

PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

Waiting getting better say patients

Hospital patients say they are waiting less time for emergency treatment and outpatient appointments, according to two major surveys of patient opinion published by the independent Healthcare Commission.

However, the findings also suggest that further improvements are needed. In particular, patients want greater information from clinicians on treatment and higher standards of cleanliness in hospitals.

The Healthcare Commission has carried out two surveys in which 140,000 patients gave their perception of local outpatient clinics and emergency departments.

The surveys, representing one of the biggest national tests of patient attitudes, will be closely watched as they provide an indicator of whether patients believe that services are really improving. Findings from these patient surveys will be used by the Healthcare Commission in future inspections and in the formulation of the trust's star ratings in 2005. Where there are areas for concern, the Commission will review the issue in detail with the individual trust.

Patients highlighted a number of areas for further improvement including:-

- Cleanliness of emergency departments
- Cleanliness of out-patient departments
- 20% of out patients felt they were not getting the right amount of information for them to be fully involved in their care
- 51% of patients leaving A&E were not given information regarding possible side effects of new medication
- In terms of patient choice, 70% of patients said they were not given a choice of appointment times, but of those only 23% expressed a desire to have the choice

Anna Walker, chief executive of the Healthcare Commission said: "This survey is very encouraging, and it is particularly good to see patients are beginning to experience a reduction in waiting times. People who are sceptical of the NHS should take note of what patients are actually saying, as it is clear how much they value the services on offer."

"There is much to celebrate but patients still, and rightly so, expect further improvement in their health service. Patients are sending a very clear message that they want more involvement in decisions on their treatment and that current standards of cleanliness are still not good enough. That must improve."

The full report can be downloaded from www.healthcarecommission.org.uk

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Sisters are doing it for themselves - In Newcastle local women didn't have to wait to get 'engaged' before making a positive response to health issues. Anne Carlile explains

Bash Street

In the days before video games, DVDs and surround sound, we did this rather eccentric thing. We read comics.

What a simple world it was back then. Saving your pocket money for a whole week to purchase the Beano, Dandy, Hotspur, Valiant or in the case of the girls Twinkle or something of that sort.

My favourite character was one of the Bash Street kids. He was the one that walked around with a questionmark permanently suspended in mid air just above his head. This left me with rather a quirky little habit, which I only embarrassingly found out that I had when I was in adulthood.

Because there is no sound to go with a questionmark, unconsciously I had invented one. Ever since I was a child I had always used the soft sound of a letter 'f' as in 'fur' to denote a questionmark. So each time I read the Bash Street kids and this character appeared looking quizzical, I would always make the sound 'f', as I did whenever I read a question. I would always sound the questionmark. That is until I did it out loud once.

I was asked "Why do you keep making that noise at the end of sentences". A questionmark must have appeared above my head. "What sound?" I said. "That 'fu' noise that you keep making". I hope that there is someone else out there that has suffered from the same affliction.

All of this springs to mind, because I heard a radio presenter asking people to call in with any real life stories about unlikely episodes that they had seen in comics. Someone said that they were disappointed not to have ever seen somebody who had swallowed an anvil with an anvil shape formed in their neck. Another complained that there never seemed to be enough mashed potato to make the sausages point upwards like they do in comics. A third bemoaned the fact that in all her years sitting in hospital waiting areas, she had never yet seen anybody with a pan stuck on their heads.

It seems that we are all increasingly unlikely to. According to a survey of patients commissioned by the Healthcare Commission, we are waiting around much less than we used to.

Now, 77% of patients report that their stay in the emergency department was no more than four hours, compared with 69% in 2003. Outpatients also reported shorter waiting times, with 80% of patients being given an appointment within three months, a five percent improvement on the previous year. Whilst time spent waiting in the outpatient department was also reported to have decreased, with 55% of patients waiting 15 minutes or less and 10% waiting more than one hour.

This is great news. The numbers are looking good. Yet we still have work to do in properly engaging with patients. According to the Healthcare Commissions press release "Only 49% of patients leaving A&E were given any information regarding possible side effects of new medication".

To put it another way more than half were given no information whatsoever. They left A&E with a questionmark floating in mid air above their heads, just like the Bash Street kid.

If we are to properly engage with people there is a lot more work to be done here.

Don't you think 'f'.

EDITORIAL ADVISORY BOARD

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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).

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.

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

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

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

David Gilbert

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

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News items

First ever global patients' congress

Leaders of over sixty associations from twenty-one countries came together in London during February, to mark the first Global Patient Congress.

Organised by the International Alliance of Patient Organisations (IAPO), the intention was to share experiences and develop strategies to improve patient involvement and patient-health professional relationships across the world.

The congress is seen as a vital step towards a global Manifesto for Patient-Centred Healthcare. IAPO Chair Albert van der Zeijden said "Research over the past ten years has shown that in patient-centred systems, patients are better able to manage their health and healthcare, cost less to health systems and are more likely to actively engage in shaping effective health policies.

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Know someone who should get recognised

Applications and nominations for the 2005 Health and Social Care Awards are now open to all organisations, sectors and professions in health and social care. The entry process closes on 29 April.

There are sixteen award categories, all of which will use the same core criteria for judging are:

People centred approach

- Seeing things through the eyes of patients, users and their families
- Supporting patients, users and carers to make genuine choices and informed decisions

Impact on patients, users, carers and staff

- Delivering clear improvements in the

health, comfort, safety and satisfaction of patients and users

- Helping staff achieve fulfilling, productive and balanced working lives

Team-working and cooperation

- Working across professions and organisation boundaries to improve the wellbeing of patients and users
- Setting clear aims and building relationships with colleagues based on mutual trust and respect of all backgrounds
- Evidence that this is not a "one-off" change but an approach that is being spread more widely

Patient and Public Involvement

- Actively seeking and using feedback of patient and user experiences
- Engaging with the local community to ensure the development and delivery of appropriate services

Reducing Burdens

- Ensuring that patients and users find services easy to understand, access and make use of
- Minimising the burdens of bureaucracy so that resources are used effectively

For more information, see www.healthandsocialcareawards.org

EPP to be mainstreamed

Chief Medical Officer, Sir Liam Donaldson has instructed all PCTs to mainstream the Expert Patient Programme (EPP) by 2008, and to include it in this year's delivery plans.

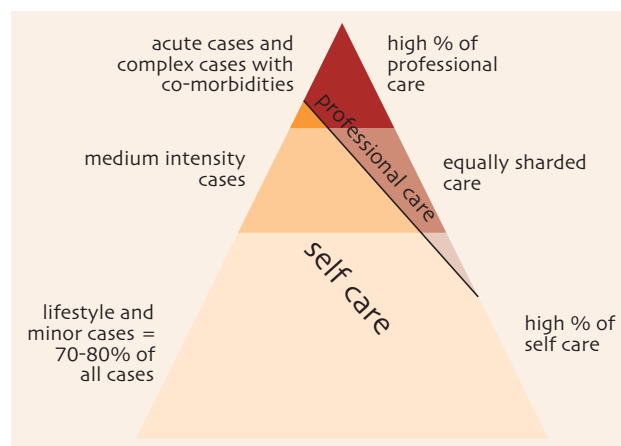
The pilot phase of EPP finished in the autumn of 2004, with 19,000 patients having been engaged with the programme. PCTs now have to commission generic Chronic Disease Self Management courses from licensed voluntary organisations and begin to develop the infrastructure to do so themselves.

www.expertpatients.nhs.uk

Take Care

A new guide focuses on where most health care exists – self care. Patients and the public can be supported to get more involved, says Ayesha Dost.

An individual's health lies largely in the hands of one person: the individual. In terms of episodes and hours, most care in daily life is self care. This is true whether we are trying to stay fit and maintain good physical and mental health, looking after a minor ailment or taking care of a long-term condition. For example, people with diabetes have on average about three hours contact with a care professional and do self care for the remaining 8757 hours in a year, using the advice given during the three hours by professionals and others, including people with similar problems. The diagram below shows in how many cases people get involved in their own care.



People have always wanted to have the choice to do self care and there was a time when the extended community of family and friends provided a great deal of support to help the individual take care of themselves. Society has undergone rapid change. There is no longer the aunt or friend next door to provide ample time and support. And so people's attitude to looking after their health is beginning to change. There is a shift towards independence and people want more control over their own lives. But they want the care system to provide them with support so that they can exercise real choice and become more independent. In a recent Department of Health survey among the general public, people said that they want more information, more training, more personalised care and easier access to facilities that would enable

them to do better self care. In another survey among participants in the Expert Patients' Programme, people with long-term conditions said they wanted more support to enable them to take better care of themselves in their own homes.

The Expert Patients Programme

EPP participants say that they want to do more self care:

"I have learnt that I need to take responsibility for my health instead of leaving it all to the GP."

