

PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

Hewitt sets herself up as patients' champion

Two announcements have seen new Secretary of State for Health, Patricia Hewitt, line herself up as the 'patients' champion'.

First, she called on NHS leaders to kick start a big programme of public engagement in order to shape the future of NHS family health services.

Speaking to the National Leadership Network, Patricia Hewitt said:

"I said when I was appointed that I wanted to spend the next few months listening and learning. I want to hear the views of people working in the NHS and Social Care. And I want to hear from the patients and users of its services about their experiences.

"I have already made clear there will be no back-tracking on the direction or pace of reform, and that under this government, healthcare will remain available to all according to clinical need and free at the point of use.

Later she announced plans for a major public engagement exercise to help shape the future of care outside hospitals.

Addressing the 'Britain Speaks - Effective Public Engagement and Better Decision Making' conference in London, Ms Hewitt promised to launch a listening exercise to involve public, patients and staff in September 2005.

The exercise will collect the views of thousands of ordinary people in order to help shape the White Paper on 'Health outside Hospitals'. Ms Hewitt said:

"I want to genuinely involve patients, public and staff in designing family health and social care to meet the challenges of the 21st century. The challenge of ensuring primary healthcare services can meet the changing expectations of patients and the public. The challenge of ensuring we shift the focus of services towards promoting good health as well as treating disease. And the challenge of managing long term conditions like diabetes, heart disease and obesity.

"This will be a major, large-scale deliberative event taking place at the local, regional and national level – beyond anything the Government has embarked upon before in the health field."

She said that there would be a particular focus on ensuring the views of disadvantaged groups and communities were heard, so that the people who most need services and support are genuinely involved in determining their future.

Ms Hewitt said public engagement would play a central role in delivering better services and in building democracy 'beyond the ballot box'.

INSIDE THIS ISSUE

All pull together - Lay people may have different roles in scrutinising health services, but working together is becoming an increasingly attractive proposition – and reality – as Tim Gilling reports from the Centre for Public Scrutiny's annual conference.

Flexibility, Flexibility, Flexibility - Involving black and minority ethnic and other excluded groups remains a challenge for PPI. Ian Flack describes one approach which was used with PPI forums in London and Essex.

The Cancer Journey - Patient and public involvement often raises people's desire to be treated as whole people, not as patients. Michail Sanidas reports on an approach to the holistic needs of people living with cancer that one participant described as "the most inclusive event in my experience."

Power to the People? - Engaging communities is a process of negotiation in which risk, and the styles of professionals, are critical, finds Mike Shiner.

Stories that change your life - Communities can challenge health inequalities, as a new book of stories shows. Bec Hanley and colleagues report.

Young Ones

I've just been given a parking ticket. Not that I didn't deserve it, but that's not the point. It always hurts.

Then I noticed the guilty traffic warden. The one that dispensed my ticket. Blonde, attractive and very, very young. Strangely enough it doesn't make it any easier to be given a ticket by someone who lacks facial hair and is old enough almost to be your daughter.

You realise, that not only are you going to have to fork out thirty quid – but you are getting old.

It comes to all of us. All of us, except Cliff Richard that is. He just seems to get younger. Perhaps it is something to do with him recording 'The Young Ones', or maybe it is that he is partial to a 'Summer Holiday'.

Who can ever forget that fabulous rendition of his old hit in a rain-soaked Wimbledon Centre Court. Rain or shine he is there every year cheering on whichever of our great British hopefuls is going to make this our year. Roger Taylor, Buster Mottram, David Lloyd, Greg Rusedski and even Tim Henman,

came in as young hopefuls. Somehow, Cliff has remained younger than they are. It is if they have passed in the mists of time as Cliff has got younger whilst our tennis hopefuls have aged.

Now there is a new pretender. Young Andy Murray takes on the baton as our latest hope of wresting the Wimbledon crown back to Britain. He has had a fantastic tournament and looks like he could be around for a long time. Probably not as long as Cliff though.

This theme of the 'young ones' really came to my attention when I attended an event organised by the Commission for Patient & Public Involvement in Health. It brought together patient and public involvement forum members from around the country. They did well and there was a good turnout – about five hundred people.

I arrived late, and made my entrance into the conference hall just as a coffee break had been announced. As I walked through the double doors one way, I was faced by a torrent of people coming towards me the other way.

I had to do a double take. No disrespect to the people who formed the torrent. They were there because they care. Because they are public spirited people who want to get involved in health. My double take though was to check that I was at the right event. For one moment, I wondered if I had walked into a shareholders meeting of Saga Holidays.

There were not many young whippersnappers about at all. In fact, you would have been hard pushed to find anyone under forty-five. I know it was during the week and that it was easier for retired people to attend, but the feeling I get is that PPI is not attracting many 'young-uns' at all.

It was appropriate that one of the workshop slots was about how to attract young people into forums. It's an enormous challenge to get anyone interested in meetings and minutes. Surely we can find some new ways.

If the PPI Forum in Wimbledon is looking for some young blood, there's a whippersnapper called Cliff who might be interested.

EDITORIAL ADVISORY BOARD

Chris Dabbs

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

Nick Bosanquet

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

Zenna Atkins

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

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

Malcolm Stamp CBE, DCL, FRSA, MIHM, MMS

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

David Gilbert

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

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News items

Public attitudes to self care – New DoH Survey

To feed into the policy context of self care support in the Department of Health and the NHS, the Department commissioned MORI to conduct this survey of the English public to establish a baseline of public attitudes towards self care and their self care behaviours. The survey was conducted in two stages between August 2004 and January 2005. The baseline data will be used to assess the impact of recent initiatives on the public a few years down the line - and to inform care policy in the short and medium term future.

Public Attitudes to Self Care - Baseline Survey is available at www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4111260&chk=Vx6HUK

Across the NHS – consistency for involving volunteers

Volunteering England is developing guidelines for involving volunteers in any NHS setting, so that all roles are equally valued. It is seeking views and comments from anyone who is involved with volunteering in a health care setting, or working on patient and public involvement, or concerned with enhancing the patient experience.

The guidelines include:

- legislation about volunteering
- volunteer policies
- requirements and guidance from the Department of Health
- access from volunteering to employment in the NHS

The draft guidelines, examples of good practice and more details about the consultation, which lasts until 31 August, are available at www.volunteering.org.uk/hsc - click on 'Consistency Project' on the left hand side of the page

NHS Networks

NHS Networks is a new initiative and website to connect leaders and innovators across the NHS with each other and with policy formers - joining networks up across geographies, sectors, professions and government.

www.networks.nhs.uk is a shop window for networks, and a working tool for networking. It launches with some inherited wealth of material including:

- patient and public involvement
- health inequalities
- long-term conditions

NHS networks is led by Edna Robinson, and draws on the legacies and experience of the Engaging Communities Learning Network, the Modernisation Agency Associates Programme, the National Primary Care Networks, and the NatPaCT website.

For more details, go to the web site at www.networks.nhs.uk or contact Kathie Andrews on 01962 825352 or kathie.andrews@weht.swest.nhs.uk

Winterton announces injection of knowledge for people with diabetes

Thousands of people with diabetes are to benefit from a better quality of life, as plans to mainstream patient education programmes in diabetes services were announced by Health Minister Rosie Winterton.

A joint report by the Department of Health and Diabetes UK on patient education published recently provides the NHS with guidance on equipping patients with the knowledge they need to manage their condition effectively. The document includes new ideas, examples of good practice, and details of patient education programmes, which will support the delivery of high-quality education, a key priority in the National Service Framework (NSF) for Diabetes.

Now that the tools are in place to provide patients with learning resources, National Institute for Clinical Excellence (NICE) guidance on patient education will be reinstated. From January 2006, all Primary Care Trusts (PCTs) will need to implement NICE recommendations by providing all people with diabetes with high quality, structured education.

News items

Healthcare Commission calls for action on inpatient services

High levels of violence in mental health and learning disability inpatient facilities in England and Wales are revealed in a national study conducted for the Healthcare Commission by the Royal College of Psychiatrists.

The National Audit of Violence in mental health and learning disability services found that one in three inpatient service users have experienced violent or threatening behaviour while in care, this ranges from raised voices and verbal aggression to the much rarer use of a weapon to threaten or attack.

This figure rose to 41% for clinical staff working in these units and nearly 80% of nursing staff. Eighteen percent of visitors to the units had experienced violent or threatening behaviour.

