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PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

PPI Forum Members' guide goes on trial

A new guide for PPI forum members has finished its consultation phase. The guide, issued by the Commission for Patient and Public Involvement (CPPIH), sets out for the first time what is expected of PPI forum members and how they might operate.

The 62 page tome also gives a basic introduction to the structure of the NHS, including a glossary which will be useful for those with little or no experience of health services.

The guide is expected to be in operation for an initial trial period of six months, and will be regularly reviewed and updated in the light of the actual experiences of forum members.

Critics of the document argue that it could discourage people from joining forums. Chris Dabbs Chairman of Passionately Curious, a forum support organisation said "forum members have, at best, two to three hours a week to devote to health. This document is welcome, in that it clarifies what they should do and how they might do it. It is also frightening in that it makes forum membership seem like a seven day a week job".

Dennis Rogers, Forum Member for Coventry Primary Care Trust disagrees "Being on a health forum is a new experience for me so I will look forward to the document being shaped by people who have already had lots of experiences, and also forum members as we settle into our roles".

Made up of nine sections, the guide covers a wide range of issues including mapping the area, partnership working, ways to involve people, collaboration, priority setting, conducting business and how to make visits to NHS facilities.

The 'on-spec' visit, which can be undertaken with just one hour's notice, is surely the most potent power of forum members, though the guide points out that these should take place only in exceptional circumstances. Forum identity cards are to be provided which will provide health facilities with authorisation when visits are made.

The CPPIH Guide is the latest in a long line of guides about PPI published over recent years and those working in the field could be forgiven for being confused. In this month's edition of PPI Monitor we publish our 'Guide to the Guides' telling what's out there and how to find out more. See pages 12-13

INSIDE THIS ISSUE

The Guide to the Guides. PPI Monitor takes a look at the vast number of PPI Toolkits out there and points you in the direction of the best.

Lessons from Mental Health. Much of the current best practice in Involvement can be found in Mental Health Services.

Local Authority Scrutiny of the NHS and how it fits into PPI.

Patient Forums: Top tips on getting started.

Case Studies: Two Trusts discuss how they achieved a rating 111 in PPI.

10 Great Myths about PPI

And much more…….

PPI Monitor connects Forum Support Organisations, Forum Members, NHS Trusts, Commissioners and health & social care practitioners to spread good practice.

Olive Oil

Last week I had lunch with Olive, a friend who makes television programmes. She's working on a new series called Mancamp. It's a fly-on-the-wall documentary which charts the progress of a group of men who are trying to become proficient at something that their fathers should have passed on to them but didn't.

Each one is allocated an 'expert' who trains them in a range of things that dads neglected to teach such as flirting, plumbing or basic electrical repairs.

This made me think about what my father had neglected to tell me about. I can't tell my switches from my sockets or my bungs from my bicarb. As for flirting. Well the less said about that the better.

It was when it came to the internal combustion engine that my father really let me down badly. He didn't teach me a thing. In his defence though, I have to say it was because he never owned a car. Never even learned to drive.

When I purchased my second hand Ford Cortina, I opened the bonnet and surveyed the contents as if this 1.6L were some kind of time machine just landed from another planet. It may as well have been. This complex tangle of wires and leads and metal bits made absolutely no sense to me at all.

Being cash strapped, I decided that I would have to get this machine in good order without going to the expense of paying for a service. I was delighted to discover the Haynes Manual. These are hardback manuals which present beautiful illustrations of your car in pristine condition, guiding you effortlessly through whatever service or repair you need to do, in a series of easy steps.

What more could a man want? I set about changing the oil immediately. Following steps 1-5 I located the sump nut and using the appropriate socket insert, released it.

The resulting flow of oil would have been familiar to anyone who recalls the opening shots of the Beverly Hill Billies. This black gold though was flooding down a suburban road in Ilford. Needless to say, I was not very popular with the neighbours. Apparently, one is supposed to place a receptacle of some sort under the sump to catch the spent oil.

Haynes manuals don't draw receptacles of any sort in their manuals. They imagine that nobody can be so stupid and ill-informed that they do not realise the need to catch the oil. How wrong they are.

The Haynes manual was very useful in illustrating how things should be. Real life can be very messy and of course lessons learned by making mistakes stay with you a long time, even if they mess up your manual.

It's interesting to see that the Commission for Public and Patient Involvement is consulting on a Reference Guide for Members of PPI Forums. It's like a Haynes manual for PPI. The problem is that communities and NHS Trusts come in more variations than even the legendary Ford Cortina.

That's not to say it won't be useful. It will. If you are as new to the NHS as I was to engines, then it will appear like a confusing set of wires and plugs and you could be forgiven for wondering how it all fits together and what on earth makes it run.

Do take a leaf out of my book. Use the manual to begin to develop an understanding. If things are not making sense right away, go slowly before you tackle a big job – and do apply some common sense.

Importantly, learn to value mistakes. After my Beverley Hill Billies horror show my oil never runneth over. Manuals lead us to believe that they have all the answers. Mistakes give us the insight to realise that we have a good part of the answer too.

PPI Monitor sets out to complement the manual. We are determined to make it the essential tool for PPI. When you have more variations than a Ford Cortina you will need a lot of different tools at your disposal. Over the coming months we will be dedicated to building up your toolkit.

As for my TV friend Olive, she looked rather perplexed when I put forward the idea of 'I'm a PPI Forum Member Get Me Out of Here'. And I thought I was flirting. Thanks dad.

Malcolm McClean

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Chris Dabbs

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

Nick Bosanquet

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

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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 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 and was member of the Transition Advisory Board that led to the setting up of the Commission for Patient and Public Involvement in Health. David's passions are Samuel and Adam (4 year and 4 week old sons respectively), poetry, and (depressingly) Leeds United.

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A Patient Centred Medical Centre

Dr Richard Fitton is GP at Hadfield Medical Centre. He was involved in the Shipman Trial and has implemented changes in practice to involve and empower patients.

Engagement for marriage to a postgraduate in anthropology, IT and information science re-directed my middle class medical aspirations in 1979. A post in General Practice in West Gorton, Manchester replaced the planned sabbatical in Brisbane, Australia. The daily problems of city dwellers in the north west of England are different to those presented on ward rounds of Guy's hospital in the early 1970's and presumably to those found in Brisbane. My Manchester practice served 7600 patients and had four doctors of differing cultural, religious and educational backgrounds. The patients were in those days' terminology mainly of manual and non-manual social class 5. Their disease prevalence and life expectancy had been shown to be poor by the "Black Report" and the later "Townsend report". One of my experienced partners explained that his patients' life expectancies were 7 years less than that of patients of social class who lived in the "gin and jaguar belt". The answers to these inequalities and responsibilities were not immediately apparent to a young newly married GP but became fairly clear whilst sharing ideas with the University of Manchester department of General Practice, the Royal College of General Practitioners. My beliefs were finalised during attendance of the MSD's intensive year long "Leadership in General Practice course". "Patients", I realised, "were the most under utilised resource in the National Health Service" But, how was any one to do any thing to empower patients about it in an NHS that was almost an untouchable icon of faith and hope?

The experienced senior partner in General Practice had explained that patients who did badly in life did not "enjoy deferred gratification" but "instant gratification". Life was for the moment and the future was out of their control. The patients believed that the doctors were there to make the patients

healthy. This was far from the truth – the doctors were there to make a living and to deal with the patients when they were ill. Health was some thing that patients were failing to achieve. Poor housing, intrusive roads, railways, factories, offices, grey and concrete highrise flats were not inspiring faith in "deferred gratification". By the advertising media's rosy standards inner city dwellers were failures and to be felt sorry for.

A gradual vision of a patient centred medical centre developed. Patients would check and monitor their own health and diseases. They would understand and enjoy healthy lifestyles with their families and communities. The Medical Centre would remain a place for management of diseases and ill health and for prevention. Health would be achieved at home. Early experience with information leaflets for patients, public health promotion and information systems suggested that radical changes were necessary.

1992 offered the opportunity of applying for a single-handed practice within my own suburban community. I accepted and started in single-handed practice on May 24 1993. With the help of patients and health officials built we developed a "patient centred medical centre". The patients met with architects and health authority administrators to design the Centre. It would be used for immediate, continuing and preventive care but would also be able to be used as a resource for meetings, exercises, meetings to share experience and for development of the practice of patient centred medicine.