"The Programme has really helped me to take more control of not just my arthritis, but also my life. I hope other people receive similar support so they can benefit as I have"

This is why the Department of Health has recently published a guide for managers and practitioners in the NHS and social care to promote a culture of self care and to encourage them to provide enhanced support for self care in their routine practice. Self Care - A Real Choice, Self Care - A Practical Option defines what self care is and describes a range of self care support options available.

Self care was highlighted in the NHS Plan as one of the key building blocks for a patient-centred health service. Self care support is already being provided through a number of national initiatives such as the Expert Patients' Programme, the NHS Direct family of services, the national service frameworks and several condition-specific patient education programmes, such as DAFNE (Dose Adjustment for Normal Eating) for diabetes. Choosing Health, the recent public health White Paper, has at its heart the notion of supporting the individual to take more control of their own health.

But there is scope for much more self care. For example, research suggests that around 40% of GP consultations are for minor ailments and 75% of A&E attendances are for minor illness or injury. With extended support for self care, many of these episodes could be better taken care of by people

themselves. There are also millions of people with long-term health conditions and there is a huge potential to provide self care support for these people.

- 17.5 million people may be living with a long-term health condition in Great Britain.
- Around 80% of GP consultations relate to long-term conditions.
- Care of long-term conditions accounts for 60% of bed days in hospitals.
- By 2030, the incidence of long-term conditions is likely to more than double.

But this is not a case of pushing care back to the public and patients to ease pressure on services. It is about giving individuals real choice and control through a range of self care options with tailored support.

Research suggests that people's health, quality of life and life expectancy can improve when they have more control. So it is easy to see that people should be encouraged to take charge of their own health and lifestyle, and be active self carers.

Benefits of self care

- improved feeling of wellbeing
- increase in patient satisfaction
- increase in life expectancy
- improvement in quality of life, with greater independence
- better symptom management for people with long-term conditions, such as reduction in pain, anxiety, depression and tiredness.
- medicines intake is regulated or reduced
- days off work can reduce by as much as 50%.

But it is for the individual to decide how they want to be involved in their own care. The shift to more self care may not always be easy because patients and the public may not always know about the benefits and the choice available to them and how to make that choice into reality.

The care professional may not also be aware of the practical options that they could develop and provide to their patients. And a self care revolution can only come about if the concept is embedded into the everyday business of health and social care, with the full backing of clinicians and managers.

'Up for it?' Self Care Support Programme

The 'Up for it' programme is a health and lifestyle scheme that aims to motivate behavioural and lifestyle change. It was set up by the Blantyre / North Hamilton Social Inclusion Partnership (SIP) and funded by the local Health Board, Council and SIP. Disadvantaged and vulnerable residents are referred from a variety of agencies, with an opportunity to participate in a 'Health Club' providing free access to services focused on reducing stress, stopping smoking, reducing weight and increasing exercise. Health checks are provided including CHD risk, stress level indicator and clinical tests. Service providers include public and private sector agencies: South Lanarkshire Leisure, Hamilton LHCC, Royston Stress Centre, Lloyd's pharmacies, Scottish Slimmers.

At May 2004 participation included:

- 3,989 health checks and health improvement opportunities
- 281 helped to quit smoking (4 week success rate of 60.2%, 3 month success rate of 26.1%)
- 1,626 have taken up leisure membership
- over 46,100 individual leisure activities undertaken
- 813 have been supported to deal with stress
- 869 have attended weight management classes with over 208 stones lost to date.

Likely outcomes:

- Reduction in CHD risk factors
- Increased number of smoking quitters
- Increased physical activity
- Reduced depression and improved mood
- Reduction in obesity
- Improved ability to cope with stress

There are also a number of self care support initiatives that are already being provided in local practices throughout the country. These include online information on lifestyle, skills training, peer networks and a very wide range of other methods. A compendium of local examples where patients and the public are involved in their own care has been put together and can be found on www.dh.gov.uk/SelfCare.

Peer Activity Motivators

A Local Health Survey in Wigan and Leigh found that almost 60% of older people did not take part in any physical activity. Wigan Social Services, together with Wigan Leisure and Culture Trust's Active Living Team and Age Concern, were one of four areas that took part in a national pilot of Senior Peer Mentoring. The mentors, once trained, visit individuals or groups of older people in places like lunch clubs and sheltered housing complexes, with the aim of encouraging residents to participate in a little more physical activity. These activities range from assisted corridor walks, chair-based exercise sessions, health walks and days out. The emphasis is on encouragement, support and fun, recognising that health related messages carry a lot of weight when given by similarly aged people, with similar life and health experiences. The mentors do not lead exercise sessions (although some of them go on to train as exercise leaders) and they do not give medical advice.

A further 16 mentors have been recruited and trained. The new mentors are very enthusiastic about their role in helping to improve both the physical well being and the quality of life enjoyed by the older people they come into contact with.

The scheme is now embedded in the Active Living Team's programme, and will see further expansion next year as part of the Stepping Out scheme, whose local partners include Social Services and Age Concern.

The Senior Peer Mentor handbook has been translated into Urdu, Punjabi and Hindi. Partly based on the success with the senior peer mentors, Wigan is now one of the national pilot sites for Moving More Often, which aims to bring more physical activity opportunities to the frailer older person in residential, nursing home and day care settings.

Likely outcomes:

- Increase in physical activity
- Reduction in obesity
- Reduction in depression and improvement in mood
- Increase in skills to train and support others
- Increased social capital through involvement of volunteers.

A pilot project funded under the new GMS contract will also aim to put together schemes to provide training for professionals to increase awareness of practitioners and to help them implement practical self care support options routinely. This will become available by the end of 2005.

As in everything else, there are some risks involved which need to be taken into consideration before implementing any self care support option. Care professionals and agencies need to consider how appropriate a particular method is for particular groups of people, and they will need to take into account people's capacity for self care – which can often be undermined by factors such as poverty or poor housing. Once a risk assessment is done, both the individual and their care manager, doctor or nurse should feel more confident to use any particular self care option for that individual. In this way, practice of appropriate referrals of patients to relevant self care support options will be the best way to approach this very exciting new national policy.

Self care is here to stay, and it is important that it is built in to all new policy development both locally and nationally with the full involvement of the public in the process of setting up such a policy.

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A healthy interest in volunteering

Health sector volunteering adds quality of life for both patients and health care professionals, as Paul Donohoe reports on a major form of PPI.

What do a single mum, a young lad bored of watching 'Trisha' and a wannabe radio DJ have in common? They are all, despite their differences, volunteers making an impact in the health sector. Each day thousands of people, of all ages and backgrounds, are making a difference to the lives of others by giving their time to volunteer.

Government figures show that 26 million people volunteer (1) with research showing that a further 11 million are waiting to be asked.(2) The challenge for the health sector during the Year of the Volunteer 2005 is to tap in to the vast pool of potential recruits whilst ensuring that those already on board can be provided with better volunteering opportunities.

Volunteers involved in the health sector help patients with no access to public transport by taking them to hospitals, health centres and GP surgeries, assisting with collecting house-bound patients' prescriptions, and supporting work with disabled patients. The volunteers don't have to be medically trained or have a health profession background – they simply give a little of their time each week.

And while volunteers become a vital 'extra resource' helping out with non-medical responsibilities like managing preventative healthcare libraries or manning help desks in doctors' surgeries and pharmacies, the workloads of GPs and nurses is lightened, allowing them to concentrate on providing medical care. Research shows that volunteer involvement at GP surgeries actually reduces patient prescriptions by 30% and hospital appointments by 35%. (3)

The volunteering charity CSV has many years' experience of harnessing the energy and dynamism of volunteers in the health sector. CSV's Retired and Senior Volunteers Programme (RSVP) through its innovative Primary Care Scheme currently deploys over 2 000 volunteers aged 50+ in over 270 GP surgeries. The volunteers help tackle the health problems of older and disadvantaged people caused by inner city deprivation and rural isolation. The scheme is such a success that GPs now regularly 'prescribe' RSVP volunteers to their patients and sometimes

What do a single mum, a young lad bored of watching 'Trisha' and a wannabe radio DJ have in common?

encourage patients to become volunteers themselves.

Despite the goodwill and effort of volunteers, the added value that they can bring to the work of health care professionals is still not fully being understood by many health managers. A major report issued as part of Health Month, the first themed month of the Year of the Volunteer, argued that it was time for those in power to recognise that volunteers have 'More than Good Intentions' with unique skills to offer the sector.

The report, authored by Helen Caton Hughes, urges sector leaders to recognise the benefits that volunteers offer in a range of health and social care settings, embrace a volunteering culture, and calls on senior managers to recognise, acknowledge and value volunteer projects more fully.

