that they needed more information in order to make decisions and choices about their treatment or care. This initiative is an important step in responding to people's needs."

David Edmonds, Chair of the NHS Direct Special Health Authority said:

"The self-help guide has always proved popular and demand has always exceeded supply. This opportunity to provide useful health information in telephone directories is an excellent way of making this valuable resource widely available to almost every home in England. It is a cost effective way of providing people with quality-assured, trusted information about healthcare choices."

Linda Pancratz, Chief Executive of Thomson Local Directories said:

"We are very proud to be part of this innovative project. With our widespread distribution and community-focused heritage we are the ideal method to provide this valuable information to over 18 million homes in England."



## Related links

[NHS Direct Online \(external link\)](#)

[Building on the Best: Choice, Responsiveness and Equity in the NHS'](#)

[Developing NHS Direct: A strategy for the next three years](#)

# Choice, choice, choice but do we really want it?

PPI Monitor sets out two opposing views in this month's news review



## First patients offered choice in the GP surgery

**The Department of Health has published a report of studies in pilot areas where patients have been offered a choice of hospital at the point of GP referral for their treatment.**

The research, carried out for the Department by Dr Foster, found that:

- Patients value the offer of a choice of place of treatment – even if they choose to stay at their local hospital
- Offering choice does not significantly increase GP consultation times
- Patients and GPs need accurate, clear information on the different options available in order to choose where they would prefer to be treated.

Patients in the studies were supported by a specially designed website ([www.makingthechoice.org](http://www.makingthechoice.org)), a patient advice line,

and other information to help them choose where and when they wanted to have their operation.

Also today, the Department published the results of a major survey carried out by MORI as part of last autumn's consultation on increasing choice across the full spectrum of health care.

The survey confirmed that patients want more involvement in decisions about their condition and treatment, and more information and support to enable them to make choices. Improvements to communication with healthcare professionals are key. Patients want both detailed information about their conditions and more information about lifestyles and preventing illness.

Health Minister John Hutton said:

"This research gives us valuable feedback as the NHS starts gearing up to put these fundamental changes in place. It raises important issues that we will address as we develop the details of implementation - with the NHS, not for it.

"We are hearing time and time again that information is essential for patients to have real choice. We are already making major investment in IT systems and patient information across the NHS and we will ensure there is no loss of momentum in this programme of reform.

"We will continue to listen and learn, working with patients and the NHS, as we move towards 2005, to ensure that patients are confident that they have the right information at the right time to make the choice that is right for them."

## Choice 'less valued' by patients

**NHS patients want more involvement in decisions about their condition and treatment, but few think that having a choice of hospital - a flagship government reform - is important, research revealed today.**

The government has pledged that from December next year, patients who need an operation will be offered a choice of four to five hospitals when they are referred by their GP.

But findings from a MORI survey commissioned by the Department of Health showed that although three-quarters of those surveyed wanted more say in their treatment, just three in 10 thought having a choice of hospital or doctor was important.

The health minister, John Hutton, said: "This research gives us valuable feedback as the NHS starts gearing up to put these fundamental changes in place. It raises important issues that we will address as we develop the details of implementation - with the NHS, not for it."

The Department of Health was also keen

to stress that the MORI survey was "not a 'population representative' sample but was a self-selecting group".

The survey of nearly 1,500 members of the public and more than 900 NHS staff - carried out as part of a major consultation on choice, responsiveness and equity in the health service - showed that involvement in decisions about treatment was the top priority, cited by 76% of respondents.

Treating patients with dignity and respect and listening to their views were cited as the second and third most important priorities, by 59% and 47% respectively. But choice of hospital or doctor was rated important by just 31% of respondents. A choice of appointment dates and times was more popular, being rated important by 42% surveyed.

The survey also highlighted patients' concerns that without sufficient information, there was little real choice. Most patients (88%) felt they would need more information to make decisions and choices about their

treatment or care.

Patients wanted detailed information about their condition, its symptoms and the range of treatments available, as well as information about how they could prevent illness with changes to their lifestyle. Survey respondents said that information should be unbiased, give the range of options available and be presented without medical jargon or specialist terms.

Mr Hutton said: "We are hearing time and time again that information is essential for patients to have real choice."

The government was investing heavily in patient information and IT systems across the NHS to support patient choice, he said, but would make sure there was "no loss of momentum in this programme of reform".

"We will continue to listen and learn, working with patients and the NHS, as we move towards 2005, to ensure that patients are confident that they have the right information at the right time to make the choice that is right for them."

# Community Health Councils in Wales

## Alive and Well

**Following the demise of Community Health Councils in England, Wales has retained its CHCs and given them greater powers. The difference in approach will no doubt become significant in the fullness of time. Peter Johns, Director, board of CHCs in Wales gives us an overview.**

The Welsh Assembly Government, from the outset has decided to involve people and to consult widely on its policies and plans. It instigated a working group to look at the development of patient and public involvement in 2001 and as a result of that, it decided to retain Community Health Councils in Wales and to enhance their powers. The significant areas of enhancement were the monitoring of NHS bodies' Patient and Public Involvement activity, and the extension of their visiting rights to include not just hospitals and clinics but GPs, dentists, pharmacy and optician premises and care homes and private hospitals where NHS care is delivered. Welsh CHCs have been given what they have been requesting for years, and in addition they have had additional funding to support Complaints Advocates. These Advocates, who are available through each Welsh Community Health Council, are there to help patients and their relatives if they wish to make complaints about NHS services.

Together with all these new developments, Welsh CHCs have considered whether a name-change would help raise their profile and discounted the idea because to start all over again would cost too much and take too long. We have decided to adopt a new logo however, and this is common to all Welsh CHCs.

When English CHCs were abolished, the parent Association of Community Health Councils in England and Wales (ACHCEW) was also abolished. This left the Association of Welsh CHCs orphaned, because it had always sought advice and support through ACHCEW rather than staff up to provide it in-house.

That has now changed. From the 1 April 2004 the Welsh Association has disappeared

and re-emerged as the Board of Community Health Councils for Wales with statutory status. The Board has a staff of six (as opposed to three and a half with the Association), and the focus for these staff will be to support the independent individual CHCs and to satisfy the Welsh Assembly Government that all CHCs are performing their core-functions to an acceptable standard. This will ensure that the public in Wales can be assured of a full range of support at a good standard from any CHC in Wales.

There are tensions in the new arrangements, which need to be worked through however. CHCs fiercely (and rightly) protect their independence to act for people and to represent their views on the NHS. The new arrangements are designed to support and maintain these arrangements but in addition, to require CHCs to show evidence that they are actually doing it. A performance framework for CHCs has been developed and each CHC will review its performance against these statements in the first quarter of 2004. In the first quarter of 2005, an external panel independent of the CHC will conduct that review, and their report will be published (some CHCs have decided to go for the External panel on the first run-through).