The Healthcare Commission has pledged to use the findings to drive much needed improvement in inpatient services, saying "best practice must become standard practice".

The Audit highlights areas of good practice across the country. For example, the use of personal alarms in one trust helps to make

visitors feel safer. Other positive results show that a high percentage of staff, service users and visitors feel that violence between service users is dealt with well. The majority of service users also feel able to speak to staff when they need to.

Around 6,500 questionnaires were submitted as part of the audit - respondents were drawn from 265 units and included over 1,500 service users.

For further information, or to arrange an interview, phone Creina Lilburne at the Healthcare Commission on 020 7448 9339 or after hours on 07941 156 827.

The true costs of participation

A new research project called "The True Costs of Public Participation" is looking for input from anyone in the involvement field.

The research is funded by the Home Office (Civil Renewal Unit) and runs until September 2005. Within this short timeframe researchers hope to gain a clear understanding of whether it is possible to assess costs and benefits of different participatory approaches and how it might be done.

Comments, both on the focus of the research itself and on specific literature or methods that might be useful, are welcome. Also, if you know of any studies where attempts have been made to assess the costs and benefits of a decision making process please contact the researchers, who are also looking for suitable participatory processes to test our method of measuring costs and benefits. They are particularly interested to know of any processes where the responsible parties would be willing to share financial

information. The interviews for the case studies will be carried out in the coming months.

More information on this research project can be found online at: http://www.involving.org/mt/archives/blog_13/TrueCostsOnePager.pdf

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The next issue of PPI Monitor will be published in September.

Have a great summer!

Pulling together for the public benefit

Lay people may have different roles in scrutinising health services, but working together is becoming an increasingly attractive proposition – and reality – as Tim Gilling reports from the Centre for Public Scrutiny’s annual conference.

What’s the difference between a PPI forum member, a local authority health scrutiny committee chair, a public governor of an NHS foundation trust and an NHS non-executive board member? The Centre for Public Scrutiny’s (CfPS) annual conference ‘Citizens, Scrutiny and Public Governance’ on 23 June gave a resounding response to this question: each have distinct roles in the PPI framework, but each feels increasingly bound to their common purpose as ‘citizens as scrutineers’.

The notion that the players in PPI are ‘fishing in the same pond’ can sometimes have negative connotations, arousing fears of duplication and overburdening commissioners and providers. However, the impression coming from health scrutineers in the plenary sessions and workshops was that there is genuine will to complement each other’s activities and work together in a coherent manner to achieve a better quality of life for the communities they represent.

PPI forums, health overview and scrutiny committees (OSCs) and NHS foundation trust governors have so far tended to concentrate on establishing and developing their distinct

role and contribution to public governance of health and social care. Whilst establishing their separate ‘camps’, however, it has emerged that they face several common challenges.

Each has faced fundamental questions about the nature of membership, election or appointment procedures; how to ensure appropriate resources and support; how to genuinely engage the public; how to attract, develop and retain members so that their contribution can be most meaningful. Not least, each has faced or is facing dynamic change: whether structurally in the case of PPI forums, politically in the case of OSCs at recent elections, or adapting to new freedoms in service delivery in the case of NHS foundation trusts. NHS non-executives also continue to keep abreast of the ever-evolving health service reform programme.

Despite these challenges there are many examples of individual success. Through each channel of public involvement, commissioners and providers are gaining useful input that is helping to ensure their priorities are patient focused. One NHS foundation trust reports that attendance at its AGM has risen from 20 to 300 people; a PPI forum has persuaded an NHS trust to introduce a new appointment system to cut waiting times for blood tests; an OSC succeeded in reversing a proposal to centralise acute mental health hospital beds; and an NHS non-executive director is focussing on younger people in the community, getting them on board with health issues and finding out what young people want and how they can working for, and with, a primary care trust.

It is, however, becoming clear that a ‘silo’ approach, although expected whilst getting to grips with distinct roles, is not always the best way to achieve outcomes for public health. Now that most health scrutineers are becoming better established, the time is ripe to move to the next level of public scrutiny, where scrutineers work more collaboratively, more creatively to maximise their impact.

An opportunity for PPI forums and OSCs to work together around the Healthcare Commission’s annual health check was presented by Anna Coote, the Commission’s Director of Patient and Public Involvement. This chance to contribute to the assessment

The notion that the players in PPI are ‘fishing in the same pond’ can sometimes have negative connotations, arousing fears of duplication and overburdening commissioners and providers.

of NHS bodies is a powerful tool to hold decision makers to account in the public arena. More detail about how OSCs and PPI forums can take this forward can be found in a new guide about ‘working together’ that the CfPS published at the end of June. The Healthcare Commission is also providing training and guidance for PPI forums and OSCs. Further examples of joint working are highlighted in the CfPS guide.

Of course, joint work is not without its problems. Partnerships must be managed well, different perspectives respected and different working styles accommodated. A balance needs to be struck between clear demarcation of roles and responsibilities whilst coordinating effort for the public good. Roles are complementary not competitive, and the option to agree to differ is always available.

As PPI forums, OSCs, governors and non-executives increasingly achieve their goal of rebalancing accountability to be ‘bottom up’ as well as ‘top down’, it is increasingly clear that by working together – across the scrutiny landscape – the vision of a patient-focused health service can be realised even quicker.

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What’s the difference between a PPI forum member, a local authority health scrutiny committee chair, a public governor of an NHS foundation trust and an NHS non-executive board member?

Flexibility, Flexibility, Flexibility

Involving black and minority ethnic and other excluded groups remains a challenge for PPI. Ian Flack describes one approach which was used with PPI forums in London and Essex.

CEMVO was one of the largest forum support organisations (FSOs) supporting the volunteer members of 34 of the patient and public involvement (PPI) forums in north-east and south-east London and parts of Essex. Our patch thus included forums working with NHS trusts in leafy suburbs, the inner city, rural areas and a (former) new town. Our role was to provide support to forum members in carrying out their role – ranging through:

- organising meetings
- making tea and coffee
- taking minutes
- planning
- helping them engage with their communities
- engaging with the NHS and with overview and scrutiny committees
- carrying out research projects and observation visits
- dealing with floods of information received

We also had an important role in working with the Commission for Patient and Public Involvement in Health (CPPIH) to act as a link between the members of Commission, its staff and the PPI forums.

What were the challenges?

Three important ones were:

- PPI forums in our area are, like most volunteer bodies of their type, predominantly made up of older people, who are often retired, white and middle class. How could we recruit a representative group of members? In diverse communities, if a forum has 15 to 20 members, how could this be representative?
- Forum members are advised that they are likely to be required to donate about four hours of their time per week. In our case the 34 PPI forums had 24 members of

staff to support them. With this resource, how could forums make a meaningful contribution to the planning and delivery of a multi-million pound local health service?

- The communities that PPI forums are expected to represent are often very mixed with an entirely different cultural and life experience than the forum members. How could forum members hope to engage with these diverse communities and extract useful information or views from them?

Which groups are we talking about?

It was essential to avoid regarding black and minority ethnic (BME) and 'hard-to-reach' groups in a stereotypical way. It was obvious that there are huge differences between highly educated members of the minority communities and new refugees or asylum seekers in this country. Even within the sub-group of new immigrants, there is a vast range in background and experience. Engaging with under-privileged people living on a neglected estate may be problematic whatever their ethnic origin or background. Added to this we had to include people living with disabilities. At the other extreme, there were people working long or unsociable hours, so were difficult to involve as PPI forum members or in forum work.

This group was vast in its range – from office cleaners and security guards to merchant bankers and foreign exchange dealers. Based on our experience, members of FSO staff would fall into this group! Another important group were children – under 18s may not become members but children's thoughts and feelings about what the NHS provides for them are very important and may be difficult for forums, NHS trusts and primary care trusts to collect.

What are the answers?

The answer may be summed up in three words – flexibility, flexibility and flexibility.

CPPIH, or whatever replaces it, has to have a more flexible attitude to the way in which it recruits members. This would allow easier co-option and working seriously to set up a pool of volunteers who may not wish to be full-time members but are available to work on specific projects. PPI forums may also work

Involving black and minority ethnic and other excluded groups remains a challenge for PPI.

in this way with their FSO. The application process needs to be simplified and made more accessible.

Forums need to move away from the formal meeting and expecting communities to approach them with their views and concerns. For example, some PPI forums we supported are now beginning to set up their stalls in shopping precincts, town shows, village fairs, etc. This publicises what they do and enables the public to express their views. There are other opportunities available like this for informal engagement – clubs, pubs, gyms, school gates, etc. Members can move out from their immediate area of experience into others as their confidence grows.