Helen Caton-Hughes says: "The Health Service seems preoccupied with so many targets that people are too busy to give volunteering the priority it deserves. Patients, other service users and carers will often speak more freely with a volunteer than with a professional. They want to be seen as more than just their symptoms and they appreciate the informality of the volunteer culture as a chance to unwind. Volunteering is also a way for people to extend their skills, developing the healthcare professionals of tomorrow."

But there is hope that in partnership with the voluntary sector, the number of opportunities matching the skills and interests of volunteers are increasing in the health service.

The National Association of Hospital and Community Friends (NAHCF) – an

organisation that places 43 000 volunteers in health care settings throughout the UK – recently began a campaign to get young people involved in volunteering in creative projects based at hospitals.

Their 'Be Surprised' campaign www.besurprised.org gives young people the chance to volunteer in projects that interests them, from hospital radio to performing musical numbers in wards. The campaign is hoping to grab the attention of young people itching to have the chance to get involved in a meaningful endeavour.

Alastair Marick, 22, a WRVS volunteer operating the trolley run at Birmingham Heartlands and Solihull Hospital is one such example. Alastair says: "I'd just started working at the travel agent Thomas Cook and my shifts were 2-8pm – I was getting a bit bored and frustrated during the day. It felt wasteful – a waste of time and a waste of life ... instead of sitting in bed watching Trisha every morning I wanted to make myself useful. People don't expect a 22-year-old lad to volunteer and I'm often treated as a bit of a novelty in hospital."

The Year of the Volunteer is led by a partnership between CSV and the Volunteering England consortium with backing from the Home Office. For more information visit www.yearofthevolunteer.org.

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To download a copy of 'More Than Good Intentions', go to www.healthmonth.org/resources/MoreThanGoodIntentionsNAHCFc2004.pdf

References:

1. 2003 Home Office Citizenship Survey
2. Davis Smith, J. (1998), 1997 National Survey of Volunteering, Berkhamsted: National Centre for Volunteering.
3. Pietroni, P. et al., "The Impact of a Volunteer Community Care Project in a Primary Health Care Setting", *Journal of Social Work Practice*, 1991.

Line Dancing for Health

Can PPI forums engage 'real people'? Maybe, but only with some fundamental changes, argue Rob Pocock and Jill Jesson.

The Government has championed PPI forums as offering a radical new way for patients and the public to influence the NHS. Their launch in 2003 was to a fanfare of headlines promising another powerful tool that would re-engineer both hospital and primary care towards a 'patient-led' NHS.

Their first year of life has, by contrast, left many questioning whether the concept is workable in practice. Comments from forum members and PPI lead officers have, for example, been buzzing around on the UK Public Health Association chatrooms, highlighting the lack of 'representative people' active in PPI forums. Questions have been posed on whether the expenses offered are generous enough, whether meeting venues and timings are suitable, and whether the role of the forum support organisations (FSOs) is adequate in enabling wider participation.

But the real problem is surely more fundamental than these issues. People 'on the street' live busy pressured lives making ends meet, coping with relationships and holding a family together. Who wants to trot off to meetings with agendas, rules and procedures? This is the reality of what you are offered in joining a PPI forum. If you haven't done this sort of thing before, it's totally bemusing – life on another planet.

In many other spheres of public service, there has been a long and painful learning curve leading to the skills and mechanisms of community engagement that can now be found in many fields of community regeneration. This contrasts starkly with NHS management structures, where there is often little awareness of the concept of 'community' as distinct from a queue of patients 'presenting' themselves for treatment. The Commission for Patient and Public Involvement in Health (CPPIH) is a fine embodiment of NHS culture but few would describe it as 'streetwise'. We should not be surprised that the organisational concept of the PPI forums is just a bit removed from reality.

The subsequent demise of CPPIH could provide an ideal and timely opportunity – or convenient excuse – to rework the PPI

forum model, keeping what's there as the 'superstructure' but introducing a vastly more effective 'infrastructure' supporting it at community and neighbourhood level.

The trick will be to put in place a bridging mechanism of engagement, which is directly rooted into the rough and tumble of the everyday world, where people meet and talk in the shops, workplaces, pubs, school gates and bus stops. Here is where their needs and concerns are best first captured. The NHS and PPI forums should not in general have to put down these roots because in many cases people are already engaged in 'little things' – after-school clubs, weight watchers, parish council meetings, neighbourhood watch, Sure Start parent groups, pub football teams, darts clubs, bingo, line dancing nights – you name it. This is where a thriving 'active citizenship' infrastructure is remarkably alive and kicking up and down much of the country.

Nationally, several £ million is spent on FSO contracts. In the main, FSOs administer meetings, issue papers, acting as a clerical channel between PPI forums and the NHS. This role could be fundamentally re-focussed on patrolling this community interface. When we have a contact in all the line dancing groups in our area, we will know we

It is quite simply unrealistic to take a pool of typically about 100,000 people, circulate some leaflets, stick some ads on the buses, and expect a 'representative' flood of people to walk into their local forum eager and ready to face those agendas, minutes and papers.

have arrived at the point where a practical and genuine interface exists between the formal structure of the PPI forum and the communities it represents – particularly the PCT PPI forums which need this capacity to touch the community base. A proactive development role by these redefined FSOs (I would then re-title them Forum Engagement and Support Organisations – FESOs) might then coax and encourage, enable and advance so-called 'representative people' into forum membership.

But we should not expect to catapult people into these settings in one go. Not if we expect the experience of 'a night at the PPI' to be repeated more than once. When forums were conceived, the reality behind the message was simply not appreciated. Developing the people who will sustain a 'representative' forum is a long job. They will need coaxing and reassuring. There needs to be an explicit and very firmly managed process to help people get the hang of this role. They may watch quietly at first and then slip away – a waiting hand and encouraging voice will be needed to guide and encourage people forward. The FESO role means giving this real practical personal support – phoning people who start missing meetings, keeping activity going aside of meetings, making sure 'meetings' are but a small part of the thrill and reward of forum membership. It's a long way from the clerical, administrative and research function that limits many existing FSOs.

We should see much of the PPI forum experience to date as 'pathfinding' – essentially an early and valuable learning experience. It's time to take stock and begin to shape up the next stage of development. The gap between forum and community needs to be bridged. Is 'line dancing for health' the way forward?

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Art for more than Art's Sake

Creative approaches to patient and public involvement are essential if it is to engage everyone. In Westminster, they have grasped the challenge, as Lisa Henschen explains.

Getting meaningful involvement from members of the public about health strategy and service development is a challenge, no matter how great the commitment.

At Westminster Primary Care Trust (PCT), we wanted to involve patients, carers and the public in influencing and shaping three key strategies: health promotion, partnership working, capital developments and equality and diversity. We had identified a number of key themes in these documents and had made the decision to coordinate the consultations to present one clear vision about the future of health services in Westminster. As we were planning to consult shortly after the New Year, we decided to present the strategies as New Year's resolutions.

There still remained the challenge of the approach to adopt to liven up a strategic consultation, which is why Westminster PCT, working in partnership with Voluntary Action Westminster (the local council for voluntary service), decided to call on the creative talents of the public.

Using art as a medium for expressing ideas and visions for future services was not something that we had previously undertaken. We therefore called upon the expertise of a London arts group to assist the facilitation of the session. After an initial project meeting, we came up with a brief for the day and members of the public were invited to attend the event.

We were delighted by the attendance figures, with around 50 people arriving, intrigued by the publicity which hinted towards an interactive and artistic flavour to the morning. The event was chaired by Andrew Whitley, Non-Executive Director of Westminster PCT, who welcomed participants and explained the purpose of the session. Managers then presented their strategies, in user-friendly form of three New Year's resolutions, after which the participants were divided into smaller working groups for discussions. They were given a large piece of coloured paper and oil crayons. The Artistic Director from the arts organisation explained how people could use art can be used to convey ideas, thoughts and visions.

Participants were asked to consider a background theme on which they could convey their ideas, such as a ship, a garden or a tree. They then positioned their thoughts from the discussions onto the background theme, building out from it. For example, one group decided to use the background theme of

Getting meaningful involvement from members of the public about health strategy and service development is a challenge, no matter how great the commitment.

a ship. The body of the ship represented a medical centre, which was what the group saw as a base from which they would like health services delivered. The sails of the ship represented services that they wanted to receive in health centres, such as optometry, podiatry and dentistry. Other sails on the ship related to where people wanted health promotion such as preventative information, links with Sure Start and Early Years and partnership working, such as social services





based in health centres. Other groups built in issues around equality and diversity into their pictures, such as women-only classes and accessibility of services for all.