The distribution of finances to individual CHCs will also need careful scrutiny so that there is appropriate funding for the activities to be carried out. That is being developed in 2004.

The challenge of finding the physical resources to carry out the extra duties associated with their new powers will also create some difficulties. Initial discussions have been held with the BMA in Wales, Care Forum Wales and Care Standards Inspectorate Wales and the consensus seems to be that there is merit in trying to work with other inspection agencies on arranging visits and for CHC members to be attached to their visiting teams as additional lay members. That would limit the demand on CHC members' time and would limit the



impact on the premises being inspected but the independence of CHCs cannot be compromised by this any more than the independence of the other organisations involved. Work on these protocols is ongoing and will be completed in the next few months.

CHCs have also been involved in carrying out sample inspections in the District General Hospitals in Wales, looking at the Hospital Patient Environment. These visits follow the Trusts' own baseline assessment of these areas a few months earlier. The HPE initiative in Wales is similar to the PEAT initiative in England.

Finally, the new Healthcare Inspectorate for Wales is interested in using CHC inspection visit reports as part of its review of NHS organisations if the reports achieve a consistent standard. This is a further (but welcome) challenge to CHCs to agree and roll out a standard approach to inspection visits across Wales.

All of this is in stark contrast to the picture in England where revolution rather than evolution appears to be the order of the day.

**Peter Johns**  
Director  
Board of CHCs in Wales

## Case Studies

### Case study

# “Managing without Shoes”

Putting an empowering approach into practice is extremely challenging and requires conscious questioning and reflection

**Stephen Young, Revans Institute for Action Learning and Research explains the challenges in moving from a position of developing services for people to developing services with people.**

This article outlines my experience in developing a community based project (The Creative Living Centre) that developed from a vision created by mental health services users who wanted more choice of responses to their distress.

To support me working in partnership with services users to realise this vision, I found that an action learning approach helped me to understand, articulate and explain the many challenges that I faced in moving from a position of developing services for people to developing services with people.

This approach provided me with the space to share my new experiences, feelings and ignorance of how to work in this way. It helped me to ask questions and reflect on key issues providing valuable insight about what to do next.

As nurse by profession I have worked in the NHS for 33 years and have had a wide range of experience both as a manager and a clinician.

“Managing Without Shoes” is a metaphor that refers to how uncomfortable and vulnerable I felt when I became involved in the development of an innovative community based project called the Creative Living Centre, and vividly recalls a real moment in time.

The centre supports people who have experience of emotional distress/mental health problems, in a way that provides the space to identify their own needs and make informed choices about how those needs might be met.

This unique service provided by the centre has a very clear person centred holistic philosophy. Each person is encouraged to make their own choices from the activities

available. In this way the individual becomes actively involved in improving his or her well-being.

Initially each person is offered an appointment where they are introduced to the centre and our approach. They are given the time to discover and express what their needs are and identify their starting point. Each individual finds their own path through the many opportunities available to them.

The health and well being of each individual is seen within their life context. The individual is treated as an integrated whole and seen as multi-dimensional. Illness is seen as an opportunity/need for change and growth, the potential to move towards more wholeness within ourselves; the need for greater integration as opposed to the removal of dysfunction.

The provision of complementary therapies promote natural healing and encourage the bodies own healing abilities. They work to treat the underlying cause of disease as well as the symptoms. This helps to create long-term health changes as well as promoting the prevention of illness and providing support to maintain health and well being. Because the therapies promote natural healing they are able to spark changes of awareness and insights for the member.

Many members become volunteers as part of their recovery process, helping to support the work of the centre. They participate in a training programme which is accredited by the Greater Manchester Open College Network

This empowering approach is easy to state, but putting it into practice is extremely challenging. It requires conscious thought and action about the relationship between giver and receiver of care so that people using the services on offer do not become passive recipients. The relationship needs to be a partnership, with each partner working as co producers.

Throughout the development of the project I

was exposed to so many new experiences, the first of which was being asked to take off my shoes. These experiences although uncomfortable in the first instance prompted in me a process of reflection. This led me to question the way I have undertaken my role, which at the time was as Director of Service Development at a mental health Trust. I realised that in developing new services I undertook this work for and not with the people who use mental health services.

This work has challenged me in many different ways and I have learnt to be creative, thinking outside of the box, and developing a “can do” view of life. This is underpinned by continued questioning and reflection both individually and collectively with members, volunteers and staff at the Creative Living Centre.

Although along the way there were many new experiences, both positive and negative. The negative experiences were as valuable as the positive, in that they provided prompts for further questions and reflection through which explanations and understanding could emerge.

Throughout this journey, one personal learning point was discovering how much I have been influenced by the external environment and expectations of the NHS and how this has constrained my thinking and behaviour.

So if there is a single message it would be to consciously think about how you might create the space to question, reflect, learn and take action to consider how you and your organisation might identify and remove the barriers to involving service users. Perhaps action learning is an approach that might help you!

**Steve Young**

Visiting Fellow, Revans Institute for Action Learning and Research Salford.

Email: [syoung@bl83ep.fsnet.co.uk](mailto:syoung@bl83ep.fsnet.co.uk)

## Case Studies

### Case study



**Shaping Health**  
Better decisions  
Better health

## PPI - The North East

**PPI Forums seem to have hit the ground running in the North East. PPI Monitor asked Sally Young, CPPIH Regional Manager in the North East to give us an insight into their experience so far.**

A new concept, new staff, new premises, new volunteers – easy – at least according to the Department of Health. Last year, a whole new concept and way of working in patient and public participation was set up with the establishment of the Commission for Patient and Public Involvement in Health. This was seen as the final piece in the jigsaw as highlighted in the NHS Plan (July 2000).

It's probably worth highlighting the problem identified in the NHS Plan:

"Patients are the most important people in the health service. It doesn't always appear that way. Too many patients feel talked at, rather than listened to. This has to change. NHS care has to be shaped around the convenience and concerns of patients"

This statement was applauded by the many people – users, carers and staff – who had been involved in patient and public involvement over the years. It captured the sense of the public who had lost their faith in doctors (Shipman, Bristol heart consultants, etc.) and reflected the shift in public services where the user should be seen not just as an active consumer, but also as a participant in the decision-making process.

The Plan established a set of new systems:

- Section 11 – legislation putting a duty

on the NHS to consult and involve

- Patient Advice and Liaison Services (PALS) which provide information and support within a Trust setting
- Overview and Scrutiny Committees – giving democratically elected councillors a voice in the health service
- Independent Complaints Advocacy Service (ICAS) – providing an independent, comprehensive support system to NHS complainants
- Commission for Patient and Public Involvement in Health (CPPIH)
- Patient and Public Involvement Forums (PPI forums)

The task given to the Commission nationally involved it in setting up nine regional offices from 1 September, taking on new staff from 1 September, establishing over 160 contracts with voluntary/not for profit organisations and recruiting 4000 volunteers by 1 December. The word 'Herculean' comes to mind.