The tools that are used to gather opinion may also be informal and flexible. It may be essential later to move to formal methods of gathering information. The NHS may have to be prepared to accept anecdote as a clue to what is going on and forum members with their support organisations need to make themselves more welcoming, using informal methods.

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FSOs and their staff also have to be flexible. This is not a nine-to-five job. Larger teams, such as CEMVOs, are able to assemble more talents, skills and knowledge. Thus our team could:

- speak over 25 languages
- ranged in age from 63 to 25
- had skills in:
 - project management
 - youth work and informal education
 - community work
 - social science research
 - public health, epidemiology and demography
 - community development and capacity building
 - information science

In the host organisation, there was the range of skills available that would be expected from a large national charity were these available to PPI forum members.

Conclusion.

It is unfortunate that, as a result of the Department of Health's recent arm's-length bodies review, CPPIH and the infrastructure that it is building is being abolished just as it is beginning to work. For example, with the CPPIH London Regional Centre and CIDA (another FSO), we are just about to pilot the use of faith groups as a way of publicising PPI forums and as a route to engagement. Forums are beginning to be comfortable with themselves and to move towards engaging with communities and health care agencies in the flexible way envisaged. In short, we are beginning to learn about the job and from each other.

It is to be hoped that the next incarnation builds on this experience and other experience in patient and public involvement – a key driver of quality improvement in the NHS.

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A One Day Conference

Thursday 8th September,
London

supported by

PPI MONITOR

Different Strokes

Tackling Choice, Diversity and Standards to Improve Services for Black & Ethnic Minority People

NHS policy and practice must better acknowledge the differences between people, rather than pretending that our health, our minds and our bodies are all the same

The NHS has an immense ethnic diversity amongst its workforce. Despite this it still fails to serve the diverse population of this country.

The NHS has diversity within it, yet according to former Health Secretary John Reid and Trevor Phillips, Chair of the Commission for Racial Equality, "It has not found a way of responding to the diversity in the population it serves".

As we move to uniform standards and uniform services we feel that we are making progress. Some argue that this is not sufficient progress. In a diverse society, like ours, to obtain equity we need diverse services.

Uniformity cannot and does not provide that. All the evidence shows that black & ethnic minority people want the opportunity to choose. They want the right to play a role, and direct, through their preferences, the way in which services are delivered.

To secure better services, NHS policy and practice must better acknowledge differences between people, rather than pretending that our health and our minds and our bodies are all the same.

More and more, this will become a key priority area.

This conference provides an important opportunity to take a wider view of what diversity really means for the shape of our health service; learn from innovations throughout the country; ensure that you can perform your duties under the Race Relations Act; and develop ways to improve the patient/user experience for BME groups in order to contribute to national targets.

Over the next twenty years the proportion of black and minority ethnic groups is set to double. Providing diverse services in a framework of uniformity is a major challenge for the NHS. This is a not to be missed event for all health organisations that are determined to make service diversity into an effective response to needs rather than being a token gesture.

www.bearhunt.org.uk/different_strokes.htm

NHS Connecting for Health

It is critical that the NHS is getting ready for change through its huge IT developments by engaging with patients and the public. Karen Foy explains how working with PPI staff will help to ensure that people have the information they need to stay well and to get the best care when needed.

At a recent workshop in Cambridge, a local patient and public involvement (PPI) lead told the story of her 18-month-old niece who developed flu-like symptoms. Over several days, she saw a series of doctors from primary care, out of hours, and emergency services. None had the benefit of any notes from the others. It was only after the little girl died that they discovered she had meningitis.

When the PPI lead asked her brother if he wanted to make a complaint, he replied: "I don't want to complain – the clinical teams did the best they could with the information that they had, they were great – and were as distressed as us at [our daughter's] death."

PPI leads and patient advice and liaison services (PALS) know that while many patients receive excellent care from the NHS, some suffer preventable harm because they and those caring for them do not have the right information when they need it. Others have to cope with the inconvenience of lost medical records, appointments made at unsuitable times, and delays caused by the paper chase between GP surgeries and hospitals as appointments are made and re-made and test results chased up and re-ordered.

NHS Connecting for Health is working with the NHS to deliver better care to patients by staff who have the latest information at their fingertips. The new era dawning for the NHS involves modern, sophisticated IT that will connect more than 100 000 doctors, 380 000 nurses, and 50 000 other healthcare professionals; benefiting more than 50 million patients in England. Eventually patients, too, will be connected to their health information via a protected link on the Internet called HealthSpace.

The main activities of NHS Connecting for Health include the NHS Care Records Service, Choose and Book, Electronic Transmission of Prescriptions, and the Picture Archiving and Communications Service that will make scans and test results readily available electronically. While it will take ten years

to make all of these changes, some patients are already experiencing the early benefits of Choose and Book. These patients can leave their GP's surgery with a first hospital appointment at a time and place to suit them, or book it later using an online or telephone service. Gradually, over the next few years, more and more patients will reap the benefits.

How can we be sure, though, that the products and services being developed provide patients and the public with the information they need to keep themselves well and get the best care when they need it? To that end, NHS Connecting for Health's PPI team are holding workshops across the country with those people in strategic health authorities and trusts who have a public engagement role - PPI leads, PALS, and communications leads. These workshops look at how developments like the NHS Care Records Service will help create the informed and empowered patient described in the Department of Health's December 2004 document *Better information, better choices, better health* - putting information at the centre of health and what needs to be done locally to ensure patients and the public get the maximum benefit.

Local groups have identified activities and topics they wish to focus on in their workshops. For example, in what we call the southern cluster, local NHS staff including PPI and PALS decided to focus on the impact that the new electronic services will have on the providers and users of mental health services. West Yorkshire PPI teams are hosting a patient jury to focus on security and confidentiality, working closely with a local health consumer council. In Greater Manchester, PPI teams are keen to explore the impact on children's services.

All of these activities will inform the continuing development of electronic information services and the confidentiality management system that underpins them. Another key objective of the workshops is to help and encourage local PPI leads to plan how they want to engage the public and what support they will need to do this. It is important for the public that what they are learning and hearing is reaching them through a local network that they know and trust.

One of the key aspects for patients will

be the NHS Care Records Service that will eventually enable every patient in England to have an integrated electronic health record. In preparation for this, there will be a public information campaign to help the people understand what it means for them, how their information will be kept and shared, the benefits and risks, and what options they have to restrict access to their records. We know from extensive research with patients and the public that the majority of people will be happy with the changes but a minority will have serious concerns. We want to give those with concerns at least three months to consider to what extent they want to participate.

Concerned people will have a variety of ways to get information and advice (NHS Direct, Citizens' Advice and other voluntary sector organisations). Some patients are likely to seek a known and trusted source like PALS. To make sure PALS and other local advisors are prepared, we are meeting with PALS and other networks across the country to talk about the NHS Care Records Service and explore the topics on which patients are likely to be seeking advice, for example, confidentiality. This work is helping PALS teams to prepare themselves and identify the support they need once the public information campaign starts at the end of the year. It is also enabling NHS Connecting for Health to put the support mechanisms in place. One outcome of these meetings is a PALS toolkit consisting of guidance for advisers and answers to patient questions.

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NHS Connecting for Health's PPI team aims to be responsive to the needs of local PPI and PALS colleagues. If you would like to know more or want to contact the PPI team, please contact Karen Foy or visit the website at www.connectingforhealth.nhs.uk

The cancer journey

Patient and public involvement often raises people's desire to be treated as whole people, not as patients. Michail Sanidas reports on an approach to the holistic needs of people living with cancer that one participant described as "the most inclusive event in my experience."

Avon Somerset and Wiltshire Cancer Services (ASWCS) is one of the 34 cancer Networks in England. The ASWCS Network was established in 1996 following the recommendations of the Calman Hine report about the development of cancer services in England. The Network's vision is to reduce the incidence of cancer in our area. It also aims to provide high quality patient focused treatment and care at all stages of the cancer journey.

Patient and public involvement has been a key element of the Network business from day one. ASWCS has signed up enthusiastically to the principles of patient and public involvement. The Network is actively seeking the views of patients and carers in the development and evaluation of local cancer services. Central to the Network's commitment to patient and public involvement is the Network User Involvement Group - a partnership forum where people affected by cancer and health professionals can work together to improve local cancer services.