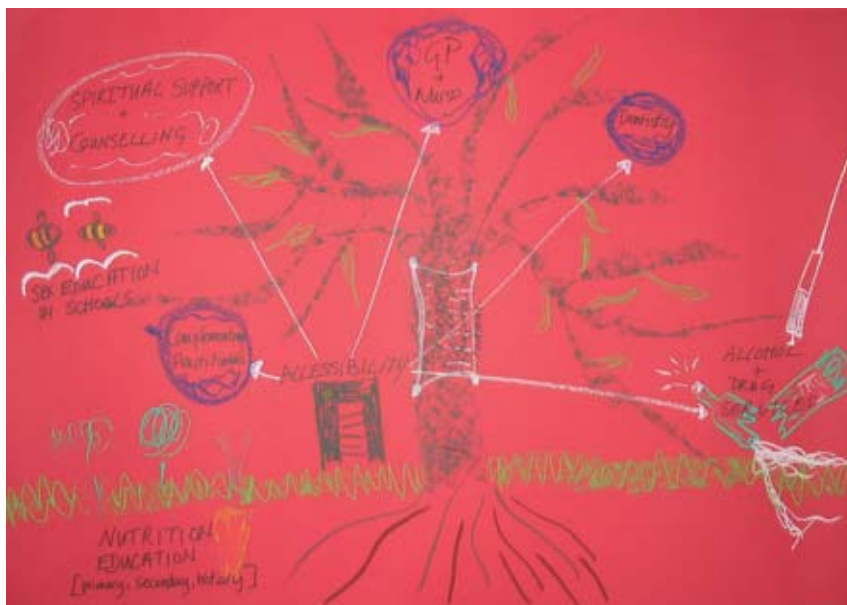
After the group work, managers and members of the public shared a meal together. This was another excellent mechanism for breaking down traditional barriers. The 'works of art' were put up on the wall at lunch for all to see and comment on!

The use of art certainly stimulated creativity and allowed for greater interaction and involvement, and gave a real buzz and energy to the event. Comments from course participants included, "It is excellent way for the providers to get a quick impression of what people want" and "Creativity was great". It resulted in a very positive experience of involvement for people who attended, and worked towards building an ongoing relationship between the PCT and members of the public, as people requested that this be an annual event. It is also a very inclusive method of involving communities, particularly for people whose first language is not English, or people with learning disabilities.

Incorporating art into consultations does require greater planning and a very clear understanding of the desired outcomes. We had arranged a three-hour session, but would recommend that at least another hour is added to this to allow a good amount of time for discussion and thinking how this would be conveyed through art. The work produced will make a greater impact than a written document and the PCT is now incorporating this into final plans for the strategies and is hoping to use the images in the documents.

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Hunting Lions and Swatting

Health Service Ombudsman, Ann Abraham, has described the health scrutiny landscape as 'crowded and confused' and outlined her ideas for creating an ideal system that truly protects patients' interests.

Giving the Centre for Public Scrutiny's Annual Lecture in January, she said that scrutiny was an opportunity for rebuilding trust in public institutions, which has eroded due to public disconnection from the political process and high profile news stories such as the Shipman case. In this environment it is more vital than ever that scrutineers – from regulators, to Parliament, auditors and commissioners – should be able to critically examine the activities of those exercising power and hold them accountable for their actions.

The plethora of scrutiny bodies that have emerged in this area may, however, provide a bewildering picture for service users. The Health & Social Care Act 2003, for example, does not have a clear and workable system for dissatisfied customers, with potential routes of redress including: the Commission for Social Care Inspection; the Healthcare Commission; the Local Government Ombudsman; the Parliamentary Ombudsman; Local Authorities; the Health Service Ombudsman; or a combination of these bodies.

Health Service Ombudsman, Ann Abraham, has described the health scrutiny landscape as 'crowded and confused' and outlined her ideas for creating an ideal system that truly protects patients' interests.



This confused picture can be improved in three key ways. Firstly, scrutiny systems must be designed with the service user in mind. Secondly, non-executive scrutineers and executive decision-makers should work together on developing new legislation, so that a customer focus and accountability mechanisms are incorporated from the start. Thirdly, the diverse scrutineers involved should take a more joined-up approach and act as a coherent network, ensuring their communal effort has maximum impact for service improvement.

Urging scrutineers to focus first and foremost on the public interest, the Ombudsman said: "We need to keep asking ourselves one simple question, does this work for the customer?" Within a truly customer-focused framework, the aim should be to develop a range of policies and services that help people to avoid problems and disputes in the first place. An ideal scrutiny system would ensure that: people's rights and responsibilities are clearly defined and widely understood; appropriate advice and assistance is available to them as early as possible; and dispute resolution services are co-ordinated, fair and efficient.

The Ombudsman highlighted the importance of open and constructive relationships between non-executive scrutineers and executive decision-makers during the development and implementation of legislation. "Too often we have a sticking plaster approach, rushed and hasty legislation is introduced, with not enough consideration and consultation, leading to flawed services, unhappy customers." This type of pre-legislative scrutiny may require additional time and discipline; however the result will be better services that have accountability built in from the start. These relationships should continue as legislation is implemented, to ensure legislation is workable in practice.

Scrutiny will provide most value to the public if organisations working in overlapping areas 'join up' their activities: by defining their individual roles more clearly, developing agreements on their remits and working

Scrutiny, the Ombudsman concluded, can indeed be "lion hunting as well as fly swatting".

together to form a coherent scrutiny network. This will ensure all public bodies are properly held to account and enable problems to be resolved as quickly, appropriately and efficiently as possible. In such a joined-up system, she said, scrutiny can become a virtuous circle whereby public services are genuinely improved on the basis of learning from what went wrong.

Within this framework of customer focus, constructive executive relationships and joining up the impact of scrutiny can be significant. For example, the Ombudsman's 2003 report into NHS funding of long-term care led to 11 000 cases being reviewed – for which the NHS expects to pay £180 million to people wrongly denied funding. This process was supported by the actions of other scrutineers: notably parliamentarians from the Health Select Committee and the media, who continued to raise awareness of the issue. In her December 2004 follow-up report, the Ombudsman highlighted the need for clear, national, minimum eligibility criteria – a recommendation that the Department of Health is now taking forward.

Scrutiny, the Ombudsman concluded, can indeed be "lion hunting as well as fly swatting".

Tim Gilling, Health Scrutiny Support Manager, the Centre for Public Scrutiny reflects on the Health Service Ombudsman's speech.

Ann Abraham focussed on the influence that "strategic scrutineers" (Ombudsmen, Regulators and Parliamentary Select Committees) can have on service improvement at a strategic level, especially in terms of complaint resolution. But how can the work of these strategic scrutineers link to the wider patient and public involvement framework that exists in NHS trusts, primary care trusts and local authorities? In particular, how can PPI forums and overview & scrutiny committees contribute to this agenda?

Patient and public involvement is about much more than NHS complaints. The PPI framework – from local authority health overview & scrutiny committees (OSCs), to Patient Advice & Liaison Services (PALS) and PPI Forums - exists to bring the voice of patients and communities in to the decision-making process and to hold decision-makers to account for the way in which health services are planned and delivered.

The Centre for Public Scrutiny (CfPS), in its work supporting health OSCs, has attempted to address the Ombudsman's concerns about a "crowded and confused" landscape. Our approach is to recognise the distinct and valuable contribution each party makes, whilst acknowledging potential overlap and emphasising the need for complementary, constructive working if patient and public involvement is going to be meaningful.

We have encouraged OSCs to have a dialogue with other parts of the PPI framework and ensure all parties are working together to monitor trends, identify issues for further investigation and coordinate how these topics might best be tackled in future work programmes. The nine annual CfPS-funded action learning projects - where OSCs investigate a local health issue then share lessons with local bodies and OSCs nationwide - will continue to emphasise the importance of partnerships. In a series of regional events for OSC chairs this Spring, we have particularly encouraged joint working between OSCs and PPI Forums. OSCs have a democratic mandate to ensure healthcare provision meets local aspirations and reduces inequalities in access. PPI Forums are able to monitor and review services from patients' perspectives, and are much more active within individual trusts than OSCs. This complementary

combination, we believe, can be very powerful in influencing service design and delivery.

There is already evidence of effective joint working that will contribute to better service provision. Surrey County Council's health OSC has worked closely with the PPI Forums for Guilford and Waverley PCT and Royal Surrey County Hospital NHS Trust around the potential closure of a local rehabilitation hospital. The PPI Forums canvassed service users' opinion and presented to the OSC at an evidence session packed with members of the public, councillors and local bodies. This effective collaboration was no doubt facilitated by a three-day 'Bridging the Gap' event held in September 2004 to build links between the OSC and the county's 14 PPI forums.