The experience in the North East of England of the Commission and the PPI forums has been interesting, and the experiences encountered might be helpful to others. The North East area has the lowest number of trusts (30) and therefore 30 PPI Forums. There are two strategic health authorities, an active Government Office (GONE), a regional development agency (ONE North East), five unitary authorities, five metropolitan districts, two county councils, 13 district councils and a number of very strategic partnerships.

People in the North East have a strong sense of identity and take great pride in the region. It is not surprising that the North East will be one of the first regions to vote for a directly elected regional assembly. North East communities look enviously at Scotland and its Assembly to the North and often feel very distant from London and Whitehall – Edinburgh is half the distance of London. The North East has a strong industrial heritage and has had to move rapidly into the service sector. There has been significant regeneration in the area and many places still retain a strong sense of community.

However the lever of post-industrial unemployment (which is often disguised as 'unavailability for work'), the skills shortages and the slow rate of economic growth should not be minimised. This reveals itself in health statistics:

- the worst health in the country
- the highest chronic illness rate
- the highest levels of poor health
- the highest circulatory disease rates
- and the highest teenage conception rate

The North East was the first region to recruit eight members on each PPI forum in November because we worked on a programme of community outreach. As well as the national and local advertising campaigns, we spent time visiting the many community, voluntary and neighbourhood projects and groups in the area. A number of our forum members have not had any formal experience in health groups, but have been involved with their communities. We also have forum members who have previously been community health council (CHC) members and/or have worked in the Health Service. There is an application and interview process which is applied systematically: weight is given to members who have an

# Case Studies

## st Experience

understanding of and links to the wider community, diversity issues and the need to take on the views of others. The most common reason for applicants being turned down was focusing on a single issue.

The North East has a relatively low proportion (3%) of people from black and minority ethnic communities. Most health evidence shows the health status and experiences of using services are much lower for people from BME communities. An active attempt was made to encourage applications from the 75 000 people who live in the North East. We were particularly pleased to recruit two members from the orthodox Jewish population who are based in Gateshead.

We recognise that amongst ten members of a forum, you will not achieve representation of an NHS trust's community. However the role of the forum is to identify those communities who are marginalised, who don't get involved for whatever reason – rurality, disability, poverty, race, age, etc. and to engage directly with them. A diversity questionnaire has been sent to all forum members across England so they can look at the features of their own forums and start to develop contacts and relationships with other groups

Just to add to the complexity, not only was the Commission new, we have contracts in the North East with six existing voluntary / not-for-profit organisations to provide services to support Forum members. These organisations had to recruit staff, establish premises and generally develop themselves. Some forum support staff are very experienced (from the voluntary sector, former CHCs and the Health Service), for others it is a completely new area of work. We provide training, support, guidance and information to the forum support organisations (FSOs) so that they can, in turn, support the forum members.

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The 30 PPI forums themselves are, inevitably, developing at different rates. Each has ten people, who maybe share no other common feature except an interest in health. The forums are artificial constructs, members don't necessarily share common views and beliefs, they are not campaigning around single issues and they have different backgrounds in relation to health experience. It is, however, precisely this diversity and challenge which can make forums different. During our Welcome Days (training sessions) with members, the emphasis is put on being a 'doing' group, not just a series of meetings. Members will obviously have to build up a bank of information of health services and structures, but their key role is with local communities and they are expected to act as a conduit for those communities. Measures of success will not be meetings attended, but the changes made as a result of their influence and input.

Most forums in the North East have been meeting since January; a few wanted to start before Christmas. In three months they have:

- started to develop as whole PPI forums, rather than a group of individuals
- met with trust chief executives, chairs, PPI leads, overview and scrutiny leads
- met with directors of public health to look at the key health issues in their area
- looked at primary care out of hours services and made recommendations about the information given to communities on local services
- engaged with the NHS trusts that are proposing Foundation status; in

particular commenting on governance arrangements

- been involved in the Healthcare Commission (CHAI) review process
- engaged in national consultations and regional events on general medical services, changes to the complaints system, health care standards, and information on choice
- met with strategic health authority representatives to discuss major changes within Tees area (the Tees Review); with some forums agreeing to act as the consultative vehicle for their area
- met with strategic health authority representatives in Northumberland, Tyne and Wear to discuss proposed changes to maternity services – and advised on the consultation process
- started to engage in the Choosing Health consultation and took those discussions into the wider community, using individual and collective networks.

Forum members are volunteers who receive no payment, only expenses for travel and care costs. For forums to work and make a difference, we need to recognise the contributions that people make and use their genuine collective goodwill to improve patient experience.

Sally Young

Regional Manager

North East Regional Centre , CPPiH

0191 448 4304

sally.young@cppih.org

# Case Studies

## Case study

# Supporting the Patient and Public the first six months

**Last September, when I was offered a position as a temp to work on a new project that Age Concern in Nottingham had just been commissioned to carry out, I was keen to get involved. I had always wanted to work for a charity and project management also appealed. Previously I had worked in Sales and Marketing in the private sector and had been looking for a change, so a new job, working in the voluntary, not-for-profit sector seemed to be a good opportunity.**

CPPIH commissioned Age Concern to manage seven forums in South Nottinghamshire. They are:

- East Midlands Ambulance Service (EMAS)
- Queen's Medical Centre University Hospital Trust
- Nottingham City Hospital NHS Trust
- Rushcliffe PCT
- Gedling PCT
- Broxtowe and Hucknall PCT
- Nottingham City PCT

The idea was that I would start the ball rolling using my sales and marketing experience, while the rest of the team were recruited. Initially, I had no idea what Patient and Public Involvement (PPI) was, as the Commission for Patient and Public Involvement in Health (CPPIH) was the first of its kind anywhere in the world. So my first job was to learn what the acronyms meant, before explaining to everybody that I met what CPPIH stood for, and what its aims and objectives were.

My sales and marketing experience were invaluable over the first two

months, while I was working alone trying to promote and recruit members for the South Nottinghamshire area. Having been briefed on my tasks, my manager and I developed an action plan on how to spread the word and encourage people to apply to become a member of their local forum.

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My first month was spent packing PPI leaflets, posters and explanatory letters, before manually addressing and stamping envelopes to as many voluntary and community groups as possible. We felt that these mailings would reach the people that would be interested in health and hoped that they would apply to be a forum member. For that first month, I didn't have my own office, and used any office space that was available.