The importance of addressing the needs of the patients and carers holistically has been a key priority for the Network User Involvement Group. The holistic approach includes social, spiritual, emotional and psychological aspects/needs of the whole cancer journey. Although in the past there has been evidence of individual good practice with regard to the assessment of patients' needs, in many cases these assessments have often been fragmented, have run a high risk of duplication and have not been easily transferable between different organisations or even health care professionals. The importance of addressing those issues in ensuring continuity of care has been highlighted in the several policy documents like the NICE Supportive and Palliative Care Guidance. The issue has also been highlighted in the National Audit Office Patients' Survey (February 2005). The survey revealed that most patients in need of help for stress and anxiety reported that they received such help, but a minority (about a fifth) did not, both

The ASWCS Network was established in 1996 following the recommendations of the Calman Hine report about the development of cancer services in England.

during hospital visits and after discharge. This was often the case because they were not asked or because they did not say they needed it if they were asked. The majority of patients (90 per cent) felt that their religious and cultural beliefs were suitably taken into account, but a minority of patients had no access to a religious counsellor.

A Network workshop was held in Bath in November 2004 that was attended by a wide range of health care professionals, the voluntary sector, service users and carers. The objectives were:

- to identify the principles of the Holistic Needs Assessment at the different stages of the cancer journey
- to assess how different tools for assessing patient needs used locally fit in the Holistic Needs Assessment Framework
- to discuss the way forward

Participants were split into five small

groups. Each group had a diverse mix of health professionals working in different organisations in the Network, voluntary sector representatives and service users. Each group had an opportunity to spend 15 minutes with a facilitator on each table to identify issues for people affected by cancer at different of the cancer journey – pre-diagnosis, diagnosis, treatment, post-treatment and end of life.

The consensus view of those attending the workshop was that whilst it would be beneficial for the Network to devise a Holistic Needs Assessment tool/measure which included specified core information and a series of 'prompts' at each significant stage in the patient journey, it would not be beneficial to have a single tool/measure to be used exclusively across the entire Network. The participants were in agreement that local solutions could be found providing that all the core principles were met and that information was easily transferable should users move around the Network and duplication of assessment did not take place.

The workshop was very well received by all participants. The discussion leaders were briefed to promote inclusive input to the extent where over 100 comments were made. The small group approach meant that both health professionals and people affected by cancer could contribute equally to the proceedings and learn from each other. The write up from the day informed the development of the ASWCS Holistic Needs Assessment Policy. The first draft of the Holistic Needs Assessment Policy was available for comments on the ASWCS website – www.aswcs.nhs.uk/supportivecare/holistic.htm during April and May 2005. The final draft of the policy is being presented to the Network User Group in June 2005.

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Power to the people?

Engaging communities is a process of negotiation in which risk, and the styles of professionals, are critical, finds Mike Shiner.

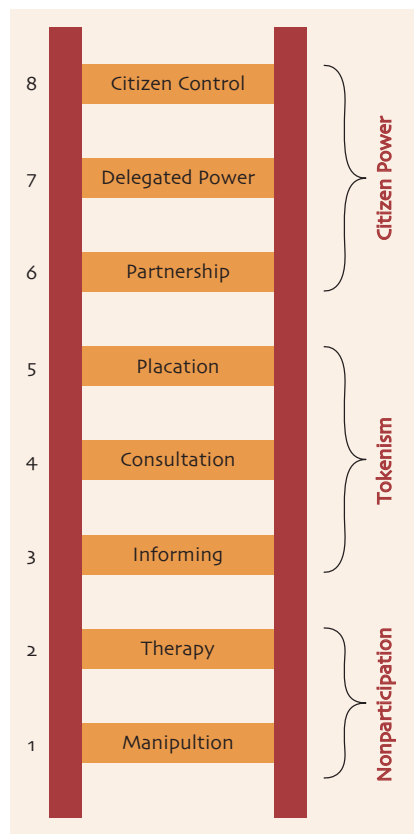
'Community consultation', 'active citizenship', 'public participation', 'user involvement', 'carer involvement' and 'patient empowerment'. These are just some of the 'buzz words' that have come to be used to describe the deceptively simple idea of involving lay people in the development and delivery of public policy. The rationale for such involvement may seem obvious, but that is part of the problem. All too often the appeal and purpose of lay involvement is considered to be self-evident and there is a consequent lack of clarity surrounding such initiatives. Power dynamics, for example, are crucial to the development of such initiatives but are often fudged and are rarely dealt with explicitly.

In the late 1960s, Sheri Arnstein claimed that 'citizen participation' is often an empty ritual because it does not involve the redistribution of power (1969, 216):

The idea of citizen participation is a little like eating spinach: no one is against it in principle because it is good for you. Participation of the governed in their government is, in theory, the cornerstone of democracy – a revered idea that is vigorously applauded by virtually everyone. The applause is reduced to polite handclaps, however, when this principle is advocated by the have-not blacks, Mexicans, Puerto Ricans, Indians, Eskimos, and whites. And when the have-nots define participation as a redistribution of power, the American consensus on the fundamental principle explodes into many shades of outright racial, ethnic, ideological, and political opposition.

In illustrating her argument, Arnstein developed a ladder of participation which distinguished between different levels of citizen participation – from manipulation, where the real aim is 'education' or 'cure', through to citizen control, where 'have not citizens' obtain the majority of decision

Figure 1: Arnstein's Ladder of Citizen Participation



making seats or full managerial power (see Figure 1). According to this framework, it is only at the level of placation that citizens begin to have some degree of influence although tokenism is still apparent here. Consultation may be a legitimate step toward full participation, but remains just a 'window-dressing ritual' unless it is combined with other modes of participation. At the level of partnership, power is redistributed through negotiation and trade-offs between citizens and power holders. In view of Arnstein's critique, the following questions should be central to the development of lay involvement:

■ What are citizens being engaged to do?

■ Which citizens are being engaged?

These questions provided a key focus for recent research exploring community involvement in drugs policy². This research was funded by the Joseph Rowntree Foundation and combined a national survey of professionals, community workers and community activists working in the drugs field with detailed case studies in three separate locations.

It was clear from this research that relationships with professionals are crucial to understanding the role of community responses. Among survey respondents, community involvement was widely supported as a principle but was generally balanced by an emphasis on professional responsibility. Possible tensions between these positions tended to be resolved through an emphasis on 'partnership'. Four main types of 'community' response were identified and partnerships were clearly central to much of what was going on in this area:

■ **Community outreach programmes** depend on the activities of paid professionals but are based in the community or on outreach work and not in institutions. This type of response accounted for 11% of those identified by the survey.

■ **Professional networks** depend on the activities of paid professionals and work in partnership with other professional agencies. Such networks may include some kind of community representation but are neither organised nor led by the community. This type of response accounted for 24% of those identified by the survey.

■ **Community partnerships** are based partly on the activities of paid professionals, but depend mainly on unpaid volunteers and/or community organisation. This type of response accounted for 52% of those identified by the survey.

¹ Arnstein, S.R. (1969) 'A Ladder of Citizen Participation', Journal of the American Institute of Planners, 34(4) 216-224.

² Shiner, M., Thom, B., and MacGregor, S. (2004) Exploring Community Responses to Drugs, York: Joseph Rowntree Foundation.

The idea of citizen participation is a little like eating spinach: no one is against it in principle because it is good for you.

■ **Grass roots initiatives** depend on the activities of unpaid volunteers or on community organisation and not at all on the activities of paid professionals. This type of response accounted for 13% of those identified by the survey.

Partnerships between community and professionals raise important questions of power and may be usefully understood in terms of risk and trust. Professionals risk losing power and influence, while communities risk being involved in ways that are 'tokenistic' and fall short of granting them genuine power and influence. It was evident from the survey that professionals tend to resolve the risks they face by falling back onto models of engagement which give away little decision-making power and limit the community to a 'sensitising' and 'gap filling' role. This orientation was particularly marked among commissioners and policy makers.

Support for community involvement was strongest in relation to those areas of work that are least tightly professionalised (such as education/prevention and campaigning) and was weakest in relation to those areas that are most strongly professionalised (such as treatment and law enforcement). While there was widespread support for community consultation, moreover, there was much less support for community involvement

in management and commissioning. These distinctions reflect anxieties about the way in which lay involvement may limit professional autonomy and were reflected in the types of activity that community responses were actually involved in. While there was considerable evidence of community consultation, for example, there was much less evidence of community involvement in management and commissioning.