In some instances, both OSCs and Forums have worked together with PALS, by ensuring that the concerns brought to trust boards by PALS are taken into account when decisions are being made about service design and delivery. For instance, when planning its work programme, Middlesbrough Council's Health Scrutiny Panel considers the top three issues that local PALS services have dealt with in the previous year.

Additionally, the CfPS believes it is important for the PPI community to think about how their work fits into the wider inspection and regulation regime. The Healthcare Commission is also working with us around this element of accountability: by talking to Chairs about how OSCs and PPI forums might have a role in providing a commentary on the declarations about performance that trusts will need to make under the new assessment regime.

By encouraging close working between all of these parties, especially in the context of taking forward the themes of the 'Choosing Health' white paper, we hope that OSCs can contribute to a PPI framework that identifies sources of dissatisfaction that are not addressed as complaints. By addressing wider health issues together, this framework can address community concerns and facilitate exactly the kind of 'joined-up' thinking that Ann Abraham said is vital to good scrutiny.

For more information on the CfPS Health Scrutiny Support Programme please visit www.cfps.org.uk/health or contact Tim Gilling on 07876 710046 or tim.gilling@cfps.org.uk

Democracy in the NHS?

NHS foundation trusts were intended to introduce democracy into the NHS in England. Johnston Birchall reflects on early days and asks whether the cup is half-full or half-empty.

When the idea of NHS foundation trusts was first thought up, opinions about their radical new governance structure could not have been more opposed. I thought they were a bold step towards participatory democracy in health care, and accepted a place on the External Reference Group that helped draw up the guidelines for their governance. But Rudolf Klein, writing in the *British Medical Journal*, predicted that members would be unrepresentative, and skewed towards people with "intense but atypical views" (*BMJ*, 25.1.04). They were meant to be a way of making health providers accountable to the public, patients and staff in a unique form of multi-stakeholder co-operative, but Klein thought this would internalise the tensions between producers and consumers. My evidence to the External Reference Group was that, provided the process is managed with a well thought-out membership strategy, and there is a genuine offer of a share in governance, people would be motivated to participate. Klein thought this an over-optimistic assumption, and that for many of the trusts the challenge was to "overcome apathy" (*BMJ*, 5.6.04).

So who was right? We now have the results from the first 25 elections to boards of governors. I suggest that how we interpret them depends on whether we take a 'local citizens' or a 'mutual members' starting point. A 'local citizens' viewpoint measures success by the proportion of the entire local population who vote. If we take this view, of course we will be disappointed, as only a small percentage of the population have so far become members, and even with active recruitment the proportion will never be all that high. In contrast, a 'mutual members' viewpoint measures success by the numbers of people in each of the three constituencies (public, patients, staff) who voluntarily sign up to become members, and then by the quality of the democracy that follows. On this view, the signing up of nearly 298 000 people as members in such a short time is a remarkable achievement. The fact that half of the public members and 37% of all members chose to vote is hardly a sign of apathy, as is the fact that

there was plenty of competition – there were 1 824 nominations for 578 places. That only 27% of staff voted is disappointing on both viewpoints, but we must remember that this is a new opportunity, and it takes time for people to be convinced of the value of membership. There is also more to be done to ensure representativeness, but the Homerton Trust, in the diverse area of Hackney, already reports a balanced ethnic original profile among its members. There are locality effects, with some trusts doing better than others. For instance, among the second wave of five trusts, Barnsley recorded a staff vote of only 27%, while Harrogate had 63%. Barnsley had a public vote of 36%, while South Tyneside had 57%.

So is the cup half-empty or half-full? On a 'local citizen' view, the cup is nearly empty because only a tiny percentage of citizens voted. On the 'mutual membership' view it is half-full and, given time, has the potential to fill up further. For instance, a Monitor report shows that since the elections the first wave of 20 trusts have increased their membership by 39%. The second wave of trusts improved their election turnout compared to the first wave by 5% among the staff and overall turnouts, but did worse than the first wave on the public turnout (44% as opposed to 53%). There is more work to be done building on the membership base to make it representative of minorities and 'hard-to-reach' groups. But that is true of democracy in general.

The voting statistics would have been better if one or two of the trusts had not signed up all patients or all staff automatically. This is the knotty problem of whether to make all patients members with the chance to opt out, or whether to have people opt in. In mutuals (such as credit unions, building societies, mutual insurers), all customers who qualify for membership become members automatically. Then a small minority tend to become active but may not be very representative. In consumer co-ops and membership organisations such as the National Trust, people have to make a decision to join. I think on balance people should have to choose to join (opt in), so a larger proportion can be expected to be interested from the start.

Those who argue that the trusts have failed should provide us with an alternative. Do we

really want to go back to a system in which all board members are appointed? This is a version of Plato's 'guardians' argument – that only the elite should be allowed to rule because the rest of us do not have the skills or cannot be trusted to make the right choices.

Serious questions do remain. First, in other countries, members of health co-ops have the incentive of paying for all or part of their health care through mutual insurance, which gives them real choices. In a health service that is free at the point of use, will member democracy make enough of a difference to motivate people to take part in governance? Second, the multi-stakeholder model is bold even for the co-operative sector: most health co-ops around the world separate out the producer and consumer interest into distinct organisations that then contract with each other.

Third, while the two-tier board is common in co-ops and mutuals around the world, it is not popular in Britain or the USA. However, the advantage of two tiers is that we can elect the top level to be representative, while the management board have the skills needed to run the business. Fourth, nearly everyone agrees that we should not have started here. Some think primary care trusts are a more natural starting point, and offering membership of these would have rooted democracy more firmly in a local community.

When all is said and done, however, we do have this unique opportunity to democratise at least part of the NHS, and we should take it. In primary care trusts, members of the new PPI forums are appointed by the Appointments Commission. In Scotland, the new unified health boards have a lot of patient participation, but only by the 'grace and favour' of governors appointed from above. If the NHS foundation trusts are a success, then this more democratic model could be applied to the rest of the NHS. The question will then be how to integrate different kinds of membership in a way that is cost-effective for members.

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Physician, manage thyself?

It's not only patients who have long-term conditions. What can the NHS do as an employer to support self-management by staff? Jane Keep has been finding out from the winner of the Model Employer category of the Human Resources in the NHS Good Practice Awards 2004.

Introduction.

'Staff as patients and how this might be different from patients as patients' is a pilot study on introducing the Expert Patients' Programme (EPP) to NHS organisations for staff with long-term conditions. Run in partnership with a range of organisations, co-ordinated by NHS Partners and sponsored by NHS Plus, the study aimed to:

"implement and evaluate a pilot self-management programme for NHS staff in two health communities to determine whether the success of Expert Patients' Programmes to date is transferable to NHS staff and makes a tangible contribution to improving the quality of their working lives."

In recent years, the EPP has had extensive publicity and support in the NHS. Research over the last 20 years has shown that self-management significantly improves the quality of life for people with long-term conditions. With demographic shifts and an ageing workforce, the prevalence of people with long-term conditions working in the NHS will rise.

In early 2004, in Bedfordshire & Hertfordshire, and Cheshire & Merseyside, participants working in health care organisations were recruited to undertake an EPP. This article outlines just three of the reflections on 'staff as patients' in a working environment where 'patients as patients' is the norm. Some of the cultural changes to enable staff to feel 'comfortable' as 'patients' seemingly still have a way to go.

Staff as patients – three reflections.

1. Staff with long-term conditions (LTC):

- It was reported from staff quotes that "aspects of their long-term medical conditions interfered with their working lives. Aspects causing difficulties included limited mobility, pain, fatigue and the unpredictability of many conditions. Most had taken time off work due to their LTC."
- Some staff said that their managers were

understanding, although there was a feeling that some managers didn't talk about the conditions with staff because they didn't know how to deal with them.

- "The overwhelming impression given by participants was that rather than managing their condition, they were ignoring it in the workplace and 'just getting on with it'."
- Questions arose (that we didn't answer directly), for instance, around whether those with LTCs felt the working environment was 'safe or supportive' enough for them to discuss their health.
- This may be a difference between staff as patients and patients as patients as there may be an underlying view that, as a member of staff, you are staff (there to work?) and not a patient; while, when labelled a patient, it was expected that you could discuss these issues and talk about them more freely.

2. Staff who work together volunteering for the EPP:

- Partly because of the points above, and around the need to ensure sensitivity for staff who wished their LTC to remain confidential, an early consideration was ensuring a number of sensitive and confidential (self-)referral processes when considering staff 'as a patient' in the work environment.
- In some cases, there was added sensitivity if two members of staff from the same organisation or department self-referred who didn't wish to share elements of their condition with a colleague. (Where this happened this was discussed with them both separately and sensitively to reach a comfortable agreement about the way forward).

