

# PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

## Going, Going...

### Independent report gives glimpse of the future of PPI after the abolition of the Commission for Patient & Public Involvement in Health

A discussion paper prepared by independent management consultant, Christine Hogg, sets the scene for PPI after the abolition of the Commission for Patient & Public Involvement (CPPIH).

The paper is purely for discussion, and does not represent the views of the CPPIH or the Department of Health. Nevertheless it provides the first glimpse of the future organisation of PPI.

Key points include: -

- Breaking up the functions of the CPPIH into seven separate elements and allocating them to a range of bodies (see table)
- PPI forums to concentrate more on their monitoring role in partnership with the Healthcare Commission
- PPI forums to hook into the wider Active Citizenship agenda and work closely with local authority scrutiny committees
- There might be fewer, better resourced PPI forums
- Fewer forum support contracts are likely to be let and these will operate on a national or regional basis
- The establishment of a Centre for PPI Excellence to promote opportunities for working in forums, set standards and develop capacity

Opinion Leader Research has been commissioned to hold a series of workshops across the country involving a sample of forum members, in order to gauge their views. A separate process will be set up to allow all forum members, staff and members of the public to record their views.

A spokesman for the CPPIH said "We will analyse the results of the consultation very carefully. The Department and the CPPIH will publish further details about the outcome of the consultation exercise early in 2005".

Functions of the CPPIH	Department of Health proposals
Appointment of Forum members.	NHS Appointments Commission
Staff support	Subject to consultation
Setting standards and monitor Forums.	Centre for PPI Excellence
Training of members and staff	Centre for PPI Excellence or NHS Appointments Commission
To promote patient and public involvement	Centre for PPI Excellence
To provide feedback from PPI Forums at national level.	Through the Centre for PPI Excellence
Commissioning ICAS (PPI Forums)	Commissioned by the Department of Health

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**Drawing, painting and talking** are just some of the ways to engage children in service redesign and mobile phone texting is important. Helen Hand tells why.

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# Bog Standard

**I guess I was lucky. I'm old enough to have experienced Greece before it became commercialised. Not quite Ancient Greece, you understand. Even my grey hairs don't stretch back that far.**

No. I mean the Greece of the early 1970s; the Greece of little old ladies clad in black, waiting by the ferryboat landing crying 'hypno' and getting ready to haggle the price for all they were worth; the Greece where twenty-five drachma could get you a good three course meal, enough drink to make you believe you could do that Zorba dance thing with a bar stool wedged between your teeth, and then even more drink until the obliging waiters carried you home – or left you in some bush covered in thorns – depending on the level of their patience.

It was uncharted territory. In those days the mere mention of 'Bobby Charlton' could open doors that otherwise would have remained closed.

It was here on a trip to the interior to see Marathon, that I wished a particular door had remained closed. It was also here that I encountered for the first time a lady with a moustache, but that's another story.

The trip to Marathon had been long and hot, and in truth, apart from the lady with the moustache, there was nothing really to see. Stopping at a local taverna to recuperate from

the journey, I used a series of ever more creative gestures to indicate that I was in need of the lavatory. Amidst what seemed like a fierce reprimand I was pointed to the aforementioned door. What lay beyond it was a revelation. This insect infested hovel contained quite simply a small hole in the floor, a rusty nail with a few pieces of Ta Nea, which I swear had been especially hardened for visitors, and a smell the like of which I have never come across before.

That day I learned in the most practical of ways, the true meaning of 'bog standard'.

How times have changed for the traveller I thought as I ruminated on the progress of privys from the pristine Portuguese porcelain palace that was the hotel bathroom during this year's holiday in Portugal. My thoughts were only interrupted by the sound of my children cheering in the adjoining bedroom. Despite the sunshine and the appeal of the hotel pool, they had become fascinated by the Olympics which were showing on TV.

Here, they were watching pictures of Greece. Not the bog standard kind of Greece that I had known, but a Greece which had remembered its ancient roots as a place of champions; a place where mere mortals can become champions; a place not of 'bog standard', but a place of 'world class'.

The more I talk to people working in PPI, the more I get the feeling that PPI as a discipline

must make the same kind of transition. If PPI is really as important as we say it is then we have to stop apologising, we have to get more investment into it, and we have to set higher and higher standards of excellence. More than that we also need to recognise and applaud our champions.

For many organisations PPI is still seen as a peripheral activity. Lip service is not enough and we must campaign for and strive for world class PPI.

It is encouraging to see that the consultation paper on proposals for the replacement of the Commission for Patient and Public Involvement include the establishment of a Centre for PPI Excellence.

We want to see this happen. We want to see PPI in the UK be proudly proclaimed as world class.

Over the coming months PPI Monitor will be campaigning for and providing guidance on, world class PPI. We want to make PPI Monitor the only place to be for those who are determined to be the best.

The journey to world class status may be a marathon rather than a sprint and its good to know that our readers are on their way. We have a duty to encourage others to follow the trail that we blaze.

Bring on those chariots of fire.

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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).

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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.

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# PPI and NHS Foundation Trusts

**The first wave of 20 NHS foundation trusts were established in April and July this year. Nigel Davies reflects on the effect this has had on PPI at Papworth Hospital in Cambridge. He describes the processes adopted to recruit and engage members and governors, the relationships and tensions created with existing PPI groups and Papworth's plans for greater social cooperation and public engagement.**

One of the Government's recent flagship reforms has been the establishment of NHS foundation trusts (FTs). Although the reforms met hostility from some quarters as the bill to enable their inception passed through Parliament, 20 trusts have now gained foundation status. The aim of NHS foundation trusts is to allow local management of services (by managers, staff and members of the public) so that care provision can be tailored to the needs of the local population. FTs have substantial financial and operational freedoms compared to other NHS trusts and have come to symbolise the Government's commitment to less centralised public services.

NHS foundation trusts are a new type of corporate body officially referred to as public benefit corporations. The involvement of local communities and the social ownership of FTs have been likened to organisations in the mutual or cooperative sector. Direct comparison must, however, be made with recognition that even in the mutual sector there is a broad spectrum of involvement and the aims of organisations differ widely.

## **So what difference has the move to foundation trust status made to patient and public involvement?**

The cornerstone of the change is the formal involvement in the NHS foundation trust of members and governors. Members are drawn from patients, the public and staff and are grouped into 'constituencies' defined in the FT's constitution.

Papworth Hospital NHS Foundation Trust now has just over 7000 public members, which include current and former patients. The members are largely drawn from the surrounding counties of Norfolk (19%), Suffolk (19%), Cambridgeshire (32%), Bedfordshire (8%) together with parts of Hertfordshire, Essex, Lincolnshire and Northamptonshire (7%). There is, however, also a significant proportion of members from the rest of England (14%) reflecting the involvement of patients who have received specialist / transplant services.

Papworth's Board of Governors, of which at least 51% must be drawn from the patient and public arena, has 21 public governors, 7 staff governors and 11 partnership or appointed governors. The public governors come from the counties referred to above with the numbers and geographical spread proportionally representing the current case mix of patients. With the help of the Electoral Reform Ballot Services, elections

were held at the beginning of 2004 with all the seats for public governors being contested.

Seven of the appointed governors represent other NHS bodies (local acute trusts, primary care trusts and the strategic health authority) and local authorities. The remaining four appointed governors are drawn from other organisations –the British Heart Foundation, the East of England Development Agency, the University of Cambridge and the Varrier-Jones Foundation (a local grant-giving charity supporting people with disabilities).

Throughout the process of establishing the NHS foundation trust it was clear that a commitment to engaging with potential members was vital. The membership strategy built on the existing platform of PPI activities and aimed to develop a membership community that could provide exciting opportunities for the people whom we believed would be eager to become members of the FT. A conscious decision was made to invite both staff and the public to join as members, rather than automatically opting-in some groups. This meant we had fewer members in the short term, but we were confident that this method would ensure all members would actively support the FT.

In order to engage members the FT has:

- devised an inclusive communications package enabling two way information flow, canvassing the views of members and facilitating consultation to make the purpose of membership more meaningful
- produced print and electronic media
- identified opportunities for informal member groups or networks and examined alternative forms of involvement (as opposed to traditional meetings)
- held Membership Forum events and "Chairman's Lunches"
- begun the preparation stage for Membership panels.

We have also started to work closely with the new governors to enable them to engage with members. This has included providing a mechanism for feedback from members including surgery-style events and electronic feedback.