The patients and staff moved the furniture and equipment from the old stable block premises to the modern purpose built premises on a Saturday morning in September 2000. The practice settled into a routine and is now tackling the new GP contract and a number of projects to empower patients. The practice electronic record work is mentioned on the cabinet office e-envoy site, it's legal informed consent work is mentioned in The Protti Report. The NHSIA, Bury Knowle practice in Oxford and UMIST have helped the patients to undertake nationally funded and commissioned evaluation of patient accessed records.

One patient was one of two patient representatives on the National Institute of Clinical Excellence hypertension working party, another was a member of the DOH working party for copying letters to patients. A recent high-level DOH paper on self care included references to self care by patients at Hadfield Medical Centre where a good number of patients own their own blood pressure machines and blood pressure record cards. Patients presented their thoughts "after Shipman" at a RISK 2003 conference in London and received a standing ovation in the presence of the president of the General Medical Council. They have showed their electronic medical records to a chief government scientist, Sir John Patterson who asked if they were real patients!!

I doubt that I will ever find out whether patient centred medicine will work as well in West Gorton but maybe one day…

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Commission for Health Improvement CHI

Involving Patients in the NHS

The Commission for Health Improvement (CHI), has just published its report on involving patients in the NHS. The key findings have been summarised as.........

CHI's findings

The Commission for Health Improvement (CHI) assesses PPI in its routine inspections of NHS organisations.

Organisations are getting better at some aspects of PPI

The NHS generally provides information for patients and gets their feedback. It is not, however, doing enough to ensure that patients' views make a difference.

PPI is not part of everyday practice

Organisations are failing to integrate PPI; it is not central to core activities.

Involvement is not leading to improvement

PPI is not having a major impact on policy and practice. There seem to be barriers preventing pockets of good practice being adopted at strategic level and shared within and across organisations.

PPI – the poor relation

The chart shows the percentage of trusts that score three or four (four is the highest score) for the various components of clinical governance in CHI inspections. PPI is the least developed component. The top score of four has never been awarded for PPI.

Steps to take to improve the involvement of patients and the public

Plan

There is no point in having a strategy on the shelf. Organisations that succeed in PPI develop plans that link PPI to existing user groups, management initiatives and ways of working.

Engage senior management

Senior commitment to the work is essential. It is not about believing that PPI is the right thing to do, but also that it can contribute to improving services. There should be a clear rationale and a business case for PPI.

Mainstream it

PPI must be part of the corporate bloodstream. It needs central support and performance must be monitored. In successful organisations, patient or user councils sit close to corporate decision making bodies.

Engage staff

PPI coordinators need to be at least as senior as the third tier of management but they cannot do it alone. Sometimes staff see PPI as something for 'other people.'

That is wrong. All staff have a PPI role. Successful organisations demonstrate the benefits of PPI to staff, celebrate success, share good local practice and create new 'champions' using professional connections.

Use feedback to influence change

Reader panels for patient information leaflets or focus groups on aspects of the ward environment are great if they lead to change. The NHS should find out what matters to patients – then do something about it.

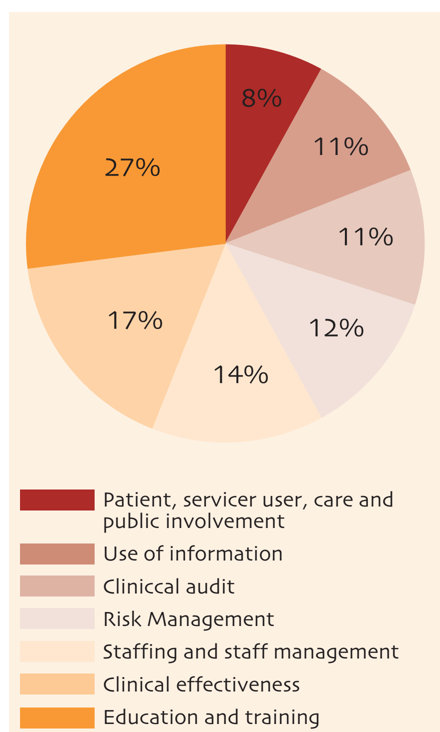
Questions that patients could ask

About my own care

- Do I get the right information and explanations at the right time?
- Does my view count? Have I been asked for my view?
- Is it easy for me to raise issues and concerns and get them sorted out?
- Am I able to make real choices about my healthcare?

About services

- Do we know how to make a difference?
- Have people from all parts of the community been able to influence change?
- Have things improved as a result of people giving their views?



A model for effective PPI

	Information	Feedback	Influence
Individual	Information to patients and carers about treatments and services	Patients can feed back on their own care and treatment, and raise issues of concern (eg PALS, complaints)	Shared decision making between patients, carers and professionals Expert Patients
Collective	Information to the wider public about how well the organisation is doing	Trends in complaints, PALS issues etc. Feedback on patient experience	Improvement in policy and planning

Outcomes

The vertical axis illustrates two levels of PPI – an individual's own care and the wider public's involvement in service planning. The horizontal axis demonstrates progression from information collection and gathering feedback to influencing change.

More information

The full report, Sharing the learning on patient and public involvement from CHI's work: i2i – Involvement to Improvement brings together the main findings from some CHI inspections. To see the report and practical examples of PPI go to www.chi.nhs.uk/patients/findings.shtml

Leading Lights

PPI Monitor looked at Bath and North East Somerset Primary Care Trust and Portsmouth Hospitals NHS Trust to find out how they achieved Rating 111 in Patient and Public Involvement.

Case study

Bath and North East Somerset Primary Care Trust scored a 111 rating from CHI in Patient and Carer and Public Involvement

Here is how we did it?

We pursue individual projects such as patient surveys and patient story interviews and host stakeholder events during the year designed to bring patients, carers, public stakeholders and planning managers together to develop priorities and influence the implementation plan. Examples include the older people's forum, mental health forum and local delivery planning fair.

Since it was established in 2001, the PCT has taken real ownership of patient and public involvement, backed up by clear strategy and complemented by a culture of transparency and openness. Throughout planning development, we create meaningful contact with patients and carers and put their perspective at the centre of service delivery.

The PCT's strategic intentions are translated into practical implementation through clear action planning. Processes for this include:

- a multidisciplinary group develops the patient and public involvement agenda
- non executive directors represent patient and public involvement on the board and professional executive committee
- an assistant director has patient and public involvement management responsibility and, along with a project manager, capacity to develop projects
- the board have allocated time for patients and the public to speak

Individuals from different layers of the organisation take an interest and responsibility in enabling patient and public involvement coordinated through the assistant director for planning, performance and public involvement as lead.

We have an established infrastructure of user and carer reference groups - constituencies of users and carers who are represented on the service planning group – current groups cover mental health, older people, learning difficulties, cancer, diabetes, and the community hospital, and more are planned. The groups come together on their own terms to express a patient opinion about health service planning and influence how the development agenda is shaped. PCT staff engage with the groups regularly.

We pursue individual projects such as patient surveys and patient story interviews and host stakeholder events during the year designed to bring patients, carers, public stakeholders and planning managers together to develop priorities and influence the implementation plan. Examples include the older people's forum, mental health forum and local delivery planning fair.

We also have a network forum for voluntary sector partnership and a disability equality forum to represent disabled peoples' perspective. The PALS service is well established and active with direct representation in all 27 general practices and community hospitals. As part of their baseline audit, we are currently interviewing a range of clinical and operational staff across the whole health community to both promote patient and public involvement and establish priority areas for development.

The PCT is active in developing the expert patient programme and, to date, over 80 patients have participated.

We run formal consultation processes about specific service changes, for example a recent reconfiguration of a hospital site, and making changes in how community hospitals and community services are used. The consultations involve extensive engagement of staff, stakeholders and the public through communication materials, accessible information and public meetings.

What advice would Bath and North East Somerset PCT have for other trusts?

- patient and public involvement work must be well organised and based on openness, honesty and transparency
- it is essential to translate strategic thinking into real action plans and then to implement them. Remember, small steps and little things are as important as the big agenda
- the more we achieve meaningful and effective dialogue with the public, the more our own perspective is influenced and it is that which ultimately effects change

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Leading lights

Case study

Portsmouth Hospitals NHS Trust scored a 111 rating from CHI in Patient and Carer and Public Involvement

How did they do it?