At the same time, I organised numerous promotional stalls around Nottingham in areas where we felt we could reach out to people from a variety of backgrounds. Consequently, I arrived early in the morning, with my display board, tape, drawing pins, balloons, leaflets, stickers and pens hoping to

attract members of the public to become forum members. These promotional days included a day in the Victoria Shopping Centre (the main indoor shopping centre in Nottingham) with my bag of tricks and a colleague dressed as a yellow chicken; an afternoon at the Indian Centre in Hyson Green (and a curry); a morning at the Pakistan Centre to meet the elders (and another curry); two trips to the local Universities for their volunteer recruitment fairs; as well as stalls at Health Events, in libraries, supermarkets, council offices and leisure centres. In fact, I went anywhere that I felt members of the public could be encouraged to get involved.

By October the PPI Team was starting to take shape as my new colleagues started to join. We organised an open day event for members of local Self-Help groups and arranged to attend meetings where we could do presentations on PPI. Meanwhile, I was helping CPPIH to interview potential members in Lincolnshire, North Nottinghamshire and Northamptonshire.

We were now into November and the rest of the team were recruited and actively promoting PPI. We were still homeless and moving from one office to another depending on where there was space.

In between organising presentations, promotional stalls and helping with recruitment the team was out canvassing daily. We split into groups and visited every village and district within South Nottinghamshire to distribute leaflets and application forms to dentists, opticians,

# Case Studies

## Involvement Forums (PPIF's) –

GP's, chemists and charity shops. We had no idea that door-to-door sales would be part of our remit, but we were still trying to help CPPIH reach its target of a December deadline. Recruitment was proving to be a slow process, but we were thrilled that all seven forums had at least seven members at the start of December - our first target had been met.

Once each of the Forum Co-ordinators had a list from CPPIH of our members, we sent a welcome letter, followed by a phone call to introduce ourselves. The first informal meetings were held in mid-December at venues around Nottingham where each forum member was given an Introduction Pack. These included the PCT's Annual Reports, Guides to Local Health Services, CHI reports, PCT publications, copies of a Reference Guide for Members, PALS and PCT information. By January / February, new forum members were being offered places on the forums, which soon grew in size to 10 or 11 members. Eventually we moved to our new offices in mid-January and started to buy office equipment and assemble furniture and shelves, before our computer equipment arrived.

Since their initial meeting, the forum members have been meeting every 3 or 4 weeks. As a Forum Support Organisation (FSO) we have been responding to the forums wishes. The Forum Co-ordinators assist the members in liaising with NHS authorities, set up meetings, facilitate them if required, carry out research and generally co-ordinate whatever is requested by the forums. If they need any training we try to organise it: so far, we have organised training on subjects as diverse as General Overviews on the different Trusts, Commissioning, Finance, GMS Contracts, Health Inequalities, Pharmacy Applications and Clinical Governance. Forum members have been on visits to EMAS headquarters, local hospitals and Health Centres. Other forums have

met the boards and Senior Management of a number of the Trusts and voluntary groups. We have also arranged a number of Team Building days. This week we will be facilitating a Chair's meeting which two members from each forum will be attending.

Forum members have been invited to a number of health events. These included the "Celebrating our Success" Conference at East Midlands Conference Centre, the "Choice" event at the Christian Centre in Nottingham and the "Stroke Awareness" event at Nottingham City Hospital.

We are currently planning our PPI Conference for June 2nd. This is aimed at the seven forums that we co-ordinate but we are also inviting Nottinghamshire Healthcare Trust PPI Forum from North Nottinghamshire, as many of their buildings are in our geographical area. The aim of the day is to give something back to our members as they are volunteering their time willingly.

We have arranged for Sharon Grant (Chair of CPPIH) and Helen Dillistone (East Midlands Regional Manager) to speak at the event. We have also arranged for representatives from NHS Direct, PALS, OSC and ICAS to give presentations about their organisations and how they will work with the PPI Forums. We hope that the day will provide our members with valuable knowledge as well as the opportunity to network with health professionals and other forum members. We will also ensure that the Press are involved to



publicise the event and raise the profile of PPI both locally and regionally.

At the moment, the Team is extremely busy, as it is year end. We are using a wide range of skills to co-ordinate, motivate and communicate with our forum members. We are in the process of completing various pieces of documentation to gauge the progress of the Forums and the Forum Support Organisation. It is also time to produce the Annual Report and Accounts, the forums are finalising their Work Plans and setting up working groups. This is a very demanding and exciting time for all of us, as well as a very steep learning curve. The forums are learning, and we, as an FSO, are still learning as well. As a team we are moving forward, and are looking forward to working on our Work Plans. Compared to September, things have certainly progressed.

**Contact Tim Hatton, Tel: 0115 919 5819**  
Nottingham City and Broxtowe & Hicknall  
PPI Forum Co-ordinator

# Take a Camera and Capture the View

## Using photography as a PPI tool



**Matthew Priestley, a photographer from Manchester successfully used photography to elicit the views of the more marginalised members of the local community in Bolton about how spending could be targeted to improve health**

Photography, unlike other art forms, is one that the majority of people have experience of. Most people own a camera or have access to one and have taken pictures during the course of their lives. Taking and looking at photographs is an enjoyable, fun and often emotionally engaging thing to do and for these reasons makes it an ideal medium for engaging groups and individuals on a wide range of issues and subjects.

For the last four years, I have collaborated with a variety of agencies in the north of England running community photographic projects. The work has been inclusive in terms of age, ethnicity and disability: groups of older and younger people, those with mental health problems and people with learning disabilities have all been involved. Much of the work has been located in designated regeneration areas and in many cases have been targeted at “hard to reach” groups such as socially excluded young people. The projects have proved a useful tool in bringing such groups into contact with statutory organisations, including local authority youth services, employment agencies and training initiatives. Projects have also been devised to encourage local participation in the planning of regeneration works. Communities often feel “done to” by statutory authorities but positive and genuine engagement in this process has been shown to deliver feelings of ownership.

In addition to providing a tool for engagement, the resulting photographic

work has also been exhibited in art venues, including the prestigious Lowry arts centre. Such events can produce great feelings of achievement and pride amongst the exhibitors and can also highlight to other sections of the community what has been achieved.

During 2003, I was invited to run a project with a group of ten adults in Bolton, all of whom experienced severe and enduring mental health difficulties. In connection with the Government’s Social Regeneration Budget, the local authorities were keen to elicit the views of the more marginalised members of the local community about how spending could be targeted to improve health.

I ran two sessions with the group. The first looked at basic photographic technique and compositional skills. Using instant Polaroid cameras the group were asked to complete a simple photographic brief that focused on shape, pattern and textures in the surrounding environment. The work produced was then evaluated. Group members were then given disposable cameras and asked to go away and document their day-to-day lives with a focus on health and well being issues. Guidance given read:

“This project is all about you and your health, where you live and what you do. It is about photographing the surroundings, activities and people in your daily life. It is about showing through photographs what aspects of your lives you consider to be healthy and unhealthy”.