We are conscious that the membership needs to continue to grow and the governors are now establishing a working group responsible for membership recruitment. We are taking the opportunity of promoting FT membership through press and public relations initiatives. We have also appointed a professional company with experience in community engagement to devise campaigns to ensure our membership remains representative.

## **How have the new membership and governor structures interfaced with existing PPI systems?**

The FT membership strategy built upon exiting PPI structures and activities. We

have retained our Patient Experience Panel (PEP), which consists of current and former patients. They meet bimonthly as a panel, with their members having further links into working groups, committees and patient support groups.

The recent introduction of PPI forums has been welcomed by the Trust. There were, however, some issues recruiting sufficient panel members as likely candidates in the various patient support groups and the PEP wished to become governors of the FT and excluded themselves from seeking appointment to the PPI Forum.

Discussions are now taking place between the members of the PPI Forum, governors and PEP to ensure all groups have a clear and meaningful remit and can interact with each other. This has in part been facilitated by some crossover of membership between the groups; to this end retaining the PEP (the terms of reference to which are within the purview of the Trust) has been helpful. The chair of the PEP happens to be a governor; two of the PPI Forum members are also PEP members.

## **What are our challenges and plans for the future?**

The FT was recently given the go ahead by the Department of Health to proceed with plans to re-develop the hospital, possibly in Cambridge adjacent to Addenbrooke's Hospital on the Cambridge Biomedical Campus. This would be a major service change and although the clinical visioning work so far undertaken has involved patients and members of the public we now see added advantages in having members and governors playing important roles in the process. If decisions are made to make this change, not only will we be consulting and engaging with the public in accordance with sections 7 and 11 of the Health and Social Care Act 2001, but we will also be including the public via the governors in real decision-making.

In becoming a first-wave FT, the Trust reinforced its commitment to involving people in every aspect of its activity. We are currently considering a series of proposals that could enable us to re-orientate every activity of the Trust. This would include a greater emphasis on organisational and cooperative development tacking account of our corporate social responsibility.

Undoubtedly, the realisation of FT status has been a major achievement for the Trust. This is not only in terms of the financial and operational freedoms gained, but also more importantly in the catalyst the change has been to accelerate development of greater patient and public involvement.

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# The Value of PALS

Patient advice and liaison services can demonstrate their worth, and where they need support. Jennie Fisher describes using an assessment framework in Essex.

## Policy context and background.

In 2000, the Government announced the creation of Patient Advice and Liaison Services (PALS) in every trust in the NHS in England by 2002<sup>1</sup>. Over 100 pathfinder PALS started in April 2001, and there were PALS in most, but not all, trusts by April 2002.

In 2002, PALS services in Essex reflected the national picture, with significant variations in resourcing and no clear understanding of the strengths and weaknesses of each. Most PALS managers were single practitioners, new in posts barely understood by some trusts. Many PALS staff felt isolated and lacked a clear sense of direction.

In July 2003, the Department of Health published revised core national standards and an evaluation framework to enable PALS to assess their performance<sup>2</sup>. Using these, the Essex PALS Network developed its evaluation, which ran from December 2003 to July 2004.

## Purpose and principles.

The main aim of the evaluation was to improve the service for the benefit of its users. The Network was keen that it was owned by trusts and the wider health economy, while being as objective as possible. A 360° approach was adopted, involving service users, staff, PALS colleagues, partner organisations and line managers. A key principle was that the evaluation should be robust and standardised across services to enable benchmarking.

## Methodology.

Services were assessed against the core national standards for PALS (Table 1).

The evaluation process included:

- gathering evidence of supporting mechanisms and processes that show how far the service meets each standard
- consultation of key stakeholders (particularly service users and trust staff) to obtain views on performance against each standard

Table 1: The Core National Standards for PALS

### The Core National Standards for PALS

Standard	
1	the PALS service is identifiable and accessible to the community served by the Trust
2	PALS will be seamless across health and social care
3	PALS will be sensitive and provide a confidential service that meets individual needs
4	PALS will have systems that make their findings known as part of routine monitoring in order to facilitate change
5	PALS enables people to access information about trust services and information about health and social care issues
6	PALS plays a key role in bringing about culture change in the NHS, placing patients at the heart of service planning and delivery
7	PALS will actively seek the views of service users, carers and the public to ensure effective services.

- analysis of this evidence to assess how far the standards are being met
- rating the performance of each service using the traffic light system
- preparation of a report and action plan

## Results.

### The stocktake.

The stocktake of services revealed wide variations in the resourcing of PALS in Essex. The average budget was £42,000, ranging from £14,000 to over £62,000 (both in PCTs). Staffing also varied: from 0.32 whole-time equivalent (WTE) staff in a specialist trust to 2 WTE (with voluntary or bank support) in an acute trust.

Just under half of the PALS in Essex, and all in acute trusts, are within nursing directorates; all except one of the rest are in corporate development or modernisation directorates. There is no standardised job description or grade for PALS staff, with wide variations in titles, backgrounds and competencies.

Unsurprisingly, activity levels vary between services. The total number of issues recorded from April to December 2003 was 6,207 (average 296 per service). This ranged from 27 in a PCT to 1,207 in an acute trust.

There is little correlation between budget, staffing and activity levels. The most likely explanation is that PALS staff are increasingly expected to assume wider PPI responsibilities, creating a dilution of resources for PALS and role confusion.

### The survey.

The questionnaire survey of patients and staff was done in January and February 2004 by the University of Essex. All service users in a four-week period were asked to participate, while 10% of staff in each trust were surveyed. 4,000 questionnaires were distributed, with 1,759 sent back (a 43%

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Table 2: Positive comments on the services

Service user responses	Staff responses
<ul style="list-style-type: none"> <li>■ having an impartial, approachable and friendly person who has the time to explain aspects of the NHS to them without judgement</li> <li>■ having a one-point source of contact to point people in the right direction be it for information or advice</li> <li>■ providing support at potentially difficult times</li> </ul>	<ul style="list-style-type: none"> <li>■ a one-stop central point for those patients, relatives and staff wanting information, support and advice</li> <li>■ helps sort out problems quickly and efficiently before they become complaints</li> <li>■ helps staff to have somewhere to refer people to when the issue, problem or enquiry is outside their field</li> </ul>

return rate) – 325 from service users and 1,434 from staff. Return rates varied between trusts.

Service users had heard about PALS in many different ways, but mainly from receptionists and leaflets. The most common way of contacting PALS was by telephone. Most PALS users (98%) found the service easy to contact and felt that staff responded to their initial contact quickly.

Service users found PALS staff to be friendly, professional, good listeners and understanding of the issues raised. They were also happy (95%) with both the handling of their enquiries and the outcomes. 97% said that they would use PALS again and would recommend it to others.

Over 50% of staff returning questionnaires worked in hospitals. 85% of staff had heard of PALS before completing the questionnaire and 72% felt they understood its role, although most had not yet used the service.

Most staff had heard of PALS by word of mouth and felt that leaflets, posters and training courses would be useful in raising awareness. Over 90% said they would use PALS in the future and would recommend it to others.

Both staff and service users had space to comment on what was good about PALS (Table 2), any problems, and how they felt it could improve.

There were generally fewer problems than positive comments. Most stemmed from PALS staff being overstretched (not available to take a call, delay in returning answerphone

messages, etc.) rather than problems with the staff themselves.

Suggestions for improvements were similar for all 21 PALS and included increased advertising to raise awareness (particularly in community settings), extra resources and longer opening hours.

### Analysis of the evidence.

Each trust commissioned a panel to analyse the evidence to assess how well its PALS service met the core national standards. Panels typically comprised executive and non-executive directors with PPI responsibilities, patient / public representatives and PALS staff and managers from host and neighbouring trusts.

From this analysis, each service produced a report and action plan to address areas for improvement. There were remarkable similarities in the performance of services. Strengths were: sensitivity and confidentiality; access to information; and recording and monitoring systems. Areas for improvement included: identification and accessibility (particularly in less resourced services); seamlessness across health and social care; and bringing about culture change. An important lesson was that seeking the views of service users is vital in bringing about many of these changes.

### What did PALS staff learn?

PALS staff found the evaluation a very positive experience that raised their confidence in the direction of the service. They valued the chance to reflect on their work, with support and constructive criticism from peers. The process promoted joint

working across health sub-economies and the sharing of resources and good practice. Lessons included the importance of keeping records, logging evidence, and allowing evaluation panels time for pre-reading. Many PALS staff highlighted the difficulties of approaching people for their views in sensitive situations. In future, the stocktake and survey could be better linked to the core standards.