The Trust has been recognised nationally as a pioneer in patient representation. A clear strategy to develop the involvement of patients and carers to improve the delivery of healthcare is in place. An important part of this strategy is the Patient Experience Council (PEC), which was established in 1998. It provides feedback and input, which is used to aid development, particularly in the area of public involvement.

Members of the PEC are past and present patients. They play an active role in a variety of Trust wide committees and groups. The PEC are recruited from many sources, e.g. the Patient Advice and Liaison Service (PALS), they may be constructive complainants via adverts, word of mouth or indeed anyone who is interested. A member of the Council also serves on the Portsmouth Primary Care Trust's Citizens Panel and this enables feedback between both trusts.

The Council are, or have been, involved in many projects:

- Acting as an editorial board to ensure the quality and effectiveness of patient literature.
- Working closely with a variety of teams concerned with the major redevelopment of Queen Alexandra Hospital under the Private Finance Initiative Scheme i.e. looking at generic wards.
- Participating in design and project meetings relating to the move of the Wessex Renal and Transplant Unit from St Mary's Hospital to Queen Alexandra Hospital.
- Advising on the upgrade of wards to comply with the single sex status.
- Facilitating discussion on the 'Do Not Resuscitate Policy' and the emotive issues around that
- Their own Patient Surveys.
- Contributing to Modernisation Team initiatives e.g. Direct Access, Patient Choice, Ward Housekeeper, Food Group (this Representative has been co-opted onto the National Group).

The PALS service also holds 'PALS' tea parties. Members of the PEC, voluntary organisations and any other interested bodies and now of course the new local Patient and Public Involvement Forums are invited to attend

- Serving on and contributing to groups and committees e.g. Divisional Clinical Governance Meetings, Risk, Planning, Medical Devices, Winter Pressures and Health Economy. A member of the PEC has also been invited to sit alongside the Trust Board at Public Trust Board meetings.

Each year the PEC receives money from charitable funds to make awards to a variety of clinical projects to benefit and promote good quality patient care. Members of the PEC carefully scrutinise all applications for awards before making their final choice. The most recent round of awards were valued at £25,500 in total. The recipients of the awards are invited back later in the year.

The PEC has recently established a ward representative project. Members of the PEC are integrated into the ward team and attend team meetings. This is purely a listening service and any queries or questions are directed in the first instance to the Ward Manager. However if the patient prefers, the concern can be referred back to the PALS service.

The Ward Representative also undertakes quality/environmental checks and feeds these issues back to the Ward Manager, to support him/her in his/hers routine environmental audits.

The first of these Ward Representatives was appointed in the Renal and Transplant Unit where patients are long-term users of the service.

It was agreed that the Representative should not be a renal patient, as this would enable her to look at the area without an emotive view. Findings and comments are fed back during staff team meetings by the Representative to work with staff to improve the care they give to the patients.

The PALS service also holds 'PALS' tea parties. Members of the PEC, voluntary organisations and any other interested bodies and now of course the new local Patient and Public Involvement Forums are invited to attend. Topical subjects that they feel would be of interest to the local community are discussed and refreshments are provided. PALS tea parties have included presentations and talks etc on the progress of the Private Initiative, the impending CHI visit, HealthFit, (the Strategic framework for future health services in Hampshire and the Isle of Wight).

In addition to our PEC the Trust supports the Equal Voice Working Group, facilitated by the Trust's Diversity Advisor. This is a Portsmouth based multi agency group, which includes the local community leaders. It tackles specific issues relating to the provision of healthcare to minority groups and works within the Trust to publicise the availability of ethnic menus, the multi faith prayer room, education programmes and handbooks for staff.

Portsmouth Hospitals NHS Trusts are very proud of their achievements so far and rightly so, but as they say, there are lots of challenges ahead!

Jill Irish
Head of Patient and Public Involvement & Patient Advice and Liaison Service

Lessons from Mental Health

Involvement in mental health services has been an issue for longer than in most areas.

David Crepaz-Keay takes a look at the lessons learned for all in PPI

Patient and Public Involvement (PPI) may be high profile at the moment, particularly with the Commission for Patient and Public Involvement in Health (CPPIH) launch of 572 PPI forums and over four and a half thousand patients and members of the public joining in, but this is building on a long tradition of involvement. Many of us who have spent a long time in mental health (over twenty years in my case) feel that the area is undervalued. But in terms of service user involvement, the history, diversity of ideas and level of sophistication has the opportunity to inform many areas where the concept of involvement is relatively novel.

There are a number of reasons why involvement in mental health services has been an issue for longer than most areas, but I think two are crucial: firstly, services have had a captive audience with relatively long periods of service use and little else to fill the time; and secondly, services have, historically been pretty grim in many places. These combined with the use of compulsion (almost unheard of in most health services) created the conditions, and indeed need, for involvement many years ago.

The first recorded instances of PPI in mental health date back to the 17th century (Petition of the Poor Distracted People in the House of Bedlam) and the earliest PPI forum was established in the 19th century (The Alleged Lunatics' Friend Society, 1845-63, recruited 158 years ahead of the Department of Health deadline). But it was in 1986 that we saw the first recognisable signs of local and national involvement comparable with today's initiatives: Nottingham Advocacy Group, Hackney Patients' Council and Survivors Speak Out (a national self-advocacy organisation) were formed.

The priorities for PPI in mental health have also evolved over time. The first priorities were the quality of services and facilities that they were delivered in. This reflected the institutional nature of their delivery. Few other health areas have equivalents of the old asylums, though there are strong analogues in social care and the criminal justice system. It was these institutions and the psychiatric hospitals and wards that followed them, which gave rise to the patients' councils still active and important today. These are the direct forerunners of the CPPIH's hospital trust based PPI forums and demonstrate the importance and value of having something based around, but independent of, particular institutions. Today there is not much that goes on within services that service users cannot be involved in including: staff recruitment and appraisal, service development and delivery, monitoring and evaluating services, and local and national policy work.

The next set of priorities was around the treatments themselves. Psychiatry has a history of moving from miracle treatment to scandal. This has led to two distinct areas for action: greater information about, and control over, our own treatment, and the search for a range of alternatives. Informed consent is a simple principle, but has been made hard work in practice.

Getting straightforward information in plain language when you're in a state of distress (or even just in a health facility) is a very simple measure of the degree of meaningful involvement that a service offers, and mental health services are often found wanting in this respect. Even when people do have access to information, there is so much and it may be contradictory. Information on the same treatment will be very different if written by a pharmaceutical company, a health professional, a service user group or a journalist. This highlights the importance of not just providing information, but also identifying its source. Experience of use of a treatment is as valuable a source of information as experience of prescribing it, but is just as subjective.

With reasonable information available, self-management becomes a real possibility. This is a practice that is becoming more widespread across health areas and fits neatly with alternative and complimentary approaches to health. The biggest advantage of self-management is that it makes an holistic approach to health a necessity. Although most mental health services talk of this, in practice they are designed and run to delivery treatments. Current Mental Health legislation reinforces this approach with its emphasis on compulsory treatment rather than access to services. The CPPIH believes that it is vital to place health issues in their broader context and to look at the whole range of health determinants and all decision that affect the health of communities and individuals.

Underpinning all these areas is the discrimination faced by people with a psychiatric diagnosis. One of the most important effects of increased involvement has been the change in the way we are treated when we get involved. What was once treated as a symptom of madness, is now seen as a valuable contribution to service or policy development. While there is still a lot of work to be done, the role of patient has changed for good. Mental Health Media has done groundbreaking research into what works in challenging discrimination in mental health and will be making initial findings widely available soon, but one clear message is that disadvantaged groups in influential roles are key to changing public opinion.

But what of the broader lessons for all health? These fall into two key areas: what we've done well, and mistakes all can learn from.

The successes: pushing back the boundaries of what can change, tackling discrimination, using a range of media, and people doing things for themselves. The lessons: a broadly white service user movement doesn't reflect the real story of service use, too much of the involvement falling on too few people.

I believe these lessons give a strong direction to everyone involved in PPI.

David Crepaz-Keay is a Commissioner for Patient and Public involvement in Health, Chief Executive of Mental Health Media, a former chair of Survivors Speak Out and a long-term user of psychiatric services.

Patients Forums

Your starter for ten...