Cameras were then collected and films processed. I then returned and ran a second session with the group. Together we evaluated the results

through group and individual discussion. Members were asked why they had taken particular photographs and how the contents related to health matters in their lives. Some of the observations were very poignant and provoked many debates around issues of health and better ways of living. As a group we then chose 24 images for an exhibition that was to take place at the local town hall.

The project was heavily reliant upon group participation / contribution and the resulting exhibition was part of the process raising self-esteem among a group of people who are usually the recipients of services rather than the creators or providers.

The possible applications for photography within patient and public involvement (as well as health promotion and development) – whether it be exploring very specific issues with certain groups or looking at more general issues – are vast. It has universal appeal and the resulting photographic work can be used to communicate views and thoughts, encourage debate and discussion and stage public exhibitions.

Matthew Priestley is a freelance photographer based in Manchester. He undertakes both public and private commissions and provides training to individuals or groups wishing to use photography within their work.

Tel 0161 881 2265  
e-mail [matthew@chorlton.com](mailto:matthew@chorlton.com)



# Using diaries as a method of collecting information

**The move towards integrating the thoughts and experiences of people who use services into the planning and delivery of these services means that gathering this information is an important activity for Trusts and other service providers.**

Quantitative methods of inquiry appear to be well suited to questions about the more concrete aspects of a subject. Concrete facts like the number of people in a treatment group or the number weeks a patient has to wait now, as opposed to last year, for treatment appear to utilise this method to it's strengths. More abstract information however, like beliefs and attitudes, do not fit nicely into numerical systems and do not produce easily displayable quantitative data. Einstein summed this up by observing that not everything that counts can be counted - and not everything that can be counted actually counts.

The acceptance of qualitative methods as legitimate approaches to gathering information has grown in recent years and there are benefits to using qualitative techniques when attempting to examine the experiences, feelings and perceptions of people in various settings. Several different qualitative methods of data collection have been used in recent years including interviews, focus groups, "video boxes" and diaries.

Although not used anywhere nearly as often as interviews for collecting data, the use of diaries can offer a useful method for collecting ideas and information. The use of diaries for the study of individuals and groups is, of course, not a new concept, data collection throughout history has included the study of autobiographies, histories and diaries. Some researchers describe the benefits of diaries over other forms of information collection in certain circumstances. They state that diaries offer the opportunity for diarists to record thoughts shortly after the event, which they suggest is more accurate than the information through recall at an interview. They also state that although diaries are more expensive than some research methods they are in fact cheaper and less time consuming than repeated interviews.

In healthcare diaries have been used to good effect in gathering information from patients and relatives on a wide range of conditions such as autism, continence, Chronic Obstructive Pulmonary Disease, alcohol misuse, postsurgical recovery, angina, lower limb fractures, epilepsy and migraine.

It is claimed that when used in cooperation with discussions with participants a diary can be used to record data that might not be forthcoming in face to face interviews or other data collection encounters. The structure of diaries may vary according to the information required and although they may be completely unstructured, they are more likely to be successful if subjects are asked to make entries about some specific aspect of their care or experience.

Systems of analysis for diary data can be similar to, or modified from, that for analysing interview material and the computer software used to help in analysis of interview transcripts for treatment ( such as Nvivo or Nudist ) can be used in data analysis of diaries when looking for recurring ideas or themes in the entries.

The benefits of diaries as methods of collecting information are seen to be :-

- Patients and relatives can complete them at a time convenient to themselves
- They offer the scope for more complete answers than most questionnaires
- The completion rate is often comparable to questionnaires
- They give a longer time frame for collecting data than the traditional snapshot offered by interviews
- They allow the diarist to use their own language to describe an experience



The drawbacks to using diaries for data collection include

- It is often difficult to verify information or opinions presented in diaries
- The quantity and quality of data collected can vary considerably from diary to diary
- Diaries can have high levels of incomplete or missing data
- It is often difficult for the diarist to seek clarification about the questions asked in the diary or the information required as they complete the diary.

More and more , Trusts are being asked to collect data from their patients, clients and relatives in line with the Clinical Governance agenda that goes beyond "number crunching" and statistical analysis, and focuses on the involvement of carers and patients in questions about quality of care and the actual experience of being treated by services. It may well be that diaries completed by people who actually use the services can offer a more complete view of service provision over a period of time then could be gained from the more commonly used questionnaire or interview.

**Alan Pringle,**  
Health Lecturer, School of Nursing at the  
University of Nottingham.  
Contact [Alan.pringle@nottingham.ac.uk](mailto:Alan.pringle@nottingham.ac.uk)

## A CUP OF COFFEE WITH...

Chrissie Strickland, Head of PALS and User Involvement, Oxleas NHS Trust

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

**Chrissie Strickland doesn't look surprised when I explain that I have no idea where Oxleas is. If you are like me you will have by now conjured up an image of dreaming spires and Oxford dons.**

She explains "It's on the south east London/Kent border. Covering Bexley, Bromley and Greenwich". This really is not a good day for my geography. In trying to compensate for my ignorance about the location of Oxleas NHS Trust, I begin to wax lyrical about the beauty and style of Greenwich.

Chrissie patiently puts me right on this one too "there are some very deprived neighbourhoods. It's the place where Stephen Lawrence was killed". Definitely not my day.

Anyway, the trust grew out of Bexley hospital, originally one of the old asylums, and is a mental health & learning disabilities trust. When Chrissie Strickland moved from a national post with MIND, to become a local MIND director she began to establish links with the trust.

In 2001 she was seconded to the trust to set up a pathfinder project around patient experience, a post which was to become permanent. She said "We weren't using patient experience as an evidence base at that time. PALS is a systematic way of gaining views on the patient experience".

"Whether individual views can be taken as an evidence base is an interesting argument. It depends upon the value you place on individual evidence. It has to be given a momentum to be given weight". The value of PALS is that it pulls together individual problems and concerns, thereby providing feedback to the Trust on common themes

She joined the trust with a clear vision "we had a particular model in mind. It is about being proactive and going out and finding concerns. You can't sit at the

end of a phone and wait for people to call expecting this to be indicative of the patient experience".

Now, with three PALS officers and an administrator in her team, the service is really taking off, covering mental health, learning disabilities, forensic psychiatry, and CAMHS. She appreciates her infrastructure "There is a huge variation in the way that PALS has been configured. Some have just a single person, some blend

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it in with other posts whilst others use volunteers. I feel very fortunate that our trust has supported it in the way that it has".

Clearly, mental health patients have complex on-going medical and social problems, and this client group presents particular challenges for the PALS service "On occasion, patient's perceptions of reality may differ from what we would regard as the norm, that does not necessarily mean that their issue isn't real".