### Conclusion.

PALS staff provide on-the-spot information, support and advice to people who may be confused, distressed or angry. At the same time, they need to work closely with, and win credibility among, all levels of staff. This interface between the NHS and the service user can be an uncomfortable and sometimes lonely place. To be effective, staff need training in core skills such as listening and negotiating. Full support from line managers and trust boards is crucial.

PALS in Essex are very effective at an operational level, both in delivering their services and in recording and reporting main issues and trends to facilitate change. Without adequate resources, however, it is difficult to see how to raise the profile of PALS or how to make the service seamless across health and social care.

Perhaps the most difficult standard to achieve is bringing about culture change. Barely 2\_ years old, PALS is still in its infancy compared to the cultures, traditions and hierarchies of the NHS. The relatively junior level of most PALS staff exacerbates this imbalance in maturity and power. If culture change is to be achieved, each trust must not only support but also champion its PALS staff and services.

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<sup>1</sup> \_ The NHS Plan: A Plan for Investment, A Plan for Reform. Department of Health, July 2000.

<sup>2</sup> \_ PALS Core National Standards and Evaluation Framework: Assessing performance against National Core Standards for PALS. Department of Health, July 2003.

# A Fantastic Opportunity

**Involving children and young people is a new field for many people. Helen Hand shows that it can be both instructive – and fun.**

The NHS Plan set out the Government’s vision for a patient-centred NHS and Kennedy’s report of the “Learning From Bristol” has been well documented. The key theme has been to charge the NHS with making significant progress in the way that we involve patients and the public. One challenge is to ensure that we involve children and young people in ways that we have perhaps failed to achieve in the past.

The task can sometimes seem daunting to those who have little experience of working with children and young people. Fears often include questions on how do we engage with them in a way that they will not only understand but also more importantly enjoy.

We were faced with this task recently at the Wrightington, Wigan and Leigh NHS Trust. As a result of local and regional initiatives to redesign services for children and young people, we needed to involve our local children and young people to help us understand what was important to them. The important issue was to ensure that we engaged directly with both children and young people, as well as their parents. A series of different approaches included questions to a citizens’ panel, one-to-one interviews with parents on the Special Care Baby Unit, group work with mixed-year groups in two secondary schools and a youth council, and artwork with young children attending outpatients or staying on our wards. We also worked together with a community-based project, the Sunflower Project, who helped us contact asylum-seeking families to obtain their views.

We began by exploring what was important to parents and grandparents if they had to travel outside of their local area to a regional children’s centre for paediatric surgery. The results showed that 42% of parents, grandparents and other guardians would be prepared to travel up to 20 miles. Almost three in ten (28%) would travel 20-50 miles, whilst one in five (20%) would travel even further. However, more than nine in ten guardians considered it important to be able to sleep over at the centre near the child, whilst over three-quarters considered

One challenge is to ensure that we involve children and young people in ways that we have perhaps failed to achieve in the past.

help in looking after other children to be important. There were some key differences in response between working and non-working guardians. Those not working were far more likely to consider help with transport (84% non-working, 67% working), help with child care (85% non-working, 74% working) and help with travelling expenses (72% non-working, 58% working) to be important considerations.

We also needed to discover from children and young people what they wanted from local hospital services. This work allowed us to get feedback from younger children through drawings and paintings. This was exciting, and provided a fascinating insight into what younger children like; not surprisingly, this was very different to the preferences of young people, but something that perhaps we have not fully thought through before.

Key themes included colour coding in departments so that the children and young people would know without having to ask where they were. Bright lights and access to fresh air was very important to all children and young people, with adolescents requesting their own spaces, including quiet areas for relaxing and an area where they could use their mobile phones for texting. Texting is a key method of communication for young people; it became clear that being able to communicate with friends and family when in hospital would make the experience much better. Playstations, computers and music were favourites for all ages in both inpatient and outpatient areas. Children and young people also wanted to be able to be with their own peers.

Important to the success of the project has been the support we received from staff, children, young people, their parents and our partner agencies. Later this year, the children’s wards will come together to form an integrated service, with areas designed around the differing needs of both children and young people. The key messages from our work have been collated and are being put into the design team’s portfolio.

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# 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: \_\_\_\_\_

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# Community Scholars

## The International Centre for Participation Studies.

**Participation is beginning to get in to the academic mainstream. One important development is in Bradford, although as Heather Blakey explains, it has roots in Latin America.**

The International Centre for Participation Studies (ICPS) is a new research centre within the Department of Peace Studies at Bradford University. Set up in May 2003, the Centre aims to establish itself as an academic and practical research unit in the field of participatory politics.

The development of the Centre grows out of strong local and international links. The Director, Jenny Pearce, has three decades of experience in working with grassroots organisations and developing civil societies in Latin America, while in Bradford, the ICPS has close links with the Programme for a Peaceful City, which is building a strong local reputation for working in a participatory way with communities in Bradford.

The Centre was formally launched on 26 February this year with a conference entitled 'Participation and Community Cohesion in the North – Making the Connections', which was supported by Government Office for Yorkshire and the Humber, and Government Office for the North West.

It was important to us that the event demonstrated our commitment to participation, not only through the subject matter, but also through a participatory approach to the day itself. With this in mind, we spent time before the conference talking to as many organisations and individuals working on these issues across the North, as we could. These conversations both shaped the conference agenda and fed into the pre-conference reading, which gave a snapshot of views on the value of participatory approaches and of the community cohesion agenda. The day itself was participatory too, with one in four participants having a role as a speaker or facilitator. We aimed for a day with minimum lengthy presentations, and maximum time for discussion. The approach

Set up in May 2003, the Centre aims to establish itself as an academic and practical research unit in the field of participatory politics.

seemed to work, as the day was full of interesting conversations and flowing ideas.

There is, however, never enough time at conferences to explore particular issues in the depth they need. We talked with a lot of participants about how we could support their work in the future, and help to deepen the discussions on key themes relating to participation. We hope to contribute to these deeper discussions through two programmes that we are currently developing.

The first of these, arising directly from conversations at our launch conference, is to offer study weeks focusing on the theory and practice of participation. This will offer an opportunity for participants to reflect on their own role and goals in relation to participation, and to review the processes they are involved in – to consider what supports meaningful participation, and what the barriers are. To help them do this, participants will explore approaches to and understandings of participation, drawn both from this country and from experiences in

the global South. The main purpose of the weeks will be to help participants use academic knowledge in support of their own experiential knowledge and learning. We hope that the study weeks will provide an opportunity to stand back from the daily pressure to deliver, with sufficient time and support to reflect on how best to go forwards.

The second project under development is a Community Scholars programme. This will be an opportunity for practitioners or community activists to spend a semester with the ICPS carrying out a research project, building on their experience and knowledge. This programme will enable experienced local, regional and international practitioners to contribute to systematic knowledge in the field.

These initiatives demonstrate two of our key priorities as a research unit, to promote practitioner access to academic resources, and to support the academic valuing of practitioner knowledge.

Other projects that we are working on at present include the development of a foundation degree in Active Citizenship and Participation (a two-year workplace based degree), and an MA in Participation Studies.

The ICPS is keen to develop relationships with other organisations and individuals working on participation. We have no desire to duplicate the important work already being done, and see our contribution to the field in terms of a practical academic approach, offering academic support to valued experiential learning, leading to a deeper understanding and informing more effective practice.

For more information on any of these programmes, to join the ICPS mailing list, or to request the conference papers for 'Participation and Community Cohesion in the North: Making the Connections' – or to get in touch for any other reason! – please contact Heather Blakey (tel.: 01274 236044, email: h.blakey2@bradford.ac.uk).

# Simple and Effective

**Involvement does not have to be complicated to be effective. Clara MacKay offers an example of one PPI Forum that has proven this rule on a potentially contentious issue.**

Although patient and public involvement techniques can and do vary widely, most successful involvement initiatives have a number of common ingredients. These include information sharing, listening to – and gathering of – stakeholder views, feedback, reflection and follow-up. To my mind the following example from the East Cambridge and Fenland Patient and Public Involvement (PPI) Forum is a good case study of how these elements can come together to form something straightforward and uncomplicated – yet quite powerful.