If you have joined or are thinking of becoming a member of a new Patients Forum, I would guess that you are looking for a challenge – the NHS can be very difficult for outsiders to understand and navigate their way through. Part of that challenge is about the facts and figures which can be a headache to learn. There is a wish to be seen as being good at the job and have fun and make friends at the same time. This can take people into new areas and involve new ways of looking at things that may be a long way away from where they feel comfortable and at home.

So what will make that process easier and more fun? We have some ideas about that based on research and training that we have done amongst consumer and user representative bodies.

When we asked people what they thought was important, they told us that it was important to get as wide a selection of people as possible including that most difficult to recruit group – young people. Also we were told "we need to recruit people who are just patients on their own who are not just representatives of organisations and who are experts". Another person made it short and simple saying what was needed was "1. Some teambuilding work. 2. More mentoring. 3. More resources".

Many made the point that they would like more training and briefing on the health service. We got a very detailed description of the information pack they would like to receive from one person:

- "Provision of an index of all local health organisations together with brief details of sizes, functions and objectives and audit reports

- A briefing pack of the area covering demographic data, "doctor" to patient ratios, special problems especially deprivation, how the area compares with similar areas in the UK and with national data. How much poor health costs the area.

- NHS statistics especially waiting times by speciality, premature death rates, emergency re-admissions and costs of service provision, current plans for NHS improvements and how the area's statistics compare with national data over a 5 year running period."

Overall people were interested in being independent, well organised, developing a sense of purpose and knowvledge with good training tailored to the individual and the job with some suspicion of the 'expert' representative committed to things as they were done in the past. They need to be respected for what they are and be reassured that their time is valued. Does this strike a chord with you?

If those we questioned did not get results, then there was always a remedy as one forum member reminded us:

"Terrific potential for forum – needs political support/ more clout. If this does not happen, (I) will resign."

Get some early wins and celebrate them - even the little ones. The big ones will take a long time to arrive – if they ever do.

Organisers in their turn have to make sure that the barriers to success are identified and overcome.

These include:

- No understanding of the purpose of involvement amongst Forum members or health service managers – "what is the job we are supposed to be doing?"
- Finding it hard communicating with the patient population – "no one ever tells us anything and if they do, it is generally too late in the day to do anything about it".
- Being so afraid of raising unrealistic expectations that they do not create any – "Everybody is very busy and I don't suppose they will be able to come to the meeting"
- Not creating the means to identify and then address poor attitudes and lack of skills on the part of either side – "no training budget this year I'm afraid. I am sure that with a bit of good will, we'll all muddle through somehow'
- Not anticipating that patients and health professionals will have different agendas and approaches and not being able to cope with disagreement – " With respect, we really had expected you to take a more positive view about…"
- Professional or organisational territorialism ie everyone just concentrates on their own patch "Never mind them, what about us?"
- Lack of resources (time and money) or support. "Sorry its all a bit of a rush – see you what you can do by Thursday." (waving 200 page consultative report)
- Anxiety about the cost of involving users and not paying out expenses which will exclude some members of the public and patients. "Can you wait till next month for the money to pay today's taxi bill? I am afraid our accounts office are a bit slow".

The prerequisites of effective participation and contribution for Patient Forums to take on board seem to us to be:

- to reflect all strands of circumstance and opinion in the community
- to offer a wide range of choices to participants in terms of the way in which they contribute and the issues on which they wish to make their opinions known
- to develop means of stimulating and gathering opinion which reflect the individual's circumstances e.g. mobility, access to IT/internet
- To assist in the identification of issues where patient representatives can make a difference, eg issues like cleanliness, noise, food, staff attitudes, information provision
- To assess effectiveness in terms of impact on standards of health care
- To minimise waste by maximising retention amongst those who come forward and quickly giving them something meaningful to do
- To understand that what creates participant or representative satisfaction can be quite different from professional expectations
- To assess effectiveness in terms of cost

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A CUP OF COFFEE WITH...

Jacqui Pollock, Senior Trainer, Expert Patient Programme

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

Driving over the Barton Bridge, where the M60 crosses the Manchester Ship Canal, it is possible in a single sweep of the eye, to glimpse two gleaming facades which symbolise the regeneration of Salford & Trafford. Ahead is the Trafford Centre, comprising 100,000 square metres of retail therapy. To the left is Salford's Lowry Centre, in its design and content, a stunning statement of creativity.

It was here in the glass and chrome surroundings of the Lowry that I shared a cup of coffee with Jacqui Pollock, Senior Trainer with the Expert Patient Programme (EPP), Salford born and bred, and intensely proud of it.

Jacqui could not be closer to the front line on PPI. At the age of eight she was told that she had Stills disease, a form of rheumatoid arthritis. She says "At first, all it meant was not 'being allowed'. Simple things like roller skating were barred".

From an early age she developed a head-on attitude to any obstacles that stood in her way "at the age of ten I had special shoes made. I kept another pair in my bag and changed at the bottom of the street. Dad secretly got me a pair of roller skates, which I would use when mum was not around".

In her twenties the disease progressed rapidly and she suffered depression, pain and lack of sleep. She began to realise that the effects were not just physical but mental and social as well. When she asked for help from her GP practice she felt that she didn't get anywhere, and in a fit of pique joined a gym and got in touch with Arthritus Care. She says "It was in the mid 90's and I had to find £30 to get a taxi to take me across to an affluent part of Manchester. The course, Challenging Arthritus was brilliant, but I was annoyed that there was nothing like this locally".

Storming into her GP practice she met a young practice nurse. Lance Gardner was in his first week in the job "I shouted at him, but it was a great meeting and he really helped me. It was from here that I began to pick up a theme which I have pursued ever since 'what can we do other than receive treatment?'".

Driving over the Barton Bridge, where the M60 crosses the Manchester Ship Canal, it is possible in a single sweep of the eye, to glimpse two gleaming facades which symbolise the regeneration of Salford & Trafford. Ahead is the Trafford Centre, comprising 100,000 square metres of retail therapy. To the left is Salford's Lowry Centre, in its design and content, a stunning statement of creativity.

She got involved in creating a new surgery with an emphasis on Patient and Public Involvement, and the Health Action Zone sent her to Stanford University to look at the Stanford Model. On her return she decided not to pursue a career in social work and began working for the Expert Patient Programme.

Now, some 98% of NHS trusts are involved in the Expert Patient Programme, with some 10,000 participants around the country "that's more people involved in EPP than there are in PPI Forums" she says. Pausing, she adds "but PPI Forums are still very new".

Of EPP she says "It's about lifestyle changes. You are your environment, and you can exercise some control over it". She feels that the EPP approach has widespread applicability "I said 'why can't we run it for mental health?'. So last year we did. Just today I was in a synagogue talking to the Jewish community about taking control, taking responsibility".

She is most excited about Salford's service redesign project known as SHIFT. She says "We are redesigning services in a way which makes self management massively important. We've worked really hard to persuade the teams that are redesigning services to take self management into account. This is so important, and it is probably a first for the UK and Europe".

As the noise of schoolchildren leaving the Lowry gallery became unbearable, she handed me a postcard "I bought you something. It's a Lowry print. It's called The Cripples". As I looked at this picture of helplessness, I mused that had Lowry been around in Jacqui Pollock's day, he would have painted an altogether different picture.

For more information visit:
www.imca.org.uk or www.dh.gov.uk

Fitting the PPI jigsaw together

Barry Taylor, Chair of Westminster Health Overview and Scrutiny Committee comments on the PPI Jigsaw and how Local Authority health scrutiny fits in

As we all know, there is currently an air of frustration within the PPI movement for a range of reasons.

The division of statutory functions – monitoring (PPI Forums), representation and accountability to local people (Overview and Scrutiny) and advice giving (Independent Complaints Advocacy Service – ICAS) are all contributory factors. As is the internal nature of the Patient Advice Liaison Services (PALS) and voluntary patient groupings set up by NHS Trusts.

Differences in the pace of change has led to complications in the formation of stable relationships.

PALS and voluntary patient groupings have now been in place the longest, followed by the formation of Local Authority Health Overview and Scrutiny committees. The latest and possibly the single largest new public bodies to be established are the PPI Forums for each NHS Trust.

The Commission for Patient & Public Involvement was given the duty of starting 570 Forums – with a minimum number of members - by 1st December last year. CPPIH will now have a duty to support their development and monitor their performance against allocated resources.