3. Staff as 'experts' in providing health care:

- An interesting finding (although not explored fully during the pilot) was around staff who treat/care for patients, when in an environment where they were the patient felt that the EPP course 'was teaching grannies to suck eggs'.
- Some future participants may need support to remove their 'professional hats' and use the time on the course for themselves as a person with a LTC.

Where to from here?

Overall, the pilot was successful in confirming that the EPP is a useful process for staff with LTCs to use as part of their self care. It is part of the overall 'package' of interventions that occupational health and human resource departments could use as part of their healthy workplaces or sickness absence approaches. The EPP is currently being adapted to shift the emphasis to staff 'working' with a LTC, and other health care organisations are invited to work with us on more pilots.

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or

Keith Johnston, Executive Director, NHS

Partners – keith.johnston2@virgin.net

Web sites:

- Employers' Forum on Disability – ('focused on the issue of disability in the workplace') – www.employers-forum.co.uk
- Expert Patients' Programme – www.expertpatients.nhs.uk
- NHS Partners (HR solutions in Health and Social Care) – www.nhspartners.org.uk/expert_patient_project.html
- NHS Plus (a network of NHS occupational health departments across England, supplying quality services to non-NHS employers) – www.nhsplus.nhs.uk
- Remploy ('to expand the opportunities for disabled people in sustainable employment within Remploy and the communities it serves') – www.remploy.co.uk

Reference:

Barlow, J. and Ellard, D. (2004), Self-management of long-term medical conditions for NHS employees: evaluation of the 'improving working lives' pilot project. Interdisciplinary Research Centre in Health, Coventry University – hsx456@coventry.ac.uk

A Foundation made in Devon

NHS foundation trusts are increasingly seeing the long-term benefits of involving a broad-based membership and sound governance arrangements. Royal Devon & Exeter has been ahead of the game, as Pauline McCluskey explains.

The journey to becoming one of the first-wave NHS foundation trusts (NHSFTs) on 1 April this year was a real challenge. At the Royal Devon & Exeter (RD&E), we considered governance issues such as the benefits of membership, the distinction between public involvement and engagement and public consultation, the links between membership and patient and public involvement (PPI) and what our governors would do.

The application process itself demonstrated some of the complexities. During this time, eligible NHS trusts were expected to involve local people, staff and their partner or stakeholder organisations in developing governance arrangements, the membership development strategy and the five-year Service Development Strategy. At the RD&E, we described this as an ongoing process of engagement and involvement, meaning that it did not begin and end with the application for NHS foundation trust status, but that it was part of an overall strategy of communicating and engaging the public, staff and partner organisations, and of gathering and analysing the opinions and ideas that would inform and influence strategic thinking. This was very much in keeping with the stipulations for PPI in section 11 of the Health and Social Care Act 2001 and the approach described in Keeping the NHS Local (Department of Health, 2003).

We used separate approaches with different groups of stakeholders to gather their views. For patients and the public, we used a number of initiatives to get information about what local people felt about the future of the RD&E, and what improvements they would like to see over the next five years. These included:

- distributing questionnaires to patients and visitors, asking what people felt was most important to them in the services the RD&E provided, what they thought the Trust did well, and where they felt improvements could be made
- discussions with a number of community groups and organisations

- a series of articles in the local press inviting readers' contributions.

Together with the work done to gather information from staff and partner organisations, this gave us four improvement strategies for the future:

- improving access to the RD&E and its services
- improving relationships with partners and stakeholders
- developing new ways of delivering care
- responding to staff

A range of specific objectives underpinned these broad headings, reflecting priorities that had been consistently highlighted.

So much for the application, but there is now a big challenge for the RD&E as an NHS foundation trust. How do we continue to involve local people and patients in the work of the Trust, and give them the opportunity for involvement as our partners in developing services for the future?

The journey to becoming one of the first-wave NHS foundation trusts (NHSFTs) on 1 April this year was a real challenge.

Our starting point is to have quarterly members' constituency meetings, led by the Head of Membership and Mutual Development, with the involvement of all of the governors, but particularly those publicly elected. These meetings fall between the quarterly meetings of the Council of Governors and take place in local communities the Trust serves. The meetings are open to anyone, but with an emphasis on Foundation Trust members. Each round of meetings (for public and staff) covers a particular topic linked to the themes in the Service Development Strategy. Recently, the topic has been transport issues facing patients, visitors and staff, linked to improving access to the RD&E and its services.

Transport is always a thorny issue, and it was with some trepidation that we spoke about the constraints as well as some of our innovative plans, unsure of the response we would receive. This anxiety was completely misplaced. At all the meetings, which have been well attended, local people appreciated being told the facts, so that they could debate possible solutions and ideas with us. This is a genuine attempt to use local knowledge and insight in providing solutions for people in our many dispersed rural communities, as well as those in and around Exeter. This continuing partnership with local people is the essence of developing as an NHS foundation trust.

We must now ensure that conversations and suggestions at the constituency meetings translate into action. With a wealth of useful intelligence, we can take PPI to a new level, and become a much more responsive organisation. We are still working on this, testing links with pre-existing PPI initiatives, discussing how to record the fantastic range of suggestions received, how to implement some of the ideas, and how to keep our members informed of our progress. But it has only been 27 weeks; we think we will get there.

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Learning through diversity

There are many lessons available about making involvement in health more diverse. Regular columnist Ian Hayes reflects on what CPPIH has learned from recruitment to PPI forums.

Time is short. There are many decisions to take and many 'work streams' to steer to successful conclusion before the Commission for Patient and Public Involvement in Health (CPPIH) is finally abolished in August 2006. The fear is that tight timetables, coupled with political imperatives, will mean that changes are made without sufficient discussion.

One area being hotly debated, in the context of transferring the recruitment function to the Appointments Commission, is diversity and how future arrangements can ensure that PPI forums are representative of the communities from which they are drawn. Diversity is a slippery subject about which I am no expert but the second of the Commission's five guiding principles is difficult to argue against. It suggests we should:

"Aspire to involve the public in all its diversity, especially those not normally involved."

And there has been success. Following the initial recruitment of PPI forum members:

- 10% of forum members were from ethnic minorities
- one-third of forum members described themselves as having a disability
- one-third of forum members had never volunteered previously
- one-third of forum members had volunteered before but not in health
- one-third of forum members had volunteered in health in the past.

There was a roughly equal balance between men and women and although older age groups were over-represented relative to the population as a whole. This might reflect a greater use of health services among older people, as well as time availability.

This was a considerable achievement. I would venture that there has never been as diverse a body of people recruited to unpaid public service. There were areas where it

proved difficult to reflect local demographics but there have been continued efforts to improve on this situation. The need to increase numbers of forum members and the relatively high turnover have presented problems in themselves, but they have provided plenty of scope for targeted efforts to increase diversity.

All of the measures of diversity are important, but for me the key is that group of people who have never volunteered before. It is within this group that the people we have traditionally failed to involve will be located if they are reached at all. It is within this group that creative ideas and opinions not preformed as a result of previous involvement will be found. We have plenty of lessons to pass on for future recruiters – for example:

- the most effective recruitment was local and targeted
- local radio spots were the most effective form of advertising
- outreach to the local voluntary sector was fundamental.

We can also say that national advertising and campaigning was ineffective in reaching people who were not 'joiners' already.

My belief is that these 'non-joiners' were attracted by a relative informality of approach in the recruitment process but also by the level of freedom in how the PPI forums were to form themselves and carry out their work. During the process leading to the establishment of the current system, there was a great deal of discussion around how regulated the working of forums should be. Did they need minimum or maximum numbers? Did they need a chair? Would the number of meetings be fixed? Although many of us would have favoured even greater flexibility, forums have retained considerable scope to chose their own form and set their own agendas.

This has meant that PPI forums have had to find their own way and this has not always been comfortable. It has also been a high-risk way to work in a health system which is driven by targets and performance management, but it has been key to obtaining and maintaining the involvement of people who may not be used to formal structures and whose motivations may be very different from the 'usual suspects.'

Time is short. There are many decisions to take and many 'work streams' to steer to successful conclusion before the Commission for Patient and Public Involvement in Health (CPPIH) is finally abolished in August 2006.

Thus, we have a great and evolving variety of working methods. Some PPI forums have chairs, some do not, while others have rotating chairs. Some forums feel much more like user groups, others work like formal committees. Some forums are combining to reflect the local health economy others are seeking to devolve their work to smaller sub-committees. This is a creative process and one which reflects local needs and the needs of the people who make up a forum. It is a process that accepts that there is no reason why a rural PCT forum in Cornwall should look like a city-based forum, or that a forum for an acute hospital should look like one for mental health services.

This diversity of form and process will continue to develop if PPI forums maintain their independence and I would contend that this diversity of form would be key to achieving diversity of membership. Allowing forums to follow their own path must be a key objective of any future arrangements. Success is not dependent on which organisation has responsibility but it does depend on learning from experience.