Earlier this summer, the East Cambridge and Fenland Primary Care Trust (PCT) undertook a formal consultation on proposals to significantly alter local services, including possible closure of a local community hospital. Given the significance of the proposals to the local community, the PPI Forum decided that the priority had to be to ensure that as many people as possible were made aware of the proposals and the detail that they contained, followed by the chance for communities to come together to discuss the proposals and to feedback views to the PCT. To support their efforts, the PPI Forum organised three highly successful local events.

These events, promoted as drop-ins, were held from 4.00 – 8.00 pm in July in three key areas affected by the proposals. The first part of the drop-in gave people the opportunity to meet individually with PPI forum members to express any views or concerns they had about the plans. Those not already familiar with the proposals were taken through the consultation document by forum members. Feedback from those attending the drop-in was formally recorded. This activity was followed by a presentation on the proposals by the PCT, further feedback and a question-and-answer session.

To ensure that as many people as possible had the chance to take part the events were widely publicised. The

PPI Forum made good use of local media, using both radio and print as outlets to raise awareness of the issues at hand and to provide information about how people could find out more as well as contribute to the debate. The PPI Forum also made good use of local contacts and networks: alerting local community and voluntary groups about the consultation and putting posters in places that would be seen by people as they went about their daily business, such as corner shops, libraries, chemists and GP surgeries.

The result was that over 150 people attended the local events, with a chance to consider the proposals and what it meant for them. Feedback from those attending was collected and considered – with the PPI Forum taking particular care not to dismiss any of the wide range of concerns and opinions offered. Those who could not attend were given the opportunity to input their views in writing or by contacting the PPI Forum. Following the events, forum members undertook an analysis of all of the feedback – and used forum meetings to discuss the outcome of this analysis with the wider community. The Forum has now submitted their response to the PCT.

Whether or not all of the recommendations made by the PPI Forum in their response will be taken on board by the PCT is perhaps not the point – although it is worth noting that the PCT has accepted most of the key points made by the Forum.

Brian Higgs, the Chair of the PPI Forum, explains why it involved people:

“The future of Dodington Community Hospital, which forms part of the PCT’s proposals under consultation, is a particularly contentious issue for many local people. We wanted to ensure that everyone was given the opportunity to contribute their views. We were very pleased with the success of the events; over 150 people attended and seemed to value the chance to meet with us and to question the PCT. Some members of the public raised questions about the proposals that hadn’t even been considered by the PCT.”

“The Forum also believe that the process has not only benefited the community but also has helped them to open a dialogue with the PCT about local services that will go on for some time.”

“We would definitely run something similar again, if warranted. Our involvement in the consultation improved our relationship with the PCT and demonstrated how well the Forum worked as a team. However, the events would not have succeeded without the fantastic support of Julie McArthur and Kim Armitt at Cambridgeshire ACRE, our Forum Support Organisation, who helped us to put everything into practice.”

Whether or not all of the recommendations made by the PPI Forum in their response will be taken on board by the PCT is perhaps not the point – although it is worth noting that the PCT has accepted most of the key points made by the Forum. What this case does demonstrate is that meaningful involvement doesn’t have to be a complicated process – indeed perhaps the most important ingredient of all is a genuine commitment to involvement and a willingness to listen and learn.

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# A programme that changes

**Can PPI really make a difference? The judges of the NHS Live Award for Patient & Public Involvement concluded that a programme in Lambeth and Southwark “should be adopted across the NHS.” Julie Backley explains.**

## What is Pulmonary Rehabilitation?

Pulmonary Rehabilitation (PR) is a multidisciplinary programme that promotes self-care and management. The aim is to restore the individual to the fullest medical, mental, emotional, social and vocational potential that they are capable of, over and above what can be achieved through ordinary medical treatments. It is an individually tailored programme of exercise and education, specifically for patients with chronic lung disease. It aims to prevent de-conditioning, improve exercise capacity and desensitise the patient to their breathlessness. The education component helps the patient to develop disease coping strategies, to manage their own condition and promotes long-term lifestyle changes.

We have excellent scientific evidence of the benefits of PR, including on exercise capacity and health status. These are greater than any drug therapy used in Chronic Obstructive Pulmonary Disease (COPD). Furthermore, people who already have the best medical therapy get the benefits of PR. There is, however, little information to show the effect on the use of health care resources, although people who complete the PR programme tend to experience fewer occupied bed days and fewer hospitalisations in subsequent years.

Despite PR being well evidence-based, PR services in the UK are generally poor, due to the absence of a National Service Framework for respiratory diseases. A recent audit conducted by the British Lung Foundation showed that the NHS provides less than 2% of the necessary PR services needed for the population with COPD.

## How did we get started?

As part of a team looking at improving the lives of people with COPD in Lambeth and Southwark, we investigated what both they

and health care professionals (HCPs) thought was needed.

Everyone – patients and HCPs – felt that PR should be at the centre of care for people with COPD. It was agreed that:

- we need to provide more of it
- patients need to be able to access it earlier in disease process and closer to diagnosis
- they wanted it closer to home
- they wanted it for life
- in a way that they choose.

Over the next two years, this excellent patient and HCP partnership agreed that these changes were needed to improve the service and make a real difference for patients with chronic lung problems. We had a big challenge on our hands!

One key action was to improve the communication and relationships between patients, the health service, the leisure sector and social care. This whole system approach has been liberating, but what made the greatest difference was patients being at the centre of this service improvement. They gave us the opportunity to think beyond the barriers and bureaucratic problems that arise within the NHS. Feeding back to them was both challenging and rewarding.

## How did we implement the changes?

**Stage 1: March 2003 – August 2003:**

**Problem:** A three-month waiting list for PR.

**Solution:** Secondment of a Senior I physiotherapist to sort out the waiting list and to set up third site to provide ‘more of it’, with an option of venue and hence ‘more choice’. This was taken one step further as

we offered different times for each person to access the PR. The result was that we had an increase in number of patients completing the programme.

**Stage 2: August 2003 – March 2004:**

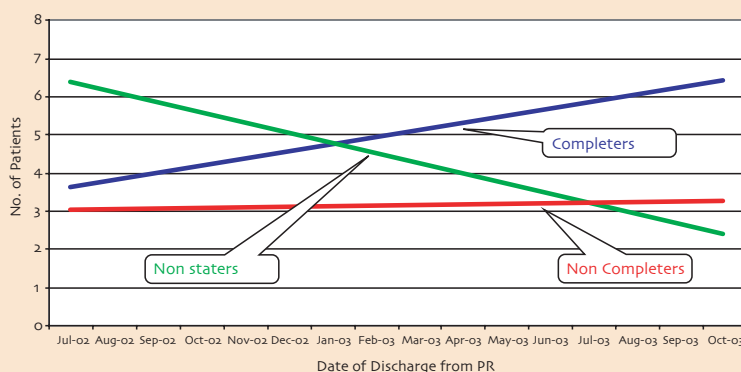
We established a segmentation model that let us think through how to offer patients more choice and personalised care. The model enabled us to stratify patients and treatment options so we can offer a programme that they specifically need while making the best use of resources.

We then needed to offer services from different venues and enable the programme to be delivered by different professions – either HCPs or leisure staff. Capacity increased by 100% through the use of new community venues: the first at Stockwell YMCA in Lambeth and the second at Dulwich Fusion in Southwark.

We also recognised the value of the Breathe Easy groups as a source of ongoing education and support for people with chronic lung problems. We thus supported the establishment of a Breathe Easy group in Lambeth; this meant everyone going to the PR could access it easily. These new sites helped us to tackle the challenges for ‘close to home’ and ‘for life’. The leisure centres provided the exit route for ongoing exercise and the Breathe Easy groups for education and group support.

**Stage 3: April 2004 – March 2005:**

We are setting up two more community venues to further increase capacity and to continue to provide PR closer to people’s homes. The model we use for PR for people with COPD could be adapted to help other



people with chronic diseases. At one of these new sites, therefore, we will develop a programme for patients with other chronic diseases such as heart failure and diabetes, and including people with multiple co-morbidities.

## What challenges did we have to overcome?

It was sometimes challenging to get HCPs to understand that improvements for patients are not always about increasing resources.

Short-term piloting / testing caused a problem with GPs. They were not happy to refer patients to programmes that were being 'tested' on a short-term basis.