The resulting frustration comes as no surprise. But we now have an opportunity to fuse together the distinctive duties of each of these bodies - in the interests of local people and patients. In this article I will focus my interest in how the PPI Forums and Overview & Scrutiny might work together in helping to improve local health care.

Overview and Scrutiny committees

The formation of Overview and Scrutiny Committees is complicated by different types of local authority – Metropolitan, Non-Metropolitan, Shire County, District Council and London Boroughs. The establishment duty resting with Social Service authorities – with the potential to devolve some elements to District Councils. Arrangements for Overview & Scrutiny may be determined at a local level and there are a variety of solutions.

I am the Chair of Health Scrutiny in Westminster -where there is a common boundary with only one Primary Care Trust – but where the problem of relating to the London Ambulance Service is not – 32 other Boroughs also have an interest.

Due to limited resources we have attempted to simplify our basic duties in respect of calling the NHS to account; our right to be consulted and our ability, if necessary, to refer 'significant variations in services' to the Secretary of State. In addition, we have taken tentative steps into the more proactive areas of our role.

Within our local authority boundary we have five NHS Trusts and another three in adjoining authorities that we wish to take an interest. And, whilst acknowledging that all elements of the PPI legislation were not in place when we started our work, we decided to organise those parts that were possible to get in place at an early stage. Training of members and officers in the conceptual divide of lay and executive decision making of an external public agency (NHS Trusts) was introduced.

We worked hard with our officers and those in the NHS to develop a protocol in public accountability. Each Trust (including the Strategic Health Authority and NHS Direct) now has a slot in our yearly timetable to attend the Overview & Scrutiny Committee to discuss more strategic and wider issues of accountability. More operational issues and matters of more immediate public concern may also be raised at any O&S meeting.

Some of the issues considered by the Scrutiny Committee have included the School Health Service; Community Paediatricians; Health Tourism; a 'Hoppa Bus' service; the future of the Western Eye Hospital and a large PPI scheme known as the 'Paddington Health Campus'.

We have also chosen to undertake a proactive review of one policy area - Health and Homelessness. The review, led by members, has considered how primary care access, chronic disease management, mental health and substance misuse services for a transient population can be achieved. The Review's findings will be used to help improve current service provision.

PPI Forums

The Overview and Scrutiny Committee has waited patiently for the establishment of the PPI Forums – as the potential impact on the work programme for O&S could be significant.

We are clear that all five Forums will be undertake independent monitoring of services within their Trusts. Such monitoring may well overlap with the work programme of the Scrutiny Committee. With this in mind we are keen to meet with the Forums at an early stage to let them know of our yearly workplan.

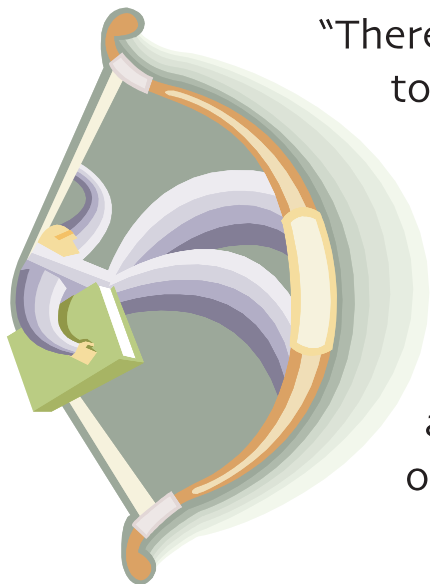
We are also keen to agree whether we can undertake joint projects – using our respective public duties – to influence health decision makers and to improve the quality of healthcare for local people. The 'eyes and ears' monitoring role of the PPI Forums within NHS Trusts – making recommendations to the Trust - complements the general duty of O&S to scrutinise local service provision.

A partnership of this sort would be an invaluable addition to the democratic voice of local people.

Barrie Taylor

Barrie has devoted most of his working life to citizen involvement in decision-making. He is an elected Councillor in Westminster and Chairs their Health Overview & Scrutiny committee. He is also a Board member of the newly formed Commission for Patient & Public Involvement in Health.

PPI TOOLKIT



"There has been an eruption of toolkits and guides to involvement since the mid-1990s. They cover everything from the individual, to groups, communities and populations. Their focus varies from fields such as regeneration and health through to specifics such as patients or tenants.

The guides also range in quality and applicability. Some are practical "how to" guides, others are strategic or evaluative documents and others are findings from research"

Each type of document has its place – but few if any of those doing involvement work on the ground has the time to review them all.

Nevertheless, a good starting framework is the long-established 'ladder of participation' (Arnstein, S. R. 1969 "A ladder of citizen participation", Journal of the American Institute of Planners 35: 216-224).

Some of the general toolkits and guides that are most relevant to patient and public involvement detailed here. This is not an exhaustive list – your comments on these or suggestions for others are welcome.

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Building strong foundations toolkit (Scottish Health Executive)

Seeking to ensure that the house is built on rock rather than sand. Two-part guide to involving the public in provision of health services, including detailed descriptions of over 30 generic approaches. Although focused on Scotland, it is of UK-wide interest, with practical application.

http://www.show.scot.nhs.uk/involvingpeople/

Every Voice Counts: primary care organisations and public involvement. (King's Fund).

Based on six case studies in London, this is a guide for people trying to put PPI into practice. Written to be accessible, practical and thought-provoking, this publication offers a good insight into challenges in primary care opening up more to lay voices.

http://www.kingsfund.org.uk/PDF/EveryVoiceCounts.pdf

Improvement Leaders' Guide to involving patients and carers (NHS Modernisation Agency)

A summary of current thinking and practical advice and tips for improvement. Principally a "professional's guide". Somewhat limited in scope – some might say focused – but with some useful outlines of six effective approaches.

http://www.modern.nhs.uk/improvementguides/patients/

Performance Improvement Framework for Patient and Public Involvement in the NHS (Department of Health)

Framework for optional use by strategic health authorities in the performance management of local NHS bodies. Uses the five key elements of the "improving the patient experience" agenda. Helpful in relating PPI to management outcomes, but confuses PPI with patient experience.

http://www.doh.gov.uk/involvingpatients/guidance.htm

A Practical Guide to Involving the Public in Health and Social Care Services (Leicester City Health Action Zone)

It does what it says on the tin – although with a focus on public 'representatives'. The guide offers practical advice on lay roles in strategic and operational decision-making. A nice alternative by going beyond the involvement process towards influence.

http://www.doh.gov.uk/cno/hazdoc.pdf

PCT Competency Framework – community, patient and public involvement (National Primary and Care Trust Development (NatPaCT))

One section of a much larger framework designed for primary care trusts (although much is equally applicable elsewhere). Identifies basic competencies in six key areas against which trusts can assess how robust their scaffolding for PPI is.

http://www.natpact.nhs.uk/newcf/index.php?showtree=y

Signposts – a Practical Guide to Public and Patient Involvement in Wales

and

Signposts Two – Putting Public and Patient Involvement into . Practice (Welsh Assembly)

A market leader – and note that it is public and patient involvement in Wales (not patient and public). Highly recommended pair of guides for NHS bodies – the first to establish firmer foundations for PPI; the second to take PPI practice forward into a more mature and far-reaching form.

http://www.cymru.gov.uk/subihealth/content/nhs/signposts/index.htm

Step-by-Step Guide to Community Involvement for Organisations – how well are we doing?

and

Community Involvement Commitments (Merseyside Health Action Zone)

A two-part community involvement toolkit, developed at the suggestion of community organisations. Based on ten community involvement 'commitments', each of four sections – commitment, process, resources, review. The guide can be used in full at strategic level, or in part for a specific purpose.

http://www.mhaz.org.uk/mhaz/achieving/communities.html

Strengthening Accountability - involving patients and the public - guidance (Department of Health)

Official policy and detailed practice guidance on the statutory duty of local NHS bodies to involve and consult patients and the public in service planning, operation and in the development of proposals for changes. Offers useful approach to think about developmental progress. The practice guidance is detailed – perhaps too much so?

http://www.doh.gov.uk/involvingpatients/guidance.htm

Well connected: a self assessment tool on community involvement for organisations (Bradford Health Action Zone and Bradford Council)

Developed from work by the HAZ and the local authority's 'Building Communities' Strategy. The tool helps organisations assess their progress, identify strengths and weaknesses, and highlight areas for action around community involvement. Good planning tool arising from an area with a strong track record in involvement.

http://www.healthaction.nhs.uk/doc.asp?doc=108&cat=77

Understanding Patients?