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Participation: who benefits?

Can the shift towards involving citizens in the governance of services really make a significant change, or are they a drain on time and resources? Paul Skidmore, Kirsten Bound and Hannah Lownsborough have begun an exploration of the benefits and trade-offs.

The mantra of “delivery” which has defined the public services debate in recent years appears to have run its course. In its place, the contours of a new reform agenda focused on making services more responsive and giving local communities more power over how they are run has begun to take shape. So can this newly reshaped, ostensibly more participatory system of local governance put citizens in the driving seat? That is the question a team of researchers at the think tank Demos is exploring in a study funded by the Joseph Rowntree Foundation.

For the last decade, UK policy-making has been brimming with debates about the need to empower communities and foster a culture of active citizenship in which local people play a more direct role in making the decisions that affect their lives. Much of this thinking originates in a growing preoccupation with the concept of social capital. Social capital suggests an enticing vision in which communities use their informal networks, capacity and shared values to tackle their own problems. Yet from the word go, one of the things that has intrigued policy-makers about social capital is the idea that it might also help to improve the service quality and focus, as well as strengthening the legitimacy, of formal public institutions like schools, hospitals and local councils.

A proliferation of new structures, partnerships and governing arrangements which seek to enrol local people in decisions about local services would seem to underline the sincerity of the government’s commitment to building and harnessing social capital.

For example, local strategic partnerships bring together public and private agencies with local community representatives to prepare ‘community strategies’ aimed at improving the economic, social and environmental well-being of local areas. Foundation status enables high-performing NHS trusts to earn substantial freedoms from central control in areas like budgeting, human resources and priority-setting in

For the last decade, UK policy-making has been brimming with debates about the need to empower communities and foster a culture of active citizenship in which local people play a more direct role in making the decisions that affect their lives.

return for embracing a new legal personality and new governance arrangements with a focus on local community participation and ownership. Crime and disorder reduction partnerships involve statutory agencies, voluntary and community groups and local people in making decisions about policing and community safety. PPI Forums are designed to strengthen the voice of patients and local people in shaping the delivery of health services.

These new initiatives join a plethora of older structures such as school governing bodies, elected local councils and tenant management organisations to form the crowded, multi-layered local governance map we see today, with forms of participation ranging from the formal and routinised to the informal and ad hoc, and from targeting users of a particular service to representing local citizens as a whole (see figure 1).

Yet are these local governance arrangements really helping to build and harness social capital? Or, on the contrary, are they a costly white elephant, a drain on communities’ scarce resources of energy, time and hope, and dependent on the commitment of a few already over-stretched community activists?

Initial findings from a review of the academic literature offer a rather sobering assessment.

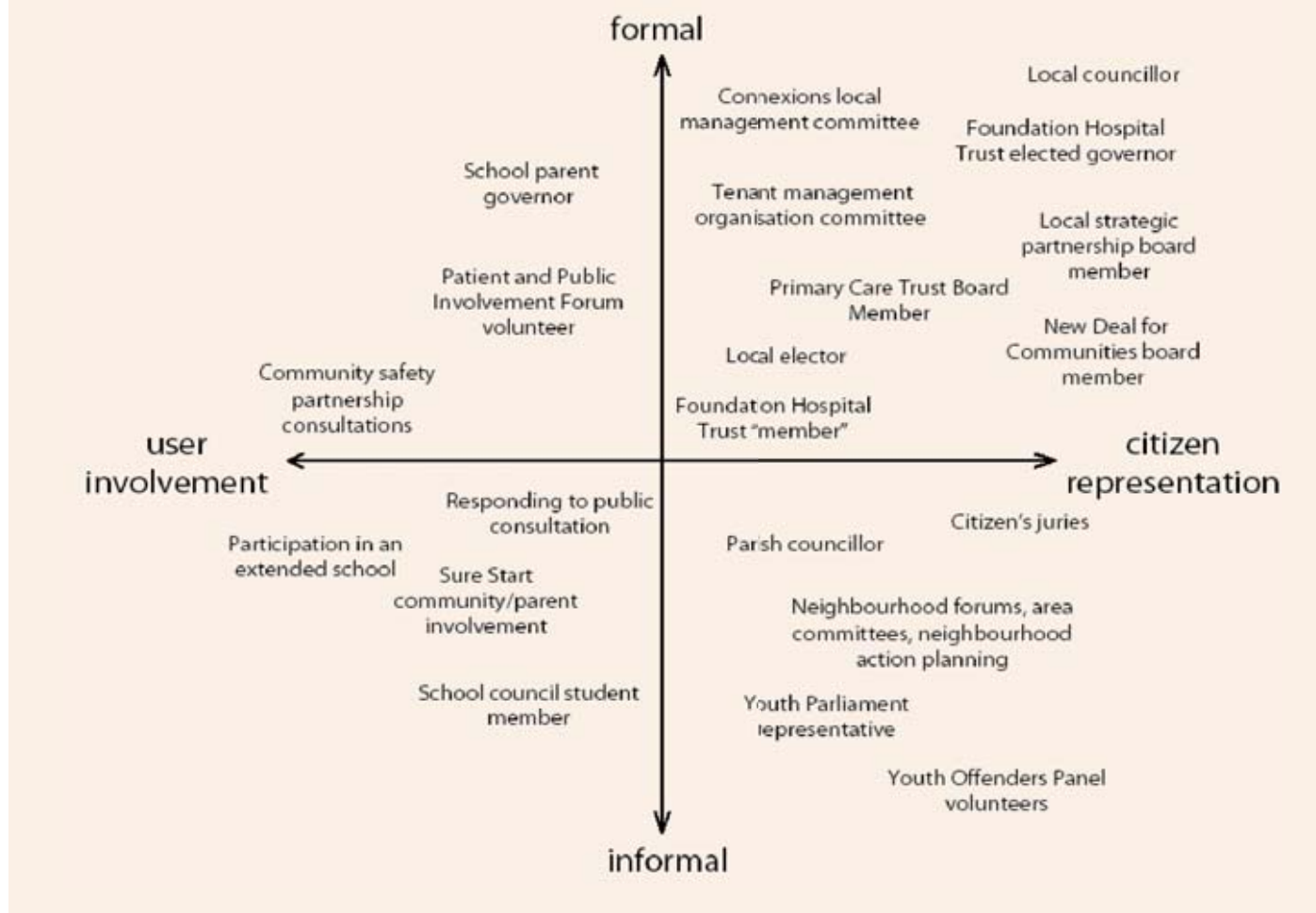
First, the sheer complexity of local governance arrangements now presents a significant barrier to citizens engaging with them effectively. One English local authority has calculated that it needs 3300 people to fill the seats on the various governing bodies and boards that have been created locally. In Wales there is an average of 92 multi-agency partnerships in each local authority area.

Second, it is not sufficient for there simply to be a “supply” of social capital. There must also be “demand” from political and public institutions. People need to be asked to participate in the right way. Equally, evidence that participation actually results in change or influence is a crucial determinant of whether people get or remain involved. The perception or experience that consultation or participation processes are simply a token gesture is the biggest contributor to disillusionment and disengagement.

Third, the design of local institutions and the political and organisational cultures within which participation initiatives are located plays a vital role in determining whether the potential impact of social capital on better governance comes to be realised. One study exploring the perspectives of community members involved in regeneration work revealed that residents felt there was a gap between the rhetoric of community participation in area regeneration programmes and the realities of work on the ground. Processes of community involvement had been inadequate and had not allowed enough time for effective consultation. Many commented that there had been insufficient support and training, a conclusion also shared by many of the professionals involved.

Fourth, apparently routine procedures and assumptions can actually play a dramatic role in shaping who is able to get involved. The way in which participants are defined and recruited can rarely be genuinely neutral. Assumptions about the skills and competence needed for participation often privilege those with more bureaucratic backgrounds. If the agenda or rules of the dialogue people are invited to join are imported from more formal, official environments it can dampen the sense of collective possibility and energy. And practical arrangements – the time and location of meetings, for example, or the provision of childcare or transport – powerfully constrain who is able to take part.

Figure 1: The crowded local governance landscape



Fifth, there are important differences between different groups' experience of the links between involvement in governance and social capital. As far as gender is concerned, although men and women have roughly equal amounts of social capital they "use" it for different purposes and women are less likely than men to cross the boundary from involvement in community life to participation in governance. Age, ethnicity, socio-economic status, geographical location and other demographic factors are also important, although it is not always easy to generalise about their effects on people's participation in governance. In rural areas, for instance, feelings of physical and social isolation can sometimes depress the formation of social capital and limit the desire and opportunity to participate in local governance. But equally they can be a stimulus, due to the potential for creating durable community ties and local governance structures in stable population groups.