## What have been our achievements?

Collecting data has been extremely important for us to evaluate how well sites are developing. The results we have demonstrated so far include:

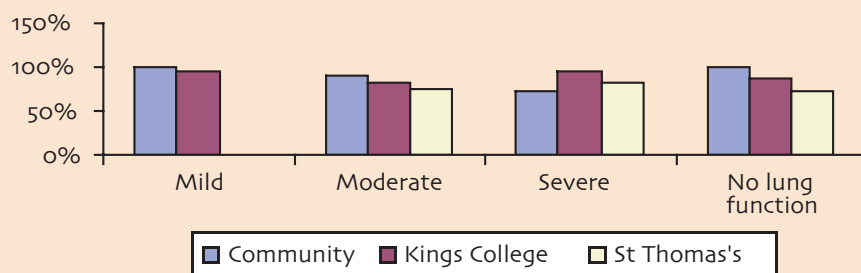
We reduced waiting times from three months to three weeks. We also increased compliance and reduced DNA (did not attend) rates – possibly due to providing more choice of venue and times.

Increased capacity – we can now offer PR to 400 patients per year in comparison to 200 only a year ago. 70 patients have been offered PR in a local leisure centre in the last six months.

Those people who have completed PR have shown a significant improvement in their exercise capacity and/or quality of life.

Percentage of patients who have had a significant improvement in their quality of life:

Percentage of patients who have had a significant improvement in their quality of life:



## This is only the start!

The PR team have gained considerable job satisfaction by providing a more patient-focused service. Over the past two years, we have dramatically improved the quality and quantity of pulmonary rehabilitation by empowering patients to tell us what they want and to guide us in providing a much better service. This is not the end: we plan to do much more. There is a strong link between the PR model and how we could work with people with other chronic conditions to help them self-manage. We will continue to evaluate the effectiveness of such programmes over the next few years.

## What do the patients say?

"He would not be here if it wasn't for PR"

"Before PR I felt I was dying inside"

"After PR life is worth living"

"Not as frightened anymore"

"Now I feel I can control my breathlessness and I don't panic"

"5 years ago I would not have dreamt of going on holiday, now we go every year"

"It's kept me out of hospital – previously I have been in once a month, the last time I was in was 5 months ago"

## Patient viewpoint.

A year ago, Pat Somers, 62 and suffering from emphysema, was facing lung reduction surgery and even life in a wheelchair. Now she can walk 200 paces on a good day and has even decorated her bedroom – an improvement she owes to her own efforts and pulmonary rehabilitation, rather than surgical intervention.

"I originally went on pulmonary rehabilitation back in 1998. My walking really improved, but after the programme I didn't keep up the exercise and things deteriorated fast. I was even in a wheelchair.

I was referred for lung reduction surgery a year ago and placed back on pulmonary rehabilitation just to get me fit enough for the operation. But the exercise improved my condition more than surgery could, so I ended up not needing the operation at all.

The programme and Julie have been inspirational – they've allowed me to start life again. I exercise twice weekly at the gym and do two sessions a week at home on my exercise bike. It means I can stay fit enough to do my housework and even decorate.

I'm now involved in setting up another programme at the YMCA. We've already got 20 people signed up and I'm hoping to tell more patients about the programme by actually going into the wards and seeing patients face to face."

**Julie Backley**

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# Patient Surveys: not just ticking the box

**Finding out what patients think is just the first step in improving health care, says Danielle Swain. Involving patients and staff in developing services as a result of this feedback will ensure that care becomes truly patient-centred.**

The National Patient Survey programme is now well established; since 2001 more than half a million patients have reported on their experiences of health care across more than 500 organisations in England. In August 2004, survey results were published for acute, primary care, mental health and ambulance trusts. This direct feedback from patients provides NHS organisations with detailed information about the standards of service they provide locally.

The Healthcare Commission uses patient survey results to help produce annual performance indicators and 'star' ratings. Many organisations may see them as an imposed chore but they are a valuable opportunity to listen to service users. Using this feedback effectively helps NHS staff to identify areas for improvement and in turn to create a more responsive, patient-centred service. Future survey results can then be used to measure changes in services over time.

The recent publication of results from the second annual inpatient and primary care surveys provide updated accounts of patients' experiences and help determine the rate of progress in improving patient-centred care.

## What is the National Patient Survey Programme?

The NHS Plan (2000) declared a commitment to ensuring that patients and the public have a real say in how NHS services are planned and developed. It also promised that every NHS trust would carry out an annual survey of patients' experiences of its services. Surveys are developed by the National Patient Survey Advice Centre based at Picker Institute Europe <[www.nhssurveys.org](http://www.nhssurveys.org)>. The questionnaires focus on specific aspects of care and treatment that patients have identified as being important to them. Rather than asking satisfaction questions, patients are asked questions on things that may or may not have happened to them.

Knowing that say 12% of patients rate the service as 'fair' or 'poor' gives few clues about

where to start to make the service better. Knowing more precise details of what went wrong – for example, the proportion of patients who felt they had to wait too long for their call button to be answered – and monitoring trends in these indicators over time can be much more useful. For each survey, 850 eligible patients are selected from trust records and a postal questionnaire is sent followed by two reminders in order to obtain approximately 500 responses.

## Identifying priorities for action.

There are a number of ways that trusts can use their survey results to determine priorities for action and this will depend on individual trust circumstances.

By comparing their results with other trusts, those areas that are performing better or worse than others can be identified. The Healthcare Commission has published national benchmark charts – <http://www.healthcarecommission.org.uk/NationalFindings/Surveys/fs/en> – that allow trusts to pinpoint questions where they are performing significantly below the best performing trusts.

Trusts may also find it useful to compare results within their organisation. Further analysis of results by sites, departments or wards will provide a more detailed breakdown of performance. From this it may be possible to identify examples of good practice that can be applied to other areas.

Looking at areas that indicate the biggest problems or where most patients report room for improvement is another way of looking at the results. It may also be helpful to focus quality improvement activities on specific aspects of the patient journey for example the admission process.

Concentrating on areas where work is already underway and solutions can be easily identified and implemented by staff and patients is worthwhile. Focusing on a couple of key themes is also more practical than trying to tackle everything at once.

## Sharing patient survey results.

Effectively communicating results and priorities for service improvement across the organisation and the local area is key to ensuring that change is implemented successfully. Staff, patients and the public are more supportive of changes when they are involved. A well-planned dissemination

strategy will engage the Board members, the local Patient and Public Involvement Forum, staff from across the organisation, patients and the public.

Results can be communicated in a number of ways, such as:

- establishing a group to coordinate the work of dissemination and action planning and involving some dynamic individuals.
- making tailored results presentations to the trust board and as many groups of staff as possible to encourage trust-wide ownership of the data
- holding a high profile local event with patients and staff to kick start improvement plans.
- producing visual displays and posters to publicise results in a user friendly way throughout the organisation
- publishing results widely in local media, trust publications and websites along with details of how the information will be used to improve the patients' experience
- illustrating themes with patient comments and other forms of patient feedback, such as Patient Advice and Liaison Service (PALS) and complaints information, to put the results in context

## Using patient survey results effectively.

After translating survey results into areas for improvement, staff and patients should work together to prioritise them and then identify the actions required. It is vital to gain board-level support and to engage staff from across the trust – including clinical staff.

Determining achievable time scales and identifying individuals who will be responsible for taking the work forward should form the basis of an action plan and can be updated at regular intervals. A successful action plan will help to ensure that patient feedback is used effectively to develop services provided. It is also a requirement of Local Delivery Plans that the local PPI forum should monitor action plans arising from national patient surveys.

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# Getting to grips with e-health

## the role of collaborative knowledge systems.

**Knowledge-sharing technologies and systems have significant potential to improve health and health care, but limited interest and investment are restraining their impact, writes Joe Cullen.**

The theme of collaborative knowledge production and innovative health technologies lies at the heart of current UK policy thinking and initiatives. Collaborative knowledge tools are central to the vision of a patient-centred National Health Service (NHS). The current policy context for health care implies a substantial paradigm shift in the ways in which different stakeholders – especially health professionals and lay people – communicate. The 1998 policy document, *Information for Health*, for example, proposed a number of initiatives – lifelong electronic patient records (EPR) for every citizen; instant access to patient data and 'evidence-based practice'; on-line public access to health information – each intended to promote the 'information society for all' with regard to health care.