Although community partnerships and, to a lesser extent, professional networks provided channels for community involvement, important questions arose about their membership. There was, for example, little evidence of the inclusion of drug users and their carers in strategic decision-making structures. Overall, one-third of the initiatives identified by the survey pointed to user involvement in management committees and steering groups, but such involvement was concentrated in community partnerships and was much less evident in professional networks.

The case studies indicated that issues of risk and trust play out differently depending on the role that professionals adopt. Three main styles of professional involvement were identified:

- **Professionals as sponsors:** professionals identify individuals in the community whom they feel they can trust and effectively promote them and their activities. Within this style, professionals tend to take an arms-length approach to the day-to-day activities of the community response.
- **Professionals as ideas brokers:** professionals identify an approach to community involvement which is implemented by a third party who acts as a mediator between professionals and the community.
- **Professionals as nurturers:** professionals identify an approach to community involvement and are actively engaged in its implementation. This is the most 'hands on' of the approaches and raises important issues of ownership.

Professionals as sponsors focused on 'respectable' elements of the community and on recruiting 'low risk' partners who could be trusted to work within the parameters set by official policy. Professionals as ideas brokers

worked through intermediaries who helped to build trust and manage risk. Professionals as nurturers adopted a developmental approach which included an extensive period of trust-building early on and incorporated diverse community interests, including some that may be considered 'high risk' (such as drug users and their carers).

Although the principle of community involvement is widely supported, there is little agreement as to what this might mean or what form it should take. One of the main messages to emerge from the study was that community involvement generates genuine dilemmas that cannot be resolved through simple formulaic solutions. The prospect of lay involvement may pose risks to professional autonomy and, faced with these risks, many professionals seem to fall back onto models of community engagement which give away little decision-making power. Such passive forms of community involvement can easily feed concerns about 'tokenism' and run the risk of alienating and frustrating community members who feel disempowered. Equally, however, approaches that rely on intense levels of community involvement may break down because community members are not prepared to take on responsibilities which they see as rightly belonging to professionals.

In this context, community engagement should be seen as a process rather than an event, which depends upon the ability to manage distinct, and sometimes competing, interests and demands. An ongoing process of negotiation and review is required which includes an explicit focus on building trust between stakeholders and gaining agreement over respective roles and responsibilities. Professionals have a key role to play in this process – either as sponsors, ideas brokers and nurturers – and their role may usefully be framed in terms of risk-taking and risk-management.

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A summary of Exploring Community Responses to Drugs is available free from the Joseph Rowntree Foundation at www.jrf.org.uk/knowledge/findings/socialpolicy/d44.asp

Moving Art

Philip Dixon-Phillips is Chair of the UK Federation of Smaller Mental Health Charities. He has recently been campaigning against the Government's draft Mental Health Bill, and also provides training on a range of service user and carer issues. Philip is a key figure behind the 'Moving Art' project to bring attention to 'lost and hidden' art created by mental health service users. He was interviewed by Andy Cowper.

How important is making art to mental health service users, and to their stake and role in the community?

I can't give a blanket answer: people who make art each have their own individual take. From the mental health service user artists I met, the outlet makes them feel empowered, and helps them to see themselves as an artist instead of the label of a diagnosis. These are assertive, astute and attuned people, who will say exactly what they think!

How have artists' work become lost or hidden?

It's a very strange thing, and there are a range of causes. I came across one artist who said that the Department of Work and Pensions' predecessor, the Department of Health and Social Security, had accused his girlfriend (also an artist) of selling her work, and stopped her benefits. She got into financial difficulties, and subsequently committed suicide. I learned that this guy (her boyfriend) was making marvellous art but wouldn't release or show it in his lifetime as a protest. He was writing about it, but it would only be released posthumously.

When I went to Millennium Awards, I was talking to other people who mentioned the 'lost art' that had been created primarily for therapeutic purposes and not really to display, or had been left in abandoned asylums. Claybury Hospital, a facility I attended, was shut almost overnight, and 2/3 of it was bulldozed in short order. And what happened there was that art with a real frisson was bulldozed, and taken away with the topsoil – and that's truly lost art!

Another kind of loss was an archive of service users' art from north-west Birmingham, ten years ago. They were streets ahead of what I'd found in Redbridge, where I live – they taught me how to apply for more benefits, and how to enjoy creative sessions with music and art. One woman from there showed me an impressive archive, and that was another lost art – little, parochial

events that had been archived, but not going anywhere or being seen. When I got in touch with her recently, she said that she'd moved from her flat to a boat on the canal, and she'd ditched the archive: lost the lost art. Which is a real pity because there was some really funny stuff, like a video of an Elvis impersonator who was doing karaoke

with the few lines of the songs he could remember. It was like modern sampling! He was a dyslexic, and when someone handed him a lyric book, he just threw it up in the air – he wasn't going to crawl away and say 'I'm dyslexic, so I can't read that'. He didn't want to hide – he was performing.

Do service user artists still have problems with the Department of Work and Pensions?

When I started to seek funding for the project and mentioned this example in an application, I was told that I was engaging in political campaigning and I had to exclude that clause – the very issue I wanted to be getting on with was one I couldn't address. Why should they not be supported as artists by the benefits system? I'm told that the DWP's message now shows a complete sea change, and that things have really changed and moved on. But I don't believe it.

You teamed up with an active user-led self-help group from Cambridge called Lifecraft, with whom the 'Moving Art' concepts emerged. What were these concepts?

It was Lifecraft who came up with the phrase 'Moving Art'. There's a double meaning, as we planned to move the shows from Jarrow to London (like the 1930s marches), as well as 'moving' in the emotional sense.

We wanted to link the inner city with semi-rural and rural communities, who a few years ago were arguing that they were being left behind. This developed into the idea about marching from Jarrow to London, to move the work around to benefit different audiences.

It was very exciting when bigger groups, like Core Arts, Mind the Gap and Reflections magazine started asking to come and join what we were doing.

You brought the work to people in venues ranging from traditional gallery spaces to pubs and a NatPaCT conference. What did you learn about the different types of audience and reception?

It was Lifecraft who came up with the phrase 'Moving Art'. There's a double meaning, as we planned to move the shows from Jarrow to London (like the 1930s marches), as well as 'moving' in the emotional sense.

In the pub, you're up against public perception mocking and scoffing at mental illness. They saw the art, and some would then come out with their own or family's and friends' problems, and wanting informal counselling sessions, and to be signposted. So you got the exact opposite of the usual taboo and stigma! That help we gave them then made the people want to pay more for pieces of work as donations, and that led to press and media interest.

Who were the 'hardest crowd'?

I would say the NatPaCT people in London. It seemed like a lot of people there were posing and careerist, and the concept of what we were doing was frightening or exciting them, maybe pulling off their blinkers. Our other fear is that they (having more money) could rip off the idea, botch it up and it would all go out of our control. So we put our ideas out on little cards promoting the project and went to the bar, and when we can back, they'd all been taken.

How did you avoid making the artists feel like guinea pigs at your events?

They did it to me! It was my blinkers coming off, and me finding a whole different take on life. One of my favourite artists had drawn psychiatrists in top hats and a pig on a crucifix, and a whole new debate opened up about how free you can be as an artist to offend or insult. How far can you go? This artist said he was painting to express how he felt when he was going insane, some of which was brought on by prescription drugs.

What was your idea about a "purpose-built London square" involving Moving Art?

A while ago, I read that the London Mayor Ken Livingstone was trying to get London squares revamped to create different spaces. We thought about the areas that ex-pats or immigrants create abroad (like a Chinatown or a Latin quarter): places where newly arrived people go to get useful information and learn the ropes and feel at home. We thought about making some mini-community like that for mental health service users, who like anyone else, come to London all the time, from all over the world.

What will be the legacy of the project?

We plan to make a website for the art. The idea for this website was that the art would be available for anybody who wanted it to

view, or print off for free. If they wanted to buy it, the original drawing, then that could be negotiated with the artist and 20% would go to non-profit fund for Moving Art – 80% to the artist.

Unfortunately, Taffy from Lifecraft – who was our leading web person – has relapsed. He, Dave Richardson and Alan Rogerson have all gone underground. But the steering group is still in place. When the current director is replaced, then we'll link up again later and move forward on this.