For many clinicians and managers in the NHS public consultation and survey research is either a necessary evil, something to be approached gingerly, or a basic way of working. The challenge for many authorities is to move from one of the first two points of view to the latter - and many are.

Nearly all Trusts "do" surveys now. But still too few really benefit from taking a systematic approach to research. The danger, particularly if patient involvement is approached in a service by service way, is that time and effort will be spent across a Trust or authority learning techniques, not sharing information, but quietly doing similar things to other services elsewhere. Surveys will overlap or duplicate each other; and for some patients being targeted, it is possible that one survey will quickly follow another through the letter box. This wastes money - because organising a separate survey to ask five questions that could have been asked on the same survey conducted by another department two months ago will cost up to £5,000 more. More importantly, it is likely to boost the spiral of silence that has traditionally infested many parts of the public sector, whereby no-one comes forward for consultation because they do not think anyone listened last time. And it makes the NHS look disorganised and wasteful; "Why are they sending me another questionnaire - I didn't hear anything about the one I filled in two months ago?"

The new prominence of understanding patient experiences reinforces the need to ensure that any research is

- action-oriented
- co-ordinated and shared across the Trust or Authority
- and as importantly that we ensure that patients and the public is aware that its views are listened to.

This in turn means using techniques which are fit for purpose.

Increasingly consultation and communication programmes need to be linked. One SHA has been regularly spending £100,000 per annum on survey research, but patients still feel that staff are not listening to them. It has completely failed to communicate how it listens. As a result, despite excellent scores on most of its clinical targets, it falls short of expectations, and is seen as remote, disinterested and "as a law unto itself".

So research is not something that can be left to manage itself, or something that sits in isolation.

Every Trust or authority needs to set out by first understanding and building on the information already available to it (and hopefully its partners). An occasional audit of research activities can help to identify what is available, examples of good practice, and indeed, training needs.

It is invariably the case that most organisations are sitting on all sorts of relevant and useful information that the corporate centre does not know exists and could help in planning and strategy, or that Departments have either forgotten about, are hiding or do not realise would be helpful or useful to others.

Once you know where you start from, one can then go on to think about devising a strategy and timetable which includes appropriate research for every service and audience, but prevents overlap and facilitates "joined-up" working. In a large authority the actual quantity of research is likely to be huge (although the centre is unlikely to know about all of it). So most authorities need to think about agreeing a cross-departmental schedule for research and consultation at regular intervals that meets the main needs of all services - and hopefully partners - and as importantly, spend a great deal of time ensuring the results are shared with Members, colleagues and partners to act as a springboard to action.

In drafting a consultation strategy you need to decide what you want; Compliance with DoH/CHI instructions? Greater awareness of health issues in your area? To make services more responsive via a better understanding of patients' priorities? More dialogue with patients and private/voluntary partners (and staff?). Getting patients and stakeholders genuinely involved in decision-making?

In choosing methods, one needs to be clear whether one is simply trying to give people a chance to have an input, trying to boost involvement/understanding, or getting an accurate measure of local views. One method of consultation (or research) cannot do all three. Increasingly organisations need to use a wide repertoire of approaches, involving both careful research (so that you really do get the views of people who cannot or will not spare the time to attend meetings and who do not send in questionnaires), as well as broader programmes which reach out to everyone in the community using questionnaires in newspapers, mailings, well publicised meetings, Visioning exercises and so on.

All types of research and consultation, be it a public meeting, a structured survey, or a Citizen's Jury or a Panel have particular strengths and weaknesses - some are more fashionable than others. What matters is being clear about fitness for purpose. Simply consulting at local events just because it is easy to meet lots of local people is fine as a form of consultation but weak as a form of research. For example, because it is very rare for any event to attract a representative cross-section of the community.

The strongest trend is in local government over the last decade has been to set up Panels of residents. MORI runs 50 Panels for different groups of SHAs, local authorities and police forces as well as a 5,000 strong People's Panel for the Cabinet Office. Panels are a valuable means of tracking individual views, and targeting individuals for further small scale projects. They can be a cheap and effective means of boosting involvement - although it is a long term process. There are also tensions between involving people and getting an objective measure of local views. The more informed and involved participants are, the less representative. Some approaches to patient involvement that are being advanced lead to a small group of better informed and engaged patients, who are increasingly divorced from the perspectives of those that have not been consulted.

However, the benefits of Panels - regular access to (in theory) a broadly representative group of citizens, speed of access, the ability to identify key groups of service users very quickly for individual projects, and understand why people's views are changing, are compelling.

One additional benefit of Panels is that by acting as a central focus for research in an authority, they help corporate co-ordination of research/consultation. They can also provide something tangible to work on in partnerships with other agencies (or even between departments!).

However , one issue to be aware of is the blurring of research and consultation. More informal, interactive forms of research are extremely helpful in building bridges with those who take part but in research terms one needs to be very clear about the impact of informing people, and of who you are really having a dialogue with. In research mode, one will want to measure the impact of knowledge to assess its effect. For example question wording, and question order have a huge impact on responses, particularly on issues that may not be as important to some members of the community as others. Research generally means selecting who you talk to carefully to ensure representatives - not just those who are interested. But when an authority is in consultation mode, it may well want to be providing information to let people make informed judgements on plans. It will be inviting as many groups/individuals to participate as possible. Because of this

one needs to be conscious of methods used and distinguish between effective research and effective community consultation and involvement.

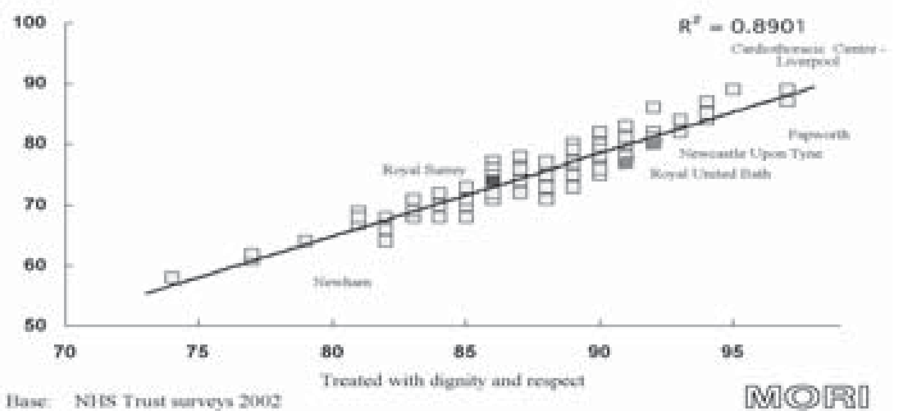
Most approaches still involve small numbers of people. Even Panels are only a few thousand out of sometimes hundreds of thousands - and Panel members do not automatically feel "involved", just consulted. For many it is just being asked their views - not real influence. The public is wary; we have to persuade non-participants that we are genuinely interested in listening and acting on their views, to build a virtuous circle. Without care there is a real danger of only "involving" the "activists" who were already interested in having their voice heard. One has to be SEEN to listen, by publicising the results of consultation; all too often we fail to tell residents they are listening. The problem is that most people in Britain know very little about the structure of health services in their area, and under half visit a hospital each year. They tend to think that their authority or trust does not consult them enough. Although the local picture varies, this applies even in the most progressive authorities. The public is not aware that the NHS is changing; to help get in touch with the people, authorities need to ensure residents KNOW they are consulting, and improve the way they communicate service information and general strategy. Allow three times as long for dissemination of research findings as you do for actually conducting any consultation or research.