Her team are proactive. They conduct

regular ward surgeries and run a freephone service for patients wanting individual appointments. Their presence on wards is about trying to establish a profile so that both staff and patients can feel comfortable with the service. She says "You have to pay for this. They have to be highly skilled to work as go-betweens to facilitate a resolution between patients and clinicians".

At Oxleas, the development and refinement of a PALS management information system has been an important issue. Everything is put into a database and analysed by themes and locations. Reports go to the clinical governance board, the user council and in time will go to patient forums. Not satisfied with this, she adds "We found out that the coding system could be refined even further so that we can do more detailed intra-organisational analyses. We want to pick up common themes whether from complaints, incidents or PALS activity".

Common themes are staff attitudes, information about diagnosis and treatment and care and treatment issues.

Describing herself as 'a leftover from the sixties', Chrissie Strickland is about making a contribution.

She is pleased that PPI is now firmly on the NHS agenda, but warns "the crunch is yet to come. There has been an awful lot of talk about the patient experience, but the effort so far has been on systems and processes. At some stage we have got to get to grips with what the users are saying".

It seems that they are certainly getting to grips with it in Oxleas. If you are ever in the neighbourhood pop in and see what they are doing – just off the M40, follow the signs for Oxford.....

# Jargon is here to stay

**Ron Peponis, NIMHE Mental Health Service User Development Champion argues that Users who are serious about representing their fellow Users need to learn the jargon and that training in this area could make a world of difference.**

Sadly ole' Charlie is no longer with us. He was a character in the Surrey area mental health user movement for years. He was a Londoner stranded in the shires after the war with no family left in London and no reason and no where to return. He had been an on and off user for years when I first started in local user representation in South West Surrey. I had been elected leader of one of the new local super user groups that were forming in the early 90's. Like loyal sheep we followed the lead and even named our group The Heathland's User Group (HUG), in anticipation of the soon to be formed Heathland's NHS Mental Health Trust. Membership rose to over 500 in less than a year.

I showed up a little late one evening to a local Community Health Council (CHC), meeting. It was chucking it down outside and I slipped in the side door to the rather ornate Farnham Road Hospital board room. Spotting Charlie I went over and sat down next to him. I asked him how it was going and he said, "We're in deep trouble brother". Strange comment I thought, so I asked him what he meant. He pointed and said, "See that guy in the suit at the head of the table; he thinks he's a chair". "A chair" I said. Charlie was quick to reply, "Yeah a chair, I'm not making this up, he actually stood up and said I will be the chair tonight". Charlie wasn't an intellectual giant. He was just an ole' fellow who had little experience of meetings and all the terminology that goes along with this world of committee working. Later in the meeting I tried to ask a question and was politely told that CHC meetings were held in public, but they were not public meetings, ergo questions could not be entertained. Charlie and I looked at each other and just got up and walked out. "Well that was a waste of time", I said and as we left he pointed to the table at the back of the room and said, "But son, did you see those trays with sandwiches and biscuits, tea, coffee and orange juice, maybe we should stay for the goodies".

Over the years I've learned that many mental health service users have problems with much of the terminology and working practices



I've learned that for every meeting with a user present, professionals attend twenty without users. I continually hear users and even some professionals say that we need to eliminate jargon. There's a better chance of eliminating the air we breathe.

employed by organisations such as the CHC and I hope the Commission for Patient and Public Involvement in Health (CPPIH), takes a long look at the failings of the ole' CHC. Terms like quorum and agenda, the inner workings of sub committees and mapping exercises. Raison d'être is a good one. Some big cheese from a national charity laid that one on us at a meeting once. We all looked at each other in puzzlement and someone said it means that users and carers are important. Then one of our group made one of those statements that only users can make, "Well

why didn't he just say that"? Over a decade later I've learned that for every meeting with a user present, professionals attend twenty without users. I continually hear users and even some professionals say that we need to eliminate jargon. There's a better chance of eliminating the air we breathe. We made a CPA training video some years ago. It was a hilarious send up of an interview between a local newspaper interviewer and a trust director. The interviewer asks the director if jargon wasn't confusing and the director replied, "Absolutely, that's why we use plain English jargon in this trust. You have to understand, we have CPNs meeting with ASWs at the CMHT in an MDT effort to"... That wasn't jargon, it was a language. A language that users who are serious about representing their fellow users need to learn if they hope to be effective. The best way to learn is through proper training and I hope the CPPIH will also look at this crucial area of public involvement. Oh yeah, *raison d'être* is a French phrase that means reason or justification for existing.

**Ron Peponis**

NIMHE Mental Health Service  
Development Champion

# 'PPIH' - What is it all for?

Bob Sang, Independent Consultant, Sang Jacobsson Ltd shares his view of the world of PPI.

## 1. Beware of Labels, Boxes and Good Intentions

In the early 1980's 'People First', the self advocacy network run by and for people with learning disabilities, produced a T-Shirt with the logo 'Label jars, not People'. Having fought and won the battle about the term 'mentally handicapped', with its strong association with social policies based on and social exclusion of their fellow citizens, people 'with learning disabilities' were incarceration still stuck with the persistent dilemma of labelling – a dilemma that lies at the heart of our work of catalysing much greater patient and public involvement in health.

In this contribution to PPI Monitor, I want to remind readers that people involved in PPI are merely at the beginning of the beginning – there are legacy issues and deep contradictions entailed in our work. Indeed, the twin threats of marginalisation and tokenism have never been greater, and even the most committed 'PPI' practitioners are at risk of becoming part of the problem not part of an emerging set of solutions. If such issues are not addressed, I fear the result will be a failure to put the recent legislation on patient and public involvement in health to good and appropriate use. As the title of this piece indicates, this is a matter of purpose, ideas, ideology, language and practice.

Take a step back and reflect: does not the very term 'involvement', in health and in all other domains of public service provision, seem a bit bizarre? People are involved: it is their health, well-being, safety, security, environment, etc. We, the people, elect the politicians, access the services, hold officials to account, and even take an active part in the governance of health and other public services .. don't we? It is our experiences that inform service improvements, and our views that shape policies and planning .. don't they? So, why bother? Especially, why bother with, and within, health? We are involved in health: our involvement may be dysfunctional and even unhealthy, but it is our health .. isn't it?

'Involvement' is a distinct process and

concept - not a function; it is a way of working and learning together, and there is a need to be clear about the concept whose underpinning notions and purposes we think we understand equally. It can be seen already that failing to address the fundamental purposes of involvement in health is resulting in a narrow, instrumental and well intentioned growth of 'PPIH' – a label that can be conveniently 'boxed' by organisations into a single function or job role: "PPI? leave it to the PALS officer". A trend that my colleague Barbara Edmonds of the Council of Ethnic and Minority Voluntary Organisations (CEMVO) has helpfully called 'managerial involvement'.