This policy dynamic is being driven by escalating pressures on welfare budgets and changing patterns of disease. In response, new policy initiatives are aimed at the decentralisation of health care from acute to both primary and self-managed service delivery. They place more emphasis on health promotion and disease prevention. They imply a movement away from the 'consultant-driven' model and towards more 'power-sharing', and the involvement of health practitioners and patients in new partnerships. This can in turn be set against the broader policy background of 'e-government', and its place within the Government's vision of communications integration.

The NHS Plan therefore provides for an ambitious re-engineering of the NHS to offer a personalised service for patients. Support services like NHS Direct On-Line promote patient and citizen empowerment in health decision-making and in managed self-care.

The evidence suggests, however, that there are formidable obstacles militating against this vision of an 'e-health society for all', and many of these problems stem from 'knowledge sharing' – or the lack of it. Conflicting 'world views' between health professionals, health service users, health service managers and designers over the design and implementation of informatics systems is a major constraint. Problems of access and equity continue to dominate debates over health. In turn, motivation

remains something that is not yet fully understood or addressed. Essentially, we do not know enough about what motivates risk behaviours and health behaviours – and what we do know is often contested.

The Tavistock Institute, funded by the Economic and Social Research Council under its Innovative Health Technologies Programme, has over the past two years undertaken research that explores these problems and their implications for creating a more accessible health service. The overall aim of the RECKS study (the Role and Effectiveness of Collaborative Knowledge Systems in Health Promotion and Health Support) was to explore how new technologies were being developed and used to promote this policy vision.

The definition of collaborative knowledge systems used in the RECKS study is: technologies that provide for feedback and evaluation of the knowledge and information provided, enable interaction between 'producers' of health information (like health professionals) and 'consumers' (like citizens and patients), enable the utilization of 'tacit' knowledge in health promotion and/or support the conversion of tacit into 'explicit' knowledge, and enable different discourses and social constructions of health to be shared. These technologies include: decision support tools; evolving knowledge bases that allow users to add to the knowledge base using editing tools like annotations and evaluation tools like 'seals of approval' (SOAPS); interactive on-line discussion groups; and interactive electronic patient records (EPR) that encourage more knowledge pooling between disparate actors in health services.

A key finding of the RECKS study is that 'knowledge-sharing technologies' are both under-developed and unsophisticated compared with other forms of health technologies. Of the current range of commercial health technology products available in the UK, for example, less than 4% are 'collaborative knowledge systems' (within the terms of the RECKS definition). Much of the investment in health technologies has focused on systems designed to increase the efficiency of health service administration and delivery (such as electronic patient records and hospital information systems), teleradiology and remote image processing. Similarly, in the 'blue sky' research and development sector, attention has been concentrated on remote sensing, 'bio-wear' and robotics.

This limited interest and investment in collaborative knowledge systems mirrors the limitations of the systems and services

themselves. Of the 70 or so examples covered in the study, around 40% were classified as 'basic'. This type of system created an illusion of collaboration and engagement for users, but invariably adopted a conventional 'transmissive' knowledge creation and learning model, in which health content is produced by 'experts'. For example, one service included in the study provided an interactive chat room to enable users to discuss 'women's health' issues. Content analysis of the communications traffic indicated that discussion themes were mainly shaped by two particular users. These users turned out to be 'product champions' for a particular (commercial) 'weightwatchers' organisation. Three other main types of collaborative knowledge system were identified by the study: 'public health' systems, aimed mainly at reducing risk behaviours of 'susceptible groups' like people at risk of coronary heart disease; 'communities of practice', targeted primarily at health professionals with an interest in exchanging information on new knowledge and medical advances; and 'multi-modal systems', acting essentially as 'bridging points' for complex new partnerships in the health sector.

This is not to say that collaborative knowledge systems do not make a contribution to health improvements. The study identified, however, a number of issues around the development and adoption of such systems. These included: 'colonisation' of systems by interest groups – particularly professionals and 'educated classes'; the need for a 'human touch' as a bridge between the technologies and their users; and the need for more user-friendly functionalities and larger capacity to handle content such as video.

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For further information on the RECKS study and its findings, please visit the project website at <http://www.pixeljunkie.uk.com/Recks/index.html>

### Bibliographic note:

Dr. Joe Cullen is Academic Dean of the Tavistock Institute, an independent research organisation based in London. He has co-ordinated a number of research, and research and development projects, with an emphasis on technology, health and education. Recent examples include: SEAHORSE – technologies to support people affected by HIV/AIDS and their carers; and HERO – health and educational support for the rehabilitation of offenders.

# Living with Risk

## Involvement of patients and service users inevitably broaches some sensitive areas, perhaps few more so than risk assessment and management in mental health care. Joan Langan illustrates one approach to hearing the voice of service users.

Much is written and spoken about service user involvement in mental health, yet little is said about how to involve people experiencing mental health problems in their own risk assessment and management. The research described here was carried out due to our concern that the voices of service users considered to pose a potential risk to other people are not being heard.

Whilst all the service users in this study were considered to pose a potential risk to other people, suicidal ideas, suicide attempts, self-harm and substance misuse were also features of many service users' lives – as were harms such as racism, discrimination and trauma.

It is important to say at the outset something that is well known within mental health services, but not necessarily outside them: many service users are aware that they could pose a risk to other people when experiencing psychosis and want help to reduce the chances of this happening.

## Involvement in risk assessment and management.

Some service users could not be asked if they wanted to participate in the study, as they did not know that staff considered them to pose a risk to other people. In relation to the service users interviewed, a few were fully involved in risk assessment. They mostly did not, however, realise that professionals were formally assessing risks; some were unaware that they were perceived to pose a risk to other people. To assess risk, professionals tended to use their own methods or simple check lists. Risk tended to be seen narrowly rather than also focusing upon risks arising from poverty, unemployment, discrimination or stigma. Where professionals knew the service user well and had a good relationship

with them – which they stressed took time – they found it easier to discuss risk.

Agreement between service user and professional ranged from complete agreement about risks to no agreement at all (in one case). One woman said:

“And the thing that worries me is that when I'm in that state of mind it is logical to take the children with me. I could not leave them with the burden of a mother who killed herself . . . and when my thinking gets like that I need to be away from them because in that state of mind they are just extensions of me.”

The extent of agreement between service user and professionals clearly has a significant impact upon the potential for collaboration.

Written risk assessment or management plans or indeed written relapse plans were rare although during the time of the study (June 1999 - December 2000) the local Mental Health Trust was developing integrated risk management and care planning.

## Accuracy of information about risk.

Whilst many accounts about risk were consistent, there were some worrying examples of inaccuracy:

“He's been accused of going to stab a staff member. I was present on that occasion and it was very half-hearted. It was with one of our table knives and he came in waving it. And there was no way he was going to stick it in him. But that's gone down as an attempted stabbing.”

Service users have the right to have accurate information about them on record. Over or under-estimation of risk can have serious consequences for them and for people with whom they come into contact. Accounts of behaviour need to be accurate and substantiated, with any difference of opinion between service user and professionals recorded.

## Support offered.

Only a small number of service users were considered by professionals as involved in developing their care plan and we suggest more use being made of advocacy and that managers should regularly review service users' experiences of support and of the professionals providing it.

Standard care offered, but not accepted in all cases, was appointments with a psychiatrist, medication and attending a group, day care or a drop-in facility. Social work or community psychiatric nurse involvement was also common. The following support was either not offered or only provided to some service users when it seemed that others would have benefited:

- supporting service users subject to racial attacks
- awareness of and respect for cultural difference
- specialist support for refugees and asylum seekers
- support for the children of parents with mental health difficulties
- advocacy
- therapeutic input
- specialist assistance for substance misuse
- anger management
- self-help or self-management groups

One of our recommendations is that a strategy is developed so that service users are given information about (i) the range of potential services on offer and (ii) the level of service that they can expect, based upon current mental health policy guidance.

To counter institutional racism we

1. The research was funded by the Joseph Rowntree Foundation. We interviewed 17 people (two women and 15 men. Four of the men came from black or minority ethnic groups). People were interviewed as they were being discharged from psychiatric hospital and again six months later. We also interviewed relatives or friends (n=16) and up to three professionals per individual (n=56) over these two time periods. The research was conducted in one English urban area in general (non-forensic) mental health services.

recommend staff training in race equality and cultural awareness as well as a review of existing strategies.