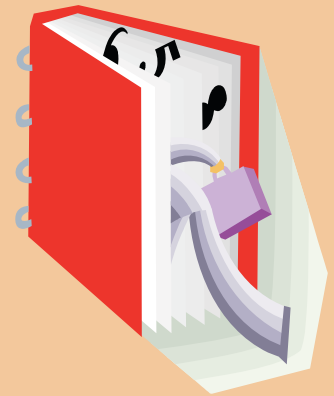
It was at first decided to repeat the kinds of activities that had turned out to be so successful there and to plan a march.

The original plan for 'Moving Art' was that artwork and performance would be showcased in the north of England as a means of advertising the Project and its aims. This would offer opportunity for yet more groups of artists / performers to gravitate towards 'Moving Art'. So that eventually a huge contingent of others like them – ready and willing to travel from Jarrow to London – would be created. We overstretched the idea of taking the work from Jarrow to London physically. But it's okay to have an idea and for things to change.

Personally, I was delighted when Taffy suggested that I should frame my own art therapy work for display. I got overjoyed by that thought – that I could make this art too. There are other personal examples of what it means. At one show, when a psychiatrist (Lewis Loren, from Zarragosa) said he would take a painting to display at a conference in New York, the artist, Angie Sheaf from 'Lifecraft', could hardly contain her delight at this having happened for her. It was a joy to watch people becoming so happy because of the project's existence.

Special thanks to Philip Dixon-Phillips for his kind co-operation in the preparation of this interview.

Andy Cowper is a freelance journalist specialising in health management issues. He is also editor of British Journal of Health Care Management.



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Forward to the past?

"Accentuate the positive ... eliminate the negative." It is a great song and, as a self-management trainer versed in the power of positive self-talk, it is a big part of Ian Hayes' personal 'coping strategy'. Yet he is finding it quite difficult to find 'positives' in the future arrangements for patient and public involvement.

Following the Queen's Speech, the scene is set for the abolition of the Commission for Patient and Public Involvement in Health (CPPIH). We all get wedded to projects we have been involved with, but I am no great lover of organisations for themselves. The one unequivocal 'positive' in future arrangements is the continuation of PPI forums.

If we were looking forward to a streamlined system, led by self-determining PPI forums, engaging communities in all their diversity where decisions are taken, then I would be delighted. But what we seem likely to get is:

- a smaller number of forums aligned with primary care trust (PCT) areas
- forums with a narrower focus on monitoring NHS services rather than involvement in health
- less scope for forums to determine their own working methods
- no independent national voice for forums.

This is a recipe for weaker PPI forums. Remote organisations, run by a strong, appointed chair and linked to NHS boundaries, feels like a return to the worst aspects of the community health council (CHC) system. At least the vocal minority of ex-CHC members who have criticised the current system, rather than working to maximise its potential, will be pleased.

I was at my local dental hospital last week; maybe this explains my general pessimism. The treatment gave me much food for thought – not least a mid-extraction musing about how you can be an 'autonomous patient' when someone has their hand and the contents of a garden shed in your mouth! I saw at first hand some of the practical problems from the 'crisis in NHS dentistry' and why so many PPI forums have been looking at aspects of dental services.

I jotted down a few points about my experience that I thought might be of interest to the PPI forum – not complaints,

just ideas. Having sent them off, I was left wondering what I would do under the new arrangements. The dental hospital I use runs a specialist service, it is outside of the PCT area where I live and relatively few people from there will need to use it. Currently it is easy: I can address my thoughts to the forum for the trust of which the hospital is part; I could even become a member of that forum. But I presume that in the future I will need to talk to my local PCT forum. But as it is a specialist service, are they going to have a sub-committee for specialist dentistry? How will they get members with experience?

Mine is a small example but it illustrates some problems which will result from the loss of the PPI forums for provider trusts. People travel to use services, particularly if they live in rural areas. 'Choice' will accentuate rather than diminish this tendency. Services are becoming ever more specialist and the people for whom health services have the greatest overall impact on life tend to be those who are using specialist services.

In an ideal world, I would want to be looking forward to more PPI forums rather than less, bringing involvement closer to the actual points where people experience their health care. This would require a diversity of form and working method which seems to run counter to the direction we are moving in but it would preserve the most valuable aspects of involvement.

One of the strongest concerns has been about the possible loss of PPI forums for mental health and learning difficulty services. These have been carrying out some of the most important and interesting work – examples include reviewing prison mental health services and looking at the needs of asylum seekers. They have been forming their own networks to address issues of common concern and are the least likely to follow a standard 'chair and members' format.

Once again, it would be the involvement of people whose lives are most impacted by the services they receive who will be adversely affected by a move to forums based on PCT areas. The loss of forums directly focussed upon mental health services would almost certainly result in a reduction in involvement of people who would not be part of larger, more formal bodies based on geography rather than services.

Involvement ought to work best when it is structured in a way that mirrors how people experience services. For many of us, the relationship of our PCT to that experience is abstract at best.

Ian Hayes

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Following the Queen's Speech, the scene is set for the abolition of the Commission for Patient and Public Involvement in Health (CPPIH).

Stories that change your life

Communities can challenge health inequalities, as a new book of stories shows. Bec Hanley and colleagues report.

We all hear about these and many other statistics that are used to illustrate how where you are born, where you grow up and what you do for a living can affect both how long you live and the quality of your life

Tackling inequalities in health seems a huge mountain to climb. What can people working in PPI do to contribute to this process? In February 2004, around 150 people from primary care trusts (PCTs) and local communities came together for a conference, organised by the Engaging Communities Learning Network (ECLN) and Middlesbrough PCT. Our focus was how communities could work in partnership with PCTs to tackle health inequalities. A number of people shared their stories, and many participants were motivated and moved by what they heard.

The ECLN then asked PCTs what further support they would like to help them to work in partnership with local communities to tackle health inequalities. A new collection of stories, published in February 2005, is the result.

"Stories that can change your life: communities challenge health inequalities" contains nine stories that describe how people within PCTs have begun to ensure that engaging communities to reduce health inequalities is part of the mainstream work of the PCT. These include a project with Middlesbrough Football Club in which 25,000 children have learnt about healthy lifestyles from football stars, a fresh fruit and vegetable co-operative in the North East and a 'community mothers' project in Thurrock.

Here's a flavour of two of the stories:

Transport and health in Easington.

Derisive laughter at a public meeting began a chain of events which has led to a major rethink of transport in Easington PCT, County Durham. The meeting was part of a major review of services by the Strategic Health Authority. One contributor presented a mapping exercise to show how patients could access local hospitals. It was at this point that the laughter began. Local people at the meeting felt that the exercise bore no relation to reality, and they challenged Roger Bolas, the Chief Executive of Easington PCT, to try a typical journey. Roger took up the

challenge. He took a child in a buggy from a village in the area to Hartlepool Hospital. He took the opportunity to talk to other passengers about their experience of public transport.

Easington PCT covers a semi-rural area. The district has one of the lowest car ownership figures in the country – 37% of households do not have access to a car. It also has amongst the highest levels of deprivation outside London. 19 per cent of adults in Easington have long term limiting illness. There is no district general hospital in the area.

Following Roger Bolas' bus journey, Liz Allan, the PCT's PPI Lead, asked members of the PPI Forum to undertake other typical journeys. The PCT is now looking at what can be done to improve transport. It has obtained money to put on special bus services to local hospitals, and hope that in future there will be a dial-and-ride facility. Using core funding, the PCT has also built a transport solution into out-of-hours provision. It is trying to obtain further funding to look at creative ways of getting health services nearer to where people live.

The issue of transport has gone from the grassroots level, at community meetings, all the way to becoming an integral part of local strategy and planning. The Board of the PCT and the whole organisation is now committed to bringing services nearer to where people live.

The Ujala Health Project.

A community group in Southampton has produced beautiful and original textiles as a result of their partnership with Southampton City PCT.

A group of Asian elders who were already meeting regularly approached Dawn Buck, Public Involvement Manager at the PCT, with a request for help. They wanted to set up a project to find out more about how to access local services, but also to learn more about specific diseases such as diabetes and coronary heart disease and to do something creative.

The Trust was able to give the group a small grant. The Ujala Health Project then met weekly. At each meeting a health professional spoke to the group, then the group translated what they had learned into a quilt.

Each piece on the quilt symbolises a health or social care service. As they made it, the group pieced together their own knowledge of

welfare systems in Britain, and are now able to access services far more confidently. They also put together recipe cards with healthy meals, following the advice of a dietician. Those who attended were able to cascade what they had learned. They also regularly share the quilt with other community groups.