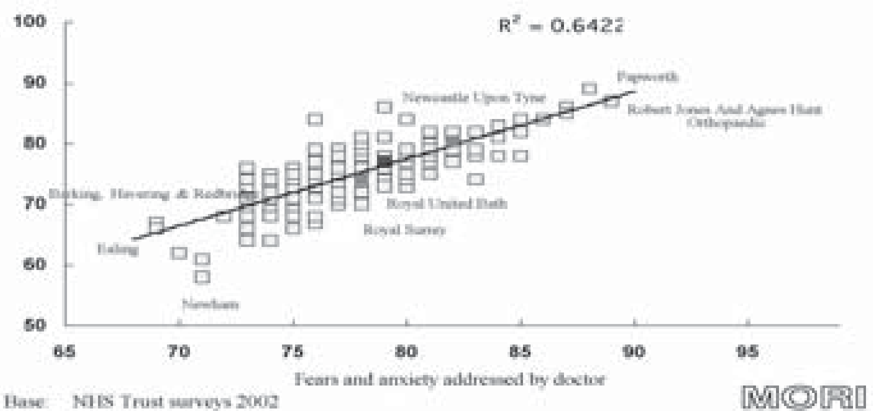
One question is the extent to which asking difficult questions about complex issues involved in some health services relies on the service changing - or instead the us "changing" or empowering the population. Do people have to be informed to be involved or even consulted? Some argue that they do, suggesting that before any consultation or research takes place one needs to build capacity, identify animateurs - the "natural" spokes people for different groups, to speak up and give more than an off the cuff view. Certainly understanding how services work, what its the constraints and medical issues are important. For certain types of consultation it is essential. But one still needs to know what the majority who do not come forward for consultation think. Unless you are trying to understand patients and communities in their entirety, you are in danger of just talking to the angry, the activists, the over 35s, and people who like filling in questionnaires – who are unlikely to be representative- however wonderful it sounds in your consultation strategy.

Another issue is how smaller organisations are going to do all of this, both in terms of researching it and managing it. The successful have driven individuals and Board level support. In management terms, even those carrying out good quality consultation are still very poor at sharing information internally and at co-ordinating research and consultation across Departments. A Consultation Strategy - that all Departments sign up to is one option. At an area level, our experience has been that SHAs, working with PCTs can boost co-operation by pooling resources, and results. Longer term, those succeed are those which are best at sharing information internally - and convince the public that services have changed and they have listened.

So far, at a national level, more people expect the NHS to get worse rather than better in the future, as MORI's Delivery Index shows (www.mori.com). The public is waiting for improvements, after accepting National Insurance rises. Making sure your research is more effective is one way of targeting improvements so that they have the biggest effect. For example, just looking carefully at the national surveys that all Trusts are obliged to undertake highlights a very wide range of performance, and looking at results for your own hospital compared to others may highlight a range of issues to consider. For example, while there is absolutely no relationship between mortality ratios and patient satisfaction, there are a range of factors that correlate very strongly with overall patient experience – we have shown some of these below. They are not necessarily things that can be measured as simple outputs, showing how important careful research can be in highlighting key issues

Ben Page
Director, MORI Social Research Institute





Research with patients tends to highlight the impact that effective personal communications by staff has on overall perceptions of how people are treated – and has more impact than waiting times. If the government paid more attention to research on these factors, rather than statistics on waits, perhaps the public would become more optimistic?

For more data contact ben.page@mori.com

TEN GREAT MYTHS... of P

by Trevor Gay, Head of Communi

The term patient and public involvement is confusing and difficult to grasp. The words can be somewhat unhelpful. It is difficult to measure. The one to one relationship between clinician and patient or carer is patient and public involvement. The mass town meeting of interested people, on a health service issue is patient and public involvement. Everything in between is patient and public involvement.

What it essentially is about **is relationships**. It is the relationship in the one to one consultation and it is the relationship between an NHS organisation and patients and public in the town meeting.

William Bridges in his book "Managing Transition" describes the management of change and talks about the "neutral zone" He argues there are three distinct aspects of coping with and living through change. **Stage one** is letting go of the old - **Stage three** is accepting the challenge of the new. **Stage two** he calls the neutral zone and I suggest we in the NHS are in the neutral zone as far as patient and public involvement is concerned. Bridges talks about being a trapeze artist and swinging through the air, in readiness to fly to the oncoming trapeze. There is a split second when we are in what he describes as the neutral zone. It is that moment when you have let go of the old – in the hope that you will meet and grab the oncoming trapeze. When you grab the new trapeze you have moved out of the neutral zone and have accepted the challenge of the new.

When in the neutral zone, as an organisation, it can of course be for many weeks, months – even years and Bridges argues this "transition" needs to be positively managed. It is in this neutral zone that people – if not shown effective leadership – will decide their own future – they will look for opportunities for their own new trapeze and you will lose good folks. Managing this transition is crucial as emotions will be running high and behaviour may not be predictable.

My experience in the NHS tells me that in this neutral zone, one of the defences created "by the nervous" is to create and develop myths. Here are what I call the, **"Ten Great Myths of Patient & Public Involvement"**

This article is based on personal experience, extensive reading and research **but most importantly discussions over many years with patients and their carers.**

This list of myths is not in order of priority:

Myth Number One: "They don't understand"

It never ceases to amaze me that this is said. There are over 60 million people living in the UK. One million of them work in the NHS. A massive workforce but almost arrogant to assume the knowledge of 1 million people exceeds the knowledge of the other 59 million. People know about their body, and therefore their health. I was impressed greatly by Alison Ryan, Chief Executive of the Princess Royal Trust for Carers. Her husband suffered from an illness that required regular injections which she performed. The Nursing profession "establishment" was up in arms about an amateur doing this. Over time she became accepted and now teaches nurses in training how to inject patients with this condition - never underestimate the value of carers.

One of my own mission statements is **"The best way to gain power is to let go of power"** – a total paradox but very real – anyone who has children will understand this phenomenon. Anyone employing staff will also understand it – get people to do your job - they usually do it better

Myth Number Two: "Patients are not representative"

Absolutely correct and why should they be?

Patients and carers generally do not profess to be, or ask to be representative. Health is an individual matter – 'twas ever thus. We should not expect any patient to be representative. Patients and carers have enough to do without the NHS asking them to do more. It is our responsibility to find representative views – if that is possible. When I speak to patients and carers they do not see themselves as representing much more than their own view – which to me is all we should expect. Anything more than that is a bonus for the NHS. It is up to the NHS whether we interpret that as a representative view. Mike Farrar a well-known civil servant, in describing individuality of General Practitioners, said "There are some 35000 GP's in this country ….. and if you've seen one ….you've seen one" – my contention is **why should we expect patients and carers to be any different.**

Myth Number Three: "Hard to reach groups"

Some groups of the population are described as this. What do we actually mean? One such classic alleged group is young men and another alleged group is middle-aged men who think they are healthy. In Torbay we have decided to go to where those people go. Torquay United played Scunthorpe United in a Division Three football match. There were approaching 3000 people at the match – mainly men. We ecided to hold a healthy lifestyle event with the wonderful

atient & Public Involvement

cations, Torbay Primary Care Trust

support of the Football club and we took the opportunity to invite people to have a "health MOT" and engage in healthy lifestyle discussions with those who are motivated to want to know.

So this is not a "difficult to reach group" – they are easy to reach – the NHS seems to find it difficult to reach them – so the mission statement here is **"GO TO WHERE PEOPLE GO"**

Myth Number Four: "Patients talk about wants we know what they need"

My view – formed over years of listening to patients is yes, they do talk about what they want. Is it unreasonable if you are the parent of a dying child that you want to clutch at every straw – every hope – however challenging that may be to you or the service? Yes, patients talk about their wants. They do not want their child to die.

On the other hand my experience has always been that when patients are told honestly the options open to them – they accept limitations on the service – but only once they have been told the truth.

We have to think very carefully about the word "needs" – for instance - in whose interests are we really acting when we talk about needs?

Myth Number Five: "Demands will mean we can't cope"

There is a famous story about the birth of the NHS in 1948 when one health centre barricaded the doors and windows fearing they would be overrun by patients stampeding to the new "free NHS"

What happened on day one was that mums turned up in ones and twos for baby milk and the odd cold and cough nervously crossed the threshold – more out of curiosity than anything else.

I am not pretending the NHS has loads of capacity. I am just contending that patients are adult, sensible people who act rationally and reasonably most of the time.

If we can just learn to be a bit brave we may well be surprised. I well remember when a residential unit for people with learning disability decided to allow every family to have a guaranteed minimum of three weeks respite care per year. This was more than had been offered in the past and equalized some inconsistency because some families got more than others did with no clear reasoning. What actually happened was that families did not take up their three weeks - but they knew it was there in case they needed it.

Myth Number Six: "The New Way is best"

The health service has existed since 1948. Over fifty years old and many dedicated staff delivering the service with all its warts and wrinkles. To assume that only new ways can work is naïve in the extreme.