Many service users were homeless: housing emerged as a source of some conflict, with some rejecting what professionals tended to suggest – supported housing. Service users either wanted more independence or had felt unsafe when resident there previously. Less unexpectedly, perhaps, medication was a source of disagreement with service users expressing a range of attitudes:

“But after this last thing where I just exploded sort of thing and did something very stupid, the depot’s the perfect thing for me.”

“They put me on a very high dose of medication, which almost killed me. And they didn’t really think nothing of it.”

Side effects from anti-psychotic medication were common. Many staff responded by varying medication or reducing dosage, but a few were unaware that service users were experiencing side effects. Staff generally saw medication as ‘the lesser of two evils’, but some service users found the effects so distressing or debilitating that it became the greater evil. For example, one man said that medication made him feel like “a cardboard cut out of myself.” The phrase ‘lacks insight’ (about the need to take medication) becomes even more controversial in the light of such side effects.

### Service users’ views about care plans and support.

Half of the service users felt they were getting a reasonable level of support. A few wanted more help and others were unhappy about valued support being withdrawn, something over which they had no control. There were some very positive comments about staff: “I really feel that she understands me and I do feel that she’s on my side.” Good relationships take time and there was dissatisfaction with staff turnover, especially for people seeing a different psychiatrist every time they went to outpatients.

Risk management for people living in the community is more likely to be successful when they receive a quick and effective response to any difficulties. For example, for two service users, there was only a small window of days (if not hours) between wanting help and becoming so unwell that they rejected it or had become a risk to other people. During the research period some service users and relatives had become somewhat more confident that systems had been established that would respond if needed.

### Conclusion.

Service user involvement in risk assessment

One challenge is to ensure that we involve children and young people in ways that we have perhaps failed to achieve in the past.



and management was variable and

depended upon individual professional initiative. Few professionals were undertaking systematic risk assessment or risk management plans; we suggest that a format for assessing and managing risk is developed that ensures that service users’ views about risks are included. A willingness to take appropriate risks, to discuss risk openly and to look holistically at all aspects of a person’s life may go some way to enable more effective risk management. In terms of care planning, service users were dependent upon professionals in terms of the services offered and needed more access to advocacy and information. Attention to the accuracy of information held about service users is also needed.

Our report has a number of examples of good practice arising from the research, as well as suggestions for improving practice in this important field.

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### Reference:

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# Patient or Person?

**We are all patients at some point in our lives. A problem is that some healthcare professionals only ever see us as "just patients", says Pete Moore.**

## What is a patient?

"A person who is waiting for or undergoing medical treatment and care."

"A term referring to the degree to which the patient has followed the instructions and dosing requirements of the protocol."

"A person who requires medical care."

These terms are all a bit stuck in the medical model – in other words, they are descriptions of what people are going to have done to them – nothing about learning self-management skills and how the doctor and patient could become players in the same team. Would a football match work with only one team playing? It would not be very entertaining and, of course, it would not work.

Patients, doctors and in fact all healthcare professionals have to work as a team to create patient and public involvement.

Wouldn't it be nice if patients were all like this person below?

### The Doctor

"Hello, Mr./Mrs./Ms. patient, we are here to help you live a richer, fuller life."

"Our healthcare professional team reassessed your situation and planned a programme especially for you. By following our carefully planned suggestions and medications, you will experience less discomfort with your condition and achieve an improved quality of life. Your condition will move from the forefront to the back of your thoughts as you move forward with your life despite your discomfort. But we need your co-operation and participation. Although our experienced healthcare team is one of the best, please remember you must do your part."

### The Patient

"Thank you so much, doctor! I realise my condition does not have to disappear entirely for me to enjoy many of my former activities. I have followed your prescribed treatments,

For a better healthcare system, we all have to work together as team – patients, healthcare professionals and the whole NHS workforce.

returned to work, and find it rewarding and gratifying. Thank you for helping me regain my life in spite of my condition!"

It is then that the doctor wakes up with the sound of his nurse saying – "here is your next patient, doctor".

From a professional point of view, how many times have you seen patients like the one above? Is it realistic to think that that you could actually have patients just like that? I think it is.

Firstly, healthcare professionals and patients need to learn how to communicate better with each other. Patients learn how to communicate better with their healthcare professionals when they attend the NHS Expert Patients Programme - [www.expertpatients.nhs.uk](http://www.expertpatients.nhs.uk)

Reading the PPI Monitor shows that you have keen interest in involving people in their own health and healthcare. The question I ask is how will you involve the professionals in people's health and healthcare?

For a better healthcare system, we all have to work together as team – patients, healthcare professionals and the whole NHS workforce.

Am I a patient? In fact I used to be a

revolving door patient – always in and out of the GP's surgery, but now I am a person again. Today, I live with four long-term health conditions very successfully and only see my doctor when I need to.

In my 'professional' patient days, I used to see my GP on a regular basis (not quite on Christmas card terms) and he would prescribe more painkillers and anti-inflammatories for my back problem. When they were shown not to work, he sent me for an x-ray, which did not reveal any major pathology. In the meantime, I also saw various osteopaths, physiotherapists and complementary therapists. In that first year, I spent £8,000 seeking a cure from these therapists. All I was doing was what I now call 'therapy or doctor shopping'. Just as you take your car to the garage to get the exhaust replaced, I was looking for someone to 'sort out' my back problem.

I saw a couple of orthopaedic consultants who told me my back problem was not serious enough to merit an operation – not that I wanted one anyway. The last consultant told me to learn to live with the pain. To be told at 39-years-old that I would have to learn 'to live with it' came as a bit of a shock, especially when I still had sciatic pain going up and down my leg at the time, and I walked with a limp. As with most patients who live with long-term health conditions, I experienced low self-esteem and low self-confidence.

I did not see my condition as my problem until I attended the INPUT Pain Management Programme (PMP) at St. Thomas' Hospital in London - <http://www.inputpainunit.org/> They involved me more in my healthcare and my management programme. After finishing the INPUT PMP my low self-esteem slowly dissipated and my low self-confidence increased – all due to the fact that I was included in my recovery.

As has been shown time and time again, by involving patients in their healthcare, they become better self-managers and better people again.

Are you a person or a patient?

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# An Engagement with Trust

What has happened to engaging the public in health as well as health care? Angela Mawle offers some thoughts.

**The impending demise of the infant Commission for Patient and Public Involvement in Health has led me to ponder the ever-widening gap between what we know to be good for community health and what actually happens 'on the ground'.**

The World Health Organisation repeatedly emphasises the need for participation in the (health) decision-making process. The Alma Ata Declaration (1977) identifies community participation as a "central component of primary health care policy", while the Ottawa Charter (1986) defines health promotion as "the process of enabling people to increase control over and to improve their health".

More recently, the much vaunted concept of 'social capital' has waxed and then almost as quickly waned within the health chattering classes. In the 1990s, studies abounded on the links between social capital and health. 'Civic engagement' and 'trust' were identified as the key elements of social capital contributing to health. A whole body of medical literature testifies to the health-enhancing properties of being in control of one's life and situation.

Yet true involvement of both the public and the individual remains unremittingly remote. Much lip service is paid to the principle but practical outcomes are thin on the ground.

Derek Wanless talks of the 'fully engaged scenario', in which an informed and discerning public work in partnership with governments to live healthy lifestyles within healthy environments. This can only happen when attitudes and cultures undergo the revolution that is necessary to change hearts and minds and to work in genuine partnership. My experience has been that those in authority (whether local authorities, governments, the NHS or any established organisation) are very happy to talk about partnership and involvement until it actually begins to work and starts to threaten the current status quo – that is, the traditional ways of working and the traditional power bases that support them.

There are countless health-related projects and initiatives that have been pioneered within communities. Projects that have

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become almost revolutionarily effective but which cannot be sustained once the funding and the workers are withdrawn. Often it is the very real and active involvement of people within those communities that has made the difference. This participation has usually only been allowed to flower by the new ways of working that has been experienced with the 'professionals'.

Unfortunately, these new ways of working are rarely if ever mainstreamed and the arcane and unwieldy bureaucracies that are the stewards of our local and individual health remain resolutely resistant to cultural change.

A long time ago, pre-NHS, the Peckham Pulse experiment showed just how effective patient and public involvement can be. Through partnership, mutual respect and understanding, two doctors revolutionised approaches to health and well-being by working together with

the community they served and by valuing and recognising each individual's role and contribution. The health of the community bloomed, so much so that Aneurin Bevan, then Minister of Health in the post-war Labour Government, was invited to visit. Apparently he did not pick up on this invitation but it is interesting to speculate how the NHS he was in the process of creating might have differed if he had.