The Trust felt the project demonstrated good partnership working. The health professionals involved also saw a benefit. For many of them, this was the first time they had worked with interpreters. Even though some of the Trust's literature had previously been translated into the main languages spoken locally, the project has resulted in a greater awareness of language issues.

The project has changed the focus of some of the work in the Trust. As Dawn explains, 'This project has helped us realise that we get far better engagement if we go out to people where they are, instead of expecting them to come to us.'

The project has also had a direct impact on the services offered by a local GP surgery. They now run a Diabetes User Group which has proved popular.

Ranjan Patel coordinated the Ujala Health Project. She says, "It was very helpful and productive. People are often only interested in the conditions they or their families have, but in this project they learnt about others and it was a real eye opener. The most outstanding result of the project is now Ujala members are doing exercise on a regular basis. The group continues to meet, and every week a professional exercise instructor comes in and leads exercise for half an hour."

We hope that the stories in this new publication will motivate and inspire you to take action, in partnership with local people, to challenge health inequalities. Each story contains the contact details of one person who was centrally involved – so that you can find out more if you'd like to undertake a similar project in your area.

Sue Cavill, NHS Modernisation Agency
Bec Hanley, ECLN Project Facilitator
Alison Kirk, Eastern Leicester PCT
Rutuja Kulkarni, Slough PCT

For a free copy of the stories, contact the Department of Health response line on 08701 555455, or email ma@prolog.uk.com. Please quote reference NATPACTHI.

For more information about ECLN, visit www.natpact.nhs.uk.

NHS foundation trusts - new op

After the controversy, NHS foundation trusts are here to stay. They offer real potential to develop PPI in new ways, argues Lance Gardner.

After two years of prolonged and often acrimonious debate, the Health and Social Care Act 2003 finally paved the way for NHS foundation trusts (NHSFTs) to come to fruition.

Whatever the pros and cons that surround NHS foundation trusts, their creation certainly led to an enormous amount of debate and discussion about what effective patient and public involvement (PPI) could mean for these organisations.

Two key features set NHS foundation trusts apart from other NHS trusts in respect to PPI:

- they have a membership
- they have a Board of Governors with an elected public majority

However, the overall objective for both of these initiatives was for the membership, through the Board of Governors, to shape the long-term future strategy of each NHSFT.

The Membership

The law allows for an NHS foundation trust to propose what its membership constituency might look like. The membership must, however, be voluntary and open to anyone who lives within the boundary of the local authority in which the main hospital site is situated. It must also include previous patients during a defined period, usually up to three years. Somewhat controversially, there was no age limit set for membership of an NHSFT, a fact that was described as "crackers" by members of the Health Select Committee, but was welcomed by some trusts. There were some late amendments to the Bill, which enabled University Hospital Birmingham NHS Trust to make all their patients during a three-month period become members unless they opted out. Sadly, the Department of Health took the very conservative stance of insisting that all votes by members must be postal, thereby ignoring the opportunities to test new methods of engagement such as via telephone, electronically, in person or by digital TV.

The Board of Governors

From a governance perspective, the Board of Governors is a unique concept, which many other corporate bodies from the public and private sector are watching with interest. The Board of Governors must have a public majority of at least one over a group of other stakeholders, which includes staff, primary care trusts, the local authority, and the university if the hospital is a teaching trust. Again, no size was stipulated for the Board of Governors, which in the first wave of NHS foundation trusts ranges from 12 to 53. Controversially, the Chair of the Board of Governors is also the Chair of the Board of Directors, but they are not classed as a governor and therefore cannot vote.

Ironically, the Proposed governance structures for each trust had to be formally consulted upon, and this consultation

exercise was often the final act of the departing community health council.

During the often stormy passage of the Health and Social Care Act through Parliament there was lengthy debate around whether or not each NHSFT should have an equivalent PPI forum. When Alan Milburn was Secretary of State he was adamant that they should not, based on his firm belief that the proposed governance arrangements would fulfil a trust's PPI functions. When John Reid became Secretary of State, however, there was prolonged debate about whether the governance arrangements really did carry the same mandate as the PPI forums to represent the patients and public views on services provided.

In light of these discussions a model was developed to clarify the respective roles of these resolve these two apparently conflicting PPI mechanisms. NHSFT governors were deemed to be directing and shaping future care, whilst the PPI forum would react and respond to service provision that had been delivered or was being introduced. In short, the PPI forum should deal with issues relating to the past or the present, but the members and the governors will concentrate on the future. The case studies show that some NHSFTs saw the value of this relationship and created seats on the governing body for PPI forum members to foster pragmatic lines of communication. Trusts began to recognise that the PPI forum and the governors need to feed each other with intelligence or anecdotal reporting. This requires governors to redirect or report on patient experience and patient stories to the PPI forum, thereby ensuring a united and cohesive PPI perspective to the PCT commissioning process. There should be equal emphasis on the PPI forum to identify key areas of concern for the governors to address with the trust as part of its strategic development process.

One approach explored by several NHSFTs was to create a sub-committee structure [see figure 1]. This was seen as an excellent way to develop a mechanism to promote

Whatever the pros and cons that surround NHS foundation trusts, their creation certainly led to an enormous amount of debate and discussion about what effective patient and public involvement (PPI) could mean for these organisations.

opportunities for PPI

For all its faults, NHS foundation trust status can provide an opportunity to pull together a citizen perspective across a health economy and ensure a cohesive set of objectives and goals.

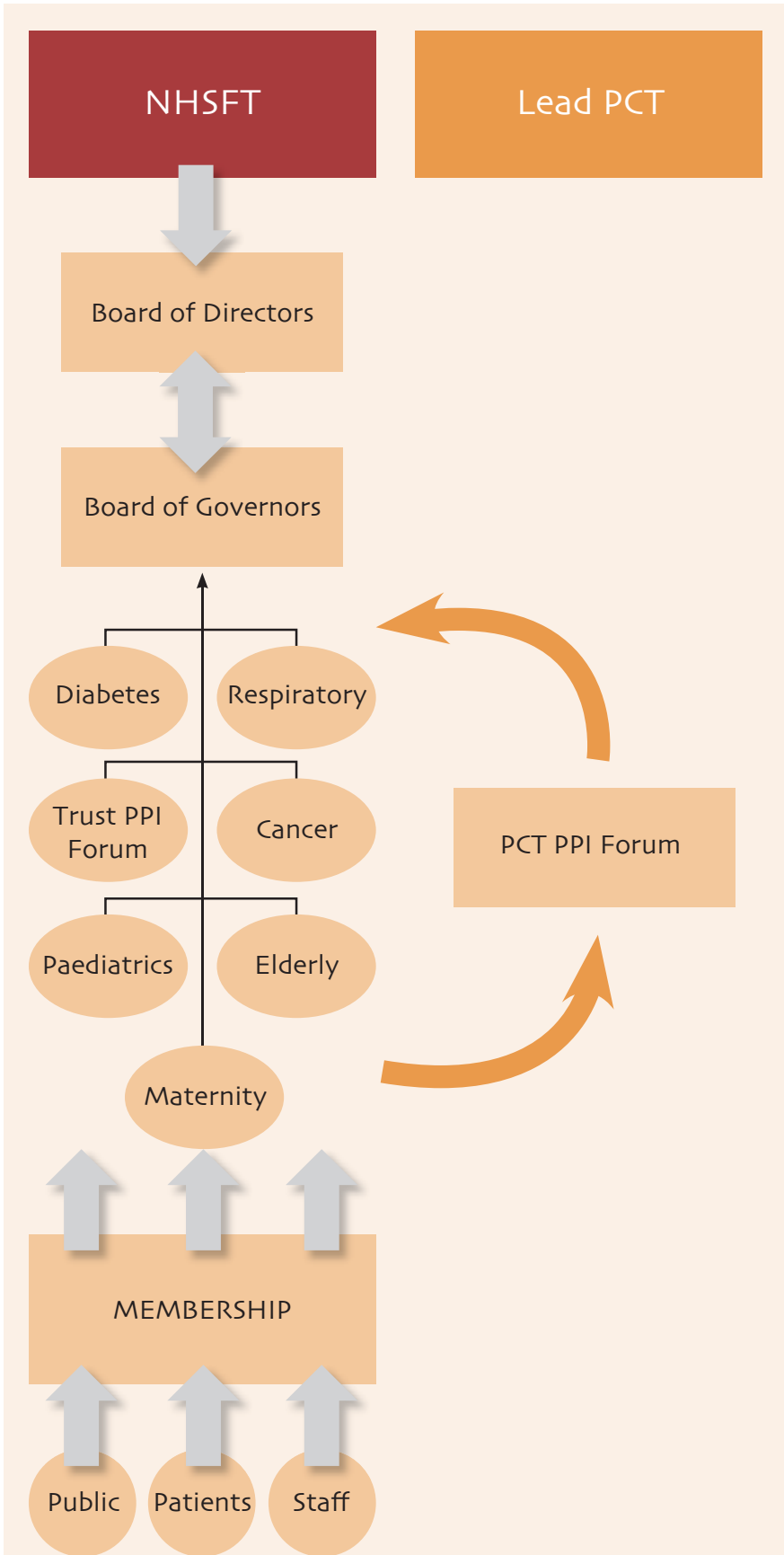
a much more active membership. The idea was to create clinical sub-groups chaired by a governor and made up of patient and public members working alongside staff members to develop strategies for specific disease areas such as diabetes, rheumatology, paediatrics and care of older people. These sub-committees can be empowered to receive reports and intelligence from the PPI forum as well as passing on information that they may gain from personal experience or anecdotally. PPI forum members would be encouraged to sit on the sub-committees and, equally, the NHSFT members would be asked to consider becoming PPI forum members as positions become available.