## 2. 'PPIH' Out of the Box: Establishing Clarity of Purpose

The very first principle, in order to steer clear of the 'PPIH' functional box, is that it is local people who will decide what involvement means. The legislation makes it clear that local people are to take part in every aspect of the involvement process, which means defining the nature of involvement too. (See also the Department of Health guidance 'A New Direction of Travel. Keeping the NHS Local', Spring 2003) The legislation makes 'PPIH' everyone's responsibility, whether we are learning from individuals' experiences to improve services, or working together to find ways to ensure healthier futures for ourselves, our friends, and neighbours – especially those most at risk of poor health. Improving health and improving services are the basic purposes of 'PPIH', but in order to ensure that we, as fellow citizens, can achieve these purposes, the public processes of governance, decision-making, and fair redress when things go wrong also need to be opened up: so we could add a third purpose 'improving accountability'. The following framework is suggested:

There are two problems with such a framework: first it does not reflect the

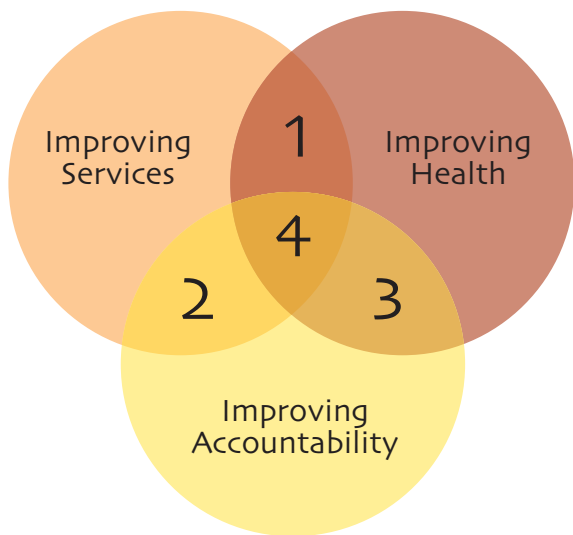
relative scale and scope of these inter-dependent domains and their levels of [dis]connectivity; second, it does not help us to consider how we are to focus our efforts in very different local context. However, it does help us to create a vision of the system that local people can craft, and the skills and qualities needed to build and sustain it.

The managerial solution to the growing challenge of achieving authentic, contestable community engagement (ie, the collectivisation of the above key roles) has been to rely on key individuals, such as PALS officers and PPI managers, and to resort to the use of toolkits and quasi social-scientific methods such as surveys, polls, and focus groups. As many of the readers of the PPI Monitor will recognise, such interventions risk producing alienation of local people rather than their involvement. Means of extracting information from people, for organisational or institutional purposes, should not be confused with involvement that is meaningful and productive of demonstrable improvement and real public accountability.

'Managerial involvement' creates tokenism through a focus on the above interventions, and avoids the need to recognise the qualities and skills that are being developed by practitioners in the field. At present there is a relatively small, loosely

# A Challenge to us all

Fig 1: Involving & Improving: Clarifying Key Roles



**Key Roles**

- 1 - Active, informed patients and carers
- 2 - Constructive Consumers
- 3 - Citizen leaders and good neighbours
- 4 - PPIH facilitators

come from mutual understanding created out of mutual challenge. To attempt to define involvement work as being the conduct of surveys and focus groups is facile and unhelpful. If people are going to trust the processes of involvement and improvement, they will learn to become full partners in those processes and, in so doing, they will transcend the deep paternalism of the NHS and wider public sector. And,

networked community of PPI practitioners whose facilitator roles can be seen as a powerful synthesis of organisational development, community development, and intrapreneurship. They are working in partnership, where possible, with committed social entrepreneurs from the community and voluntary sector and together are beginning to develop the relationships and deal with the complexities that make for meaningful/ impactful involvement. For the past few years I have been working with networks of such 'cultural pioneers'. Their commitment, willingness to learn, and their courage, is astonishing when we consider what they are taking on: for example, in developing a comprehensive PALS systems, or engaging local people in major service changes.

## Valuing and Validating the Change Agent Role in PPI

The importance of a 'Change Agent' role as outlined above is not only consistent with the Health and Social care Act, 2000(Sections 7 & 11) which validates 'PPIH' work; it is also consistent with a whole raft of 'bottom-line' legislation that promotes our equal citizenship: the Human Rights Act, the Disability Discrimination Act, the Race Equalities Act, Health and Safety at Work, as so on Yet, all too often our experience is that this basic legislation might as well

not exist. Health inequalities remain an intransigent source of misery and injustice; people dread the dehumanisation of many 'caring' environments; negligence and abuse go unchallenged in many service settings.

Whilst there are now many brilliant examples of community engagement in health and healthcare improvement, there are core issues not being addressed. The legislation exists to enable our PPI work; but how will we attain the legitimacy and capability that will achieve a genuinely involving and engaging system: locally, regionally, and nationally? What are the fundamental barriers to change? What resources can be called on?

My starting point would be that we are all fellow citizens. Because we are all fellow citizens, labels such as 'patient', 'doctor', 'manager' – even 'PPI manager' – must not get in the way of the dialogues we need to facilitate in order to 'co-produce improvement'. This is the essence of PPI work: the facilitation of mutually meaningful dialogues for good purpose.

In order to achieve such dialoguing, we often need to design and plan interventions that make it safe for people to begin to relate to each other at a basic human level; to understand each others hopes and fears; to negotiate change and the conflicts that are inherent in 'improving things round here', and, to achieve the robust consensus that

by choosing involvement and, then active engagement, they will begin to demonstrate just how much improvement can be achieved when we learn to work and learn together as fellow citizens.

I learned the basis of involvement practice nearly twenty five years ago, when people with learning disabilities taught me their methodology: GTKY ('Getting To Know You'), whereby everyone has equal time, listen and notice, respectfully speak one at a time, and meet each person in the group as a fellow citizen. Labels, boxes, silos and paternalistic good intentions soon become meaningless when we give the time to peer learning. It is an approach that works equally well when we want to improve services or to reach a vision and direction for a major change programme in public health or services redesign. It works especially well for board and committee meetings – if colleagues are willing to share the risk and drop practices that allow divisions to remain.

In sum, the practice of 'PPI' is at root concerned with the facilitation of deep cultural change. In health and healthcare it is the key to creating a sustainable health system. Ironically, it is within this sector that we will encounter the greatest resistance and subversion of the purposes of PPI ... and the most inspiring innovation too.

Email: [bob.sang@btinternet.com](mailto:bob.sang@btinternet.com)

## The Engaging Communities Learning Network (ECLN) - Supporting PCTs with Community Engagement

**PPI Monitor will run a series of features on Networks in the next few issues to keep you up to date with the best sources of help, guidance and information in the PPI field. Featured this month is the Engaging Communities Learning Network. Kathie Andrews, Programme Manager outlines their work:**

Since Spring 2001 ECLN has been helping Primary Care Trusts (PCTs) to engage with local people and front line staff. The ECLN's base is at Highcroft, Winchester and has a membership of over 270 PCTs. We are part of NatPaCT and the Modernisation Agency.