The NHS must now be one of the largest bureaucracies of all time. It is increasingly driven by the demands of the acute sector and the almost exponential costs of curative medicine.

The forthcoming White Paper on Public Health and the current debate on the concept of 'choice' should offer major opportunities to the government to re-engage with the public in developing genuine partnerships that will work towards the health and well-being of both individuals and communities.

Trust and civic engagement will be vital to the development of any initiatives which are brought forward. Partnership and involvement are essential elements of enduring success.

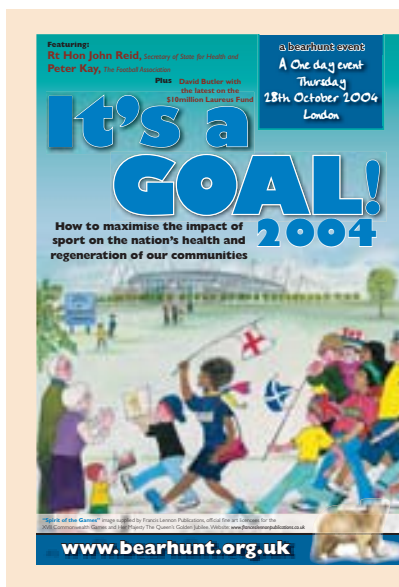
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The Secretary of State for Health will be giving a keynote speech at It's a Goal! 2004 – How to maximise the impact of sport on the nations health and regeneration of our communities. For details see [www.bearhunt.org.uk](http://www.bearhunt.org.uk)

# Constructive Change?

**Whither PPI forums? Ian Hayes argues that their constructive role for involvement should be further developed and not reduced to just inspection and monitoring.**

So, the worst kept secret is out of the bag. The Commission for Patient and Public Involvement in Health (CPPIH) is to be abolished, after less than two years of existence, at a time when the system the Commission was established to introduce is beginning to bear fruit.

Right now, we are awaiting detailed plans and time scales for the redistribution of functions. It is a difficult time for the staff teams at the Commission and in forum support organisations; perhaps worse, there is uncertainty for the dedicated volunteers who came forward to play their part in establishing the PPI forums. A set of principles for a new system has been suggested (see box), but there is no certainty that these will be met.

An effective patient and public involvement system must:

- ensure the independent voice of patients and the public is heard at all levels where decisions are made
- involve the diverse public and those not normally engaged
- work in partnership with the NHS and other stakeholders to produce continuous improvement in service delivery and public health
- be cost effective and clearly add value to health improvement
- recognise that the patient experience is not defined by organisational boundaries
- operate effectively within the wider active citizenship agenda

Given that recent months have seen ministerial guarantees that the PPI forums will continue, endorsements of the Commission's work in creating the system, and assurances that there will be no reductions in funding, one has to wonder at the motivation for the change.

A cynic, and I am afraid my cynicism has increased of late, would say that this can only stem from Government fears about what an independent patients' voice might say. It

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seems possible that the role of PPI forums may be reduced to one of monitoring and inspection rather than the active engagement and involvement originally promised.

This is more than sad, especially as it is based on fears that are not borne out when one looks at the responsible and constructive way that most PPI forums are carrying out their role.

I want to illustrate this – and the importance of some of the principles – with an example of high-quality involvement involving PPI forums and trusts in my home town of Bristol.

Historically, there have been two large health groupings to the north of Bristol based on Southmead and Frenchay hospitals. They have each had their own accident and emergency facilities and, for at least ten years, it has been widely acknowledged that the individual services were inadequate and that rationalisation was needed.

But, as we all know, people are very attached to the services they use; every time that change has been mooted there has been a public outcry which has served as excuse enough for delay. With both sites part of one amalgamated NHS trust and with

overriding need for change resulting from the well-known deficits within the local health economy, it is only now that sufficient resolve has been mustered to make the change.

This is just the situation where those who are fearful of the reaction of the PPI forums would expect the worst. Surely they will use their position to create an outcry, sabotage the consultation and prevent vital change which would have improved services?

This extract from a letter written to the local press by the Chair of the North Bristol PPI Forum illustrates that this fear is often without ground:

“Our time spent at both the Emergency Departments at North Bristol has been most interesting. The job we had to do was to listen to the problems faced by staff and relate them to the patients that both centres serve. Overwhelmingly, we were surprised by the strength of the argument made by the medics who we found to be committed and passionate.

After having a full tour of the Southmead emergency facility we were convinced that excelling would be difficult at best. ...So, with that in mind it was easy to see why the decision has been taken to centralise the main acute emergency service at Frenchay.”

What an excellent example of partnership working for continuous improvement in service delivery. More than that, this surely illustrates the value of a recognised independent voice in reassuring the public that their interests have been at the heart of decision-making. Better decisions, better understood by those involved – that for me is what patient and public involvement is all about.

It is fundamental to the continued existence of patient and public involvement that the principles of independence and constructive involvement remain central to the system. This will best be achieved by building on the work already under way in PPI forums throughout the country.

**Ian Hayes**

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# EVENTS CALENDAR

## Last Word from Chris Dabbs



Do you have an event coming up in the Patient and Public Involvement field? If so then please email Malcolm McClean with dates and a brief overview of the event at [m.mcclean@bearhunt.org.uk](mailto:m.mcclean@bearhunt.org.uk)

### Dear Mrs. Buggins,

Thanks for coming to the neighbourhood forum; it was fascinating to observe. Some councillors clutching to power, while others see that effective politics is equally about giving away power as seeking it. Community 'representatives' – some genuinely out there engaging, but most claiming status that no one ever gave them.

Most interesting, though, was who was absent. No children or young people, almost no one with a sensory impairment, and nobody with a learning disability. Not really surprising – the meeting was not only turgid, but was also designed precisely to suit those who already attend.

Even more significant were those not even there in spirit. Prisoners, refugees, people with dementia, people who are housebound were largely considered with disdain or pity, if at all. Communities are mainly defined by whom they exclude.

Societies have wonderful ways of dealing with people they dislike or fear. Open approaches like demonisation create monsters so we don't have to think that they might be anything like us. Watch the portrayal of Arabs – and compare it to how Jews were painted a century ago. See what can be whipped up when a place for people with mental health problems is proposed.

More subtle, though, is how societies portray people they would rather disappear. How often do you now hear people described as 'vulnerable', when really they are marginalised? How many individuals and communities are defined in terms of their 'needs' – usually in someone else's terms? It suits more powerful groups to think of

others as having needs or being vulnerable. This lets professionals in institutions – government, the NHS, large voluntary organisations – avoid recognising their role in excluding and disempowering others. It also lets them off the hook of having to change their own ways or lifestyles much.

This is where 'needs' come in handy. If someone is already psychologically distressed, how will they feel after a process that probes and defines their 'needs' – what they don't have, cannot do or don't know? What does it do to a poor community to have to repeatedly compete with others by demonstrating how bad they are at certain things, in order to get NHS or regeneration resources?

Yet there is an alternative. We could ask what assets people have that may be invested in. We could help them to build on their knowledge and skills. We could celebrate what energises them. Rather than locking offenders up to stew, for example, we could discover what they are good at and then ways to use this constructively – to mutual benefit. We could reflect on how much immigrants have enhanced our nation – see how many British artists and scientists of the past century were born abroad. We could learn from the perspectives of people with dementia – if we shut up and really listen.

We each have this choice. But it is political – how far are we prepared to challenge, or will we continue to be part of the problem that disrespects many fellow citizens?

Perhaps we might start with our neighbourhood forum?

Keep well

**Chris**

Chris chairs Passionately Curious Ltd, a social business that is a forum support organisation for PPI Forums.

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### Community arts - a creative tool for developing communities

28/10/2004

Location: Birmingham

Price: Vol orgs £105, others £155

Community arts are increasingly being recognised for their positive impacts on social development within communities.

[www.healthvoice-uk.org](http://www.healthvoice-uk.org)

### Involving volunteers with disabilities

27/10/2004

Location: London

Price: Vol orgs £105, others £155

This event will give you practical ideas to on how to make contact with and recruit volunteers with disabilities.

[www.healthvoice-uk.org](http://www.healthvoice-uk.org)

### PPI Monitor Annual Conference

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