For all its faults, NHS foundation trust status can provide an opportunity to pull together a citizen perspective across a health economy and ensure a cohesive set of objectives and goals. If this can be achieved, it will give local citizens a distinct advantage over the NHSFT and the primary care trusts, which are often locked in adversarial roles.

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Lessons Learned

For many years, Community Action on Health has been a pioneer in supporting community-driven approaches to engaging in health issues. Nick Forbes explains its ethos and practice.

Community Action on Health (CAH) is an independent charity in Newcastle upon Tyne, funded mainly by the local Primary Care Trust. We support networks of communities and groups in Newcastle, particularly those considered most marginalised and disadvantaged, who have something to say about health.

Our starting point is local communities. We are here to help communities define their own health agenda, rather than make them work from agendas imposed by government and/or other interests. We recognise that local communities are best placed to identify their own health needs – they simply need help sometimes to identify health issues and get their messages across to decision-makers. NHS consultation processes, inevitably, start by asking a question about a particular service or issue. By the time local communities have a chance to comment, the questions have been shaped and defined by people often steeped in Health Service culture and practice.

The whole CAH ethos is built upon helping develop community agendas from community voices. We do this in a variety of ways, including 'community conferences'. We recently held one at St. James' Park (home of Newcastle United). Over 550 people involved in community groups in the city came together to talk about health issues.

The conference gave people the opportunity to:

- hear feedback / progress about issues raised at previous events, so that they understood the context in which issues were discussed and heard about the progress made over the previous year
- talk about what health issues are important to them for the following year, to say what could be changed to make it easier to use services, or to share ideas about ways to improve the health of people in their community
- speak directly to managers and decision-makers in key organisations about issues that are important to them; the opportunity to share experiences and

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ideas with service planners and providers is highly valued by both groups

- meet with others, work together to tackle shared issues and gain collective strength; by providing structured opportunities for people to work together, we contribute to the development of stronger community networks

Over one-third of attendees were from black and ethnic minority community groups. The conference report summarised all of the issues raised, and has formed the basis of our work programme for the coming year.

Our model of working relies on the existence of local community groups and other community workers. This working approach has advantages in that we are able to enhance work already under way and help build trusting networks between groups. It can be difficult, however, to work in areas where there are few groups and/or where groups are not strong. In one part of the city, for example, we have spent a great deal of time doing basic work to develop community groups and build relationships between them and health care decision-makers. This has highlighted the need for community development resources to be more closely matched to community needs, rather than being allocated according to historical circumstances.

We recently had an independent evaluation carried out into our work, and it found a number of factors critical to our success. Our 'community development' approach; our networking approach across many agencies at many levels; and that the kind

of partnerships we initiate and help develop are vital for effective communication, to facilitate understanding and to bring about real change where change is required. The CAH conferences were also noted as effective mechanisms for influencing policy decision-makers.

The constructive approach we adopt was described as one of the reasons why change is brought about. We try to avoid criticising for the sake of it, but instead aim to offer useful suggestions and advice to decision-makers wherever possible. And we are flexible – we do not use a 'one size fits all' model – we adapt working practices to reflect local community circumstances. No two communities are the same, and we work in the most appropriate way, doing the most appropriate things, depending upon local community needs and aspirations.

CAH's check list of 'lessons learned'.

Effective engagement with communities takes time and resources. It should not be an 'add-on' to someone's job – it is a skilled role that needs professional expertise.

Adequate support (interpreters, crèche, transport, refreshments, etc.) must be budgeted for if marginalised and disadvantaged groups are to be given the opportunity to participate.

The perception of independence is a critical factor in gaining the long-term trust of local communities.

It is important to start with the actual views of communities, rather than the views of statutory organisations or with pre-conceived notions about what communities want.

Communities are not homogenous and will often appear to want different things. This diversity of views should be noted and respected, and the prospect of conflict should be anticipated.

It is important to listen to local communities, but it is even more important to turn what people say into action plans and deliver on them. Long-term engagement relies on people knowing that getting involved makes a difference.

Nick Forbes

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Last Word from Chris Dabbs



Dear Mrs. Buggins,

I hope that you enjoyed the healthy eating sessions this week. It was great to see local people experiencing new foods and meals from different cultures.

It astounds me that most doctors and nurses receive little if any education about nutrition and its role in health and in managing illness. Although food is something all of us have to have, the clinical focus tends to be on medicines. Yet food is unavoidable, often cheaper and tends to have fewer side effects.

Our recent activities reminded me of the work by Professor Kikunae Ikeda in Tokyo a century ago. He thought that, beyond bitter, salt, sour and sweet, there is another taste. This is in protein-rich foods like asparagus, broccoli, grapes, mushrooms, seaweed and walnuts, fermented foods such as Parmesan and Roquefort cheeses, and soy, tomato and fish sauces. The taste makes your mouth feel as though it is expanding inside. It is the culinary equivalent of Dr. Who's Tardis.

Ikeda called the 'fifth taste' umami (delicious flavour), and found that glutamate is its essence, most intense when combined with sodium. It is considered basic in cooking in Japan and in China (where it is called xianwei). In the East, the word has a spiritual quality, associated with perfection in taste or an emotional circumstance in which a taste is experienced. The appearance, smell, texture and even the sound of each food all make a significant difference to our eating pleasure.

Although a century has passed since Ikeda's work, umami has only recently been recognised in western cuisine, despite the fact that he created the widely used seasoning we know as monosodium glutamate. (By the way, it is a myth – disproven by scientific

research – that MSG can be bad for you, even in significant quantities).

If many of us have gone through life mistakenly thinking that there were only four tastes, I wonder what other things might be known but unrecognised.

For example, about much patient and public involvement work in health directly addresses nutrition? This is a key factor in health in which most knowledge is held by lay people. Some of the best involvement work I know is led by elders working with younger neighbours in their own communities to learn about making good meals on low incomes or with limited products available in local shops.

Most of us are also aware of the continuing problems about adequate nutrition of patients in hospitals and nursing homes, whether this is about the nature of the food or the physical process of eating. There is some evidence, including for example through the local procurement of foods by the NHS in Cornwall, that people get better quicker (and may be discharged earlier) if they eat fresh food that they enjoy.

Simple stuff that lay people know about and in which they can confidently engage. Perhaps we are sometimes taken too far along a clinical or pharmaceutical path in PPI, when maybe we are overlooking some (very tasty) things literally under our noses.

Keep well

Chris

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

EVENTS CALENDAR

Involving Patients in Clinical Audit

Thursday 15th September 2005

Britannia Hotel, Birmingham,
B2 4RX (next to train station)

9:30am - 4:00pm
(refreshments and lunch provided)

Cost: £100 (vat inc.) per delegate

Programme:

1. Introduction to clinical audit
2. Why to involve patients (national/ local)
3. Ways of working with patients
4. Clinical Audit Patient Panels - How to set up your own panel
5. Example Audit projects - practical feedback
6. Benefits - staff and patients

Spaces are limited, therefore places will be held by confirmation email and by prompt payment.

Confirmations of interest should be sent including full details: number of attendees, name, title, payment address and email.

Emma Challans, Clinical Effectiveness
Manager, Sheffield South West Primary
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The Smoke Free NHS

How to make your Trust smoke
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