The ECLN started with 12 PCTs from different regions and provided an environment where they could share innovative ideas, covering issues such as working with local communities, developing the Patient Advice and Liaison Service (PALS) and involving both public and staff in decision making.

By Spring 2002 we had 190 PCTs involved in our network. Our target had only been 150 but good news travels fast. Members were attending national and regional events and sharing their ideas.

It is important to make sure this work is consistent with policies and the NHS Plan. We have designed national events in co-operation with officials so that network members can both learn and contribute e.g. developing the policy guidance and statutory regulations that become Sections 7 and 11 of the New Health and Social Care Act.

Our national events have covered many different themes from Overview and Scrutiny and Reconfiguration to The National Patient Survey and The Expert Patient Programme (EPP). At the EPP event, attendees discussed their issues directly with Sir Liam Donaldson, the Chief Medical Officer. Our latest theme, Challenging Health Inequalities was hosted by Middlesbrough PCT who also co-designed the event along with Slough PCT and Leicester East PCT. It was co-funded by the Health Development Agency and there were many contributors from a variety of organisations on the day. Feedback was tremendously positive and can be viewed on our website along with reflections of all our events.

The strength of the network has been the innovation of PCTs, the highly participatory events designed by our lead facilitators, Bob

Sang and Jane Keep and the communication hub at Winchester where members have learnt to expect a friendly and helpful response to any queries. ECLN arranges national events, local support workshops and co-ordinate the information to be sent out by e-mail or posted on our website.

The ECLN has invested in several projects including funding PCTs to road test competencies – final feedback is expected in the next few weeks. A health reporter was commissioned to write five articles about success stories in PCTs which we called "Communicating with Communities", and can be seen on our website along with our learning resource "Connectors". These have recently been published as "Engaging Now" (available from [natpact@hfht.org](mailto:natpact@hfht.org)).

Those involved with our network have reported considerable benefits both to themselves and to their PCTs. They have learned about how other people do things, gained new ideas about strategies and had factual input from speakers. The ECLN has also been fully endorsed by the practitioner community (source: 2nd ECLN Evaluation Report – Henley Management College, February 2004).

We commissioned Henley Management College to evaluate the ECLN independently. Every part of the programme was assessed from planning meetings to events. Evaluation forms were sent out and phone polls conducted with members and associates of our network. The results were very positive and the Executive Summary has been posted on our website.

In this coming year we are handing over the design to the network members. Three themes have already been very clearly highlighted by you in recent months: Choice, Chronic Disease Self Management (CDSM) and a further event on Challenging Health Inequalities. We have already started by inviting members and associates to join a planning group to decide how to tackle the issue of health inequalities and will be



meeting for the first time in May. More will follow....

We will also be working with Strategic Health Authorities (SHAs) and PCTs to deliver some work locally across two or three SHA areas. Further "networking the networks" is also very important in this year's goal of sustainability, bringing together a whole health community.

To become a member of the ECLN simply e-mail us your contact details. Our services are free. We ask no promises and tick no boxes. You can be involved as much or as little as you want. We encourage PCTs to be involved with the design of the programme and to keep in touch with each other. If you need help, let us know. If you have some good practice that might help others, then we'd love to hear from you.

### ECLN Hub:

**Kathie Andrews**  
Programme Manager

**Janine Zdziebczok**  
Programme Administrator

### Facilitators:

**Bob Sang and Jane Keep**  
Lead Project Facilitators

**Bec Hanley and Jeanne Hardacre**  
Project Facilitators

### NatPaCT:

**David Common**  
NatPaCT Programme Director

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## Last Word from Chris Dabbs



### Dear Mrs. Buggins,

**It seems as if there is no longer any such thing as too much television. While advice is steadily moving in the direction that the best thing for very young children is no television at all, many hospitals now have TV sets by every bed that have no off switch!**

In the new healthcare world in which patient choice is a new priority, it seems strange that people have no option but to have the screen flickering at them all day. While it will keep some people entertained, it could be positively harmful to other patients, and I can imagine few people would want TV all the time while they are ill.

This may reflect the law of unintended consequences. What started as a good intention – preventing boredom for patients – has (by accident or design?) is giving an impression of NHS imposition in many places. Certainly, my most recent visit to our friend in hospital suggested that there was little option of peace and quiet away from the TV sets.

In a similar way, there is a constant risk that those of us engaged in patient and public involvement may have a similar effect. We want to make sure that as many citizens as possible have their say about health issues, and that their preferences really influence what is planned and delivered. We may forget, however, that this will only be a high priority for relatively few people over an extended time.

Most people, quite reasonably, do not want to spend hours and hours, or be committed for months and years, to health issues. How many people employed in the health field, after they have finished their working day, want then to have a lot of their spare time

at meetings or events on housing or policing issues? Most will have higher priorities, whether it is caring responsibilities, further education, or simply relaxing or enjoying some entertainment.

As we have both found, for most citizens on most things, the best involvement in health means short engagement (usually no more than 5-10 minutes) by people who come to them. The difficulty is that, still too often, what involvement really means is having to travel to somewhere (often unfamiliar) for hours or more to engage in activities that can often come across as dull.

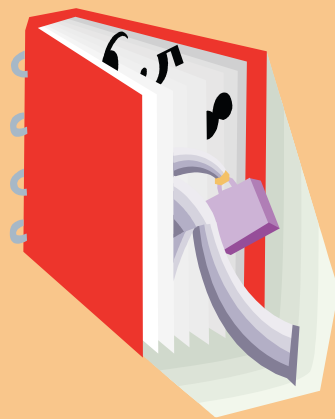
Sure, the activists and enthusiasts will commit to much more than this – and this must be welcomed and used effectively. But we cannot either assume this to be the norm, nor to lazily rely on the same few “suspects”. The aim must be to tailor the length and nature of involvement to suit people’s preferences, taking regard for their lifestyles – and also remembering that every other public service is obliged to involve and consult.

Engaging people must be on the terms of patients, carers and citizens – and always remembering to demonstrate what difference their contributions have made. Unlike some of the hospital TVs, having an on/off switch – and using it judiciously – will always be critical for effective involvement.

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?

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

Will one of your case studies help someone else?

Share your challenges and successes with other readers.

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Talk to Sarah on 0161 266 1978  
or email on  
s.bashford@bearhunt.org.uk

Publishing, Editorial and Advertising Offices  
Bearhunt  
Suite 108, 3000 Manchester Business Park  
Aviator Way, Manchester M22 5TG  
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