That is not to say lets not change. To throw away experience as if it is irrelevant, is very unwise at best and we do it at our peril. A recent quote from one of my management gurus, said he was fed up with reading annual reports that said in many different ways ….. "Our staff are our greatest asset….. His response **"NO, NO, NO, …… staff are our only asset!"**

Myth Number Seven: "It will all cost too much"

Doing things differently is one way to look at this – if we always do what we always did we will always get what we always got. I like Harry Cayton's story about dead flowers in a vase on a bedside cupboard in the hospital. It was said that we just don't have the staff to do everything. Taking out dead flowers…… not a big job…… lack of money and staff cannot be accepted as a reason for saying dead flowers cannot be removed.

I went to a GP and said I was very interested in this new way of getting a cholesterol test. He pricked my finger, placed the blood sample in a machine and within two minutes I had my result. He explained that to do the same thing in his neighbouring practice would have involved an appointment with the practice nurse, sending the blood to the local hospital waiting two days for the result and the patient ringing to get the result three days after having the test. I am not saying it is affordable to have this type of service in every practice. I am not suggesting this particular test is urgent enough to justify a Rolls Royce service. I am simply arguing that lack of money is always a good reason not to do things. Maybe the service needs to be braver – always remembering this is public money.

Myth Number Eight: "Staff don't have time to do all this as well"

It is my contention that staff do not need to find time to "do" patient and public involvement – they already do it all the time. All we need to do is to make sure that the NHS culture is about partnership with patients not a master servant control command relationship. Everyone has something to bring to the party – patients, staff and carers. The relationship needs to be on an equal basis. The seven-hour shift of the typical nurse is all about patient and public involvement – and if it is not – then it should be. Let patients and front line staff make the rules and make managers responsible for making the job easier for front line staff and therefore a better experience for the patient – not rocket science but seemingly not palatable to some people.

Myth Number Nine: "All this stuff cannot be measured"

Why oh why do we have to measure everything? Of course as a gnarled twisted old NHS manager, I know the answer to my rhetorical question. It is simply untrue that we cannot measure patient and public involvement. There are creative people around who can help us measure anything. If we can measure teachers and the teaching experience for children, if we can measure policemen's productivity and crime, I simply cannot accept it is not possible to measure patient and public involvement– we just need to be creative. This needs to be done by more skilled, experienced, creative and innovative people than managers like me ….. perhaps we need to ask those people …… we often call them patients and carers.

TEN GREAT MYTHS... continued

Myth Number Ten: "Patients and the Public are not really interested in all this anyway"

The Audit Commission January 2003 report entitled **"Connecting with Users and Citizens"** offers an interesting insight to this.

I quote from Page 4 of the report

"Ordinary folk don't want to be involved. That is a fact of life

Our own consultation with service providers highlights the difference in approach between those who feel that they are achieving a good standard of public involvement, and those who don't. For those who don't, a major stumbling block is the sense that the public are not really interested in taking part in consultation."

I rest my case – if it is good enough for the Audit Commission through valued research it is good enough for me.

Conclusions

The NHS is changing month by month– sometimes it seems like day to day. We should celebrate this change – not create and perpetuate myths. We all have that responsibility. Your position enables you to influence your own organisation. Take that opportunity. Why can't all Board Reports have a heading "How have patients and carers been involved in this proposal?"

I have always wanted to be brave enough to suggest a payment reward system for all NHS managers, based on how many patients' problems they can prove they have actually resolved in the preceding month.

Board members – particularly Non-Executive Directors - should challenge managers to justify how decisions are made without patients being involved in the decision making process.

Finally I would commend to you Harry Cayton's three messages about Patient & Public Involvement?

Trust me I'm a patient - I use the services you provide. I have views on how you could make then better for me and people in my community. I understand my illness better than you do – I am the one suffering from it. I have views to offer about the way I am treated. Trust me, listen to me, trust my expertise – we can both benefit from this relationship.

Tell me the truth – I know that the NHS has a strong political influence. I know that there are uncertainties in medical practice. But I have a right to be given the opportunity to understand what these are, to make choices about my care, to be involved in the service I pay for. Share the truth with me.

Nothing about us without us – You decide on our behalf the services you think we want, and how you think we want them. Ask us; involve us in your decisions. Bring us inside for the benefit of all.

The views expressed in this article are personal and should not be read as the opinion of Torbay Primary Care Trust

Comments to trevor.gay@torbay-pct.nhs.uk

PATIENT CHOICE

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John Reid

Secretary of State for Health July 2003

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  Thursday 11th March 2004 : London

- **Obesity Imperative**

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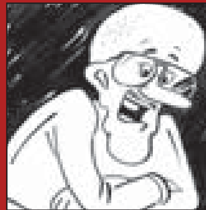

Dear Mrs. Buggins,

Thanks for calling yesterday. I was sorry to hear that you had been ill. It is good to know that you are better now, and that the treatment you got seems to have worked.

It's just a shame that more was not yet available closer to home, including at your chemist. Traipsing back and forth to health centres and hospitals is a real bind, especially when you still have your own caring responsibilities at home. The amount of planning you had to do, and the number of favours you had to call on, would faze most of us.

Transport really is a major issue, especially when you don't have a car. Taxis are too expensive to use all the time. The buses are not always reliable, and it is worse when they won't enter your estate because of the bricks being thrown at them. It's a shame that the new tramline doesn't stop near the hospital.

After all the hassle of travelling, a good rest is important. It seems strange that some centres don't even have water to drink when others provide fruit and small snacks. Given some of the conditions, like diabetes, that many people will have, these things can decide how good a visit is. It can also affect the usefulness of the tests done – and keep some of the kids from careering round the place!

As for the toilets – why is it that some places can keep them clean and accessible, when you would hardly venture into others without a gas mask and a rescue team at the ready? Maybe if all the senior professionals had to use them at the time, things might improve. Surely everyone should know by now how important good toilets are. Like the warmth of the welcome from a receptionist, they can determine what people think of a place. If motorway services understand this, why not every NHS facility?

I am sure that the Trust appreciates you raising your appreciation and concerns with the Patient Advice and Liaison Service. That new blue leaflet about "advice, support and having your say" might come in handy again, although it was a bit difficult to read. I wonder how clear it will be to most people about who to contact about things?

Still, these new patient and public involvement forums might do well to start with some of the important things that you identified. They make a real difference to nearly everyone who uses health services. Some of them can be improved fast. What better for a forum to start to get itself known and valued by local people than prompting small but meaningful changes in their first few months? Here's hoping that they take up issues important to you, rather than just being sucked into the agendas of professionals and managers.

It will be interesting to see at the end of the year if you and your neighbours think that this new system for involvement has made any difference to what you hold dear.

Chris.

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

EVENTS CALENDAR

Do you have an event coming up in the Patient and Public Involvement field? If so then please email Sarah Bashford with dates and a brief overview of the event at s.bashford@bearhunt.org.uk

WHOSE CHOICE?

Preparing for Choice in Childrens Services in the context of a National Service Framework

Wednesday 10th March 2004 London. A bearhunt event. For more information contact Malcolm McClean on 0161 266 1977 or email m.mcclean@bearhunt.org.uk

LONG TERM CONDITIONS – PEOPLE NOT JUST PATIENTS

Preparing for Choice in long term conditions in the context of a National Service Framework.

Thursday 11th March 2004 London. A bearhunt event. For more information please call Malcolm McClean on 0161 266 1977 or email m.mcclean@bearhunt.org.uk

EMPOWERING PATIENTS

Examining patients' need of knowledge for self management and the implications for service providers and practice.

Tuesday 30th March 2004 London. Contact Harrogate Management Centre on 01423 506611 or email: info@hmc.co.uk

PATIENT INVOLVEMENT EMPOWERMENT INFORMATION

A practical guide to Patient Involvement and Empowerment plus Focus Issues and Workshops.

Monday 17th May and Tuesday 18th May 2004 Manchester. For more information contact Healthcare Events on 020 8541 1399

THE OBESITY IMPERATIVE

Strategies, tactics and techniques for acting now to create a healthier future

Thursday 15th April 2004 London. A bearhunt event. For more information please call Malcolm McClean on 0161 266 1977 or email m.mcclean@bearhunt.org.uk

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