Finally, in searching for ways to involve and engage citizens many institutions mimic (or are required to mimic) the dry, committee-like structures of traditional accountability models. This heavy reliance on "communities in committee" points to a degree of tunnel vision about how legitimate participation can best be promoted. Real questions remain about just how effective these kinds of structures are and the depth of legitimacy they actually engender. The disappointing public response to the new arrangements for electing NHS foundation trust boards would seem to underline this concern. The quest for legitimate participation may also lead to an over-reliance on a few "usual suspects" claiming (not always rightly) to be community representatives and exclude those not already involved in group activity.

Whilst it might seem more opaque and messy, the development of a plurality of approaches to participation aimed at engaging different parts of the community in

different ways may result in more effective and legitimate governance than the often fruitless search for "representativeness". With devolution to the local and even neighbourhood level emerging as a key theme of the general election campaign and beyond, developing these new models of participation looks set to become a policy priority for the next few years.

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Demos

We would be keen to hear your views and experiences.

Please email kirsten.bound@demoss.co.uk or phone 0845 458 5949

Doing it for themselves

Local people don't have to wait to get engaged or to make a positive response to health issues, as Anne Carlile illustrates. Newcastle PROPS has developed from the concerns of local women to support the carers and families of drug and alcohol misusers.

Newcastle PROPS is a community-based and community-led voluntary organisation based in Newcastle-upon-Tyne. A registered charity, it provides support for the carers and families of drug and alcohol misusers. The organisation works to improve the health and reduce the health inequalities experienced by the carers and families of substance misusers.

Newcastle PROPS was originally set up as Scotswood Family Drug Support Group in the Scotswood area of Newcastle upon Tyne in 1997 as a result of local women's concerns regarding the need in the community for support for parents and partners of substance misusers. The initial group set up their own self help group and as this progressed, the women became active in addressing issues surrounding drug and alcohol misuse, in particular the emotional, health and economic effects on carers.

The Scotswood group identified a gap in provision of support and counselling services specifically targeted at the parents and partners of drug and alcohol misusers. The initial aim was to provide support to the local community, and support was provided to enable people to cope with the problems they were experiencing. Owing to the demand of families outside the Scotswood area, services were offered citywide from October 2002. The Project has now developed into Newcastle P.R.O.P.S. (Positive Response to Overcoming Problems of Substance misuse), a charity recognised locally and nationally.

The project facilitates family counselling and one-to-one help sessions. It also develops support groups across the Newcastle area to meet the needs of carers, offering drug information, training and advice to a range of individuals and organisations.

A major part of the service is to liaise with relevant external statutory and voluntary agencies in order to expedite various processes on behalf of families: supporting them in meetings if necessary, assisting with letter writing, accompanying them on prison visits, court visits, liaising with prison CARAT workers (counselling, advice, referral,

Newcastle PROPS is a community-based and community-led voluntary organisation based in Newcastle-upon-Tyne.

assessment and throughcare), the probation service and schools.

In order to get clients out of the immediate environment, the project has provided and manages an out-of-area respite facility for families. This accommodates six family members and is situated by the sea, 20 miles north of Newcastle.

Since its inception, PROPS has grown quickly and is the only organisation in the City to be focussed on carers and families of substance abusers. We moved into our current office in the Sandyford area of Newcastle when we had three workers. We now have six and need to move to new premises.

The Project is run as an efficient and effective business. We have a highly qualified, passionate workforce comprising the Project Manager, Family Support Team Leader, two recently appointed experienced family support workers, a part-time qualified accountant and a full-time volunteer who is a retired ICT manager.

Addressing the needs of local community lies at the very heart of Newcastle PROPS' philosophy. One of the main focuses of the work is providing support through community development principles to enable people to gain skills and knowledge. This allows them to become actively involved in the management and ongoing development of the project (Trustees and the sub-groups) and also in the delivery of services and support. We have 12 volunteers, some trained in committee skills, others having completed accredited courses in counselling, facilitating and drugs awareness training and who work with family support workers in the field.

Real community involvement and community empowerment underpins all aspects of our future development plans. To this end we are training and developing self-help groups as a tool for community involvement. Newcastle

PROPS has been developed and flourishes on the principle of peer support within the community:

- we seek the views of the relevant communities
- we incorporate the views of families and carers at all stages including planning, design, delivery, ensuring all service contact is user friendly and supportive
- some volunteers are Trustees of the charity

We seek the views of families to establish customer satisfaction and to evaluate the services provided. Performance of the Project is continuously and objectively evaluated by researchers from the University of Northumbria under Professor Nick Heather.

The Project is represented on sub-groups of the Newcastle Drug Action Team (DAT). Newcastle PROPS represents the interest of its clients through practical support and through membership of community partnerships and other projects.

In order to further expand into specific areas of need, we need larger premises and ideally a single source of funding. A considerable amount of valuable time is wasted continually searching for small amounts of money in order to run this highly regarded and expanding operation. Last financial year, the Project facilitated 203 one-to-one, 36 Family and 48 carer support group sessions. We had 92 carers registered with the project and volunteers committed 1812 hours. That was achieved with 1.5 family support workers – now we have 3.5 and demand is growing.

As a result of our achievements, we have received national recognition. At the end of 2003, Newcastle PROPS was awarded the Queen's Golden Jubilee Award that recognises the achievement of groups who volunteer their own time to improve the quality of life and opportunities for others in their community. As part of the Year of the Volunteer 2005, our Chair, Val Clark, was presented with the Local Heroes Award by the Home Secretary in appreciation of the work being done by Newcastle PROPS.

Anne E Carlile

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Last Word from Chris Dabbs



Dear Mrs. Buggins,

I have been looking at Wikipedia in the past few weeks. Never heard of it? It is an encyclopaedia on the World Wide Web, with 1.3 million articles – 470 000 in English – and 187 independent language editions. Free, openly accessible and covering a wide range of topics, Wikipedia gets some 80 million hits per day.

Another big web site – so what? Well, Wikipedia's content is created by its users. Any visitor to Wikipedia can edit articles, although in practice about half of all edits are done by just 2.5% of the users. Pages are always subject to editing, so no article is ever 'finished'.

This approach means that Wikipedia is, in effect, a never-ending discourse not only on encyclopaedic subjects, but also on topics more familiar in almanacs and magazines. It also contains topics that relate to current events. The wiki software is also used to support parallel projects such as Wiktionary and Wikibooks.

The wiki approach is a triumph of free collaboration. A variety of rules, policies and practices are proposed, and each has a varying amount of support. When these are violated, the Wikipedian community decides on a case-by-case basis how strongly they are enforced.

Critics argue that Wikipedia lacks authority when compared to a traditional encyclopaedia, has systemic bias in its content, and is deficient in some traditional encyclopaedic topics.

Nevertheless, what is really interesting is that Wikipedia has been successful and continues to work. In IT terms, it is aligned with the 'open source' movement. Instead of corporations planning and determining everything and then charging and arm and a leg, the open source approach is to open up software to anyone who wishes to contribute and to have a continuous process

of development and refinement – at lower or even no cost to the end-user.

This whole approach suggests that a broad community can, without a large or rigid hierarchy, produce efficient and effective products and services. The trick seems to be to provide the right sort of environment that enables this to happen – and then stand back. With no one to direct everything, only the rules and policies required will be developed and enforced.

Drawing on a wealth of experiences, without directly filtering or judging people (rather than their contributions), collective knowledge can be harnessed to produce something of use and interest. If something has little relevance, then it will not be reflected.

The whole approach simply requires trust in people to do the right things for themselves, and then allow them to get on with it. Perhaps there are clear lessons here that health and social care might adopt?

There might even be a direct challenge to what we might see as patient and public involvement. Rather than something that is mainly controlled by large NHS agencies that then allows citizens to do certain things, perhaps PPI might be about developing a conducive environment and then letting patients and the public decide what they think is relevant to their lives and what to do about them.

Keep well

Chris

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

EVENTS CALENDAR



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

Urban health by design

**Sustainability - a basis for holistic
planning involving people**

Wednesday May 4 - Liverpool

Health, Wealth and the Environment are inextricably linked. 'Choosing Health' the UK White Paper insists that people must take more responsibility for their own health. However planners, architects, designers, developers, health professionals and citizens must also take more responsibility for creating a healthy environment in order to reduce the 'risk' conditions that determine health.

This is about much more than buildings.

It is about meeting basic needs; inclusivity; participation & control; access; cultural experience & social interaction; heritage; and engagement in health.

These are the elements that create a Healthy City, Town or Village. What we do today will determine the legacy that we leave for tomorrow. We must see beyond our immediate day-to-day imperatives, so that the future becomes our imperative today.

A Bearhunt and Liverpool Healthy City Conference

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