

PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

Whose Choice?

Last month, the spotlight fell on the Government's Patient Choice initiative, as PPI Monitor supported three conferences on some of the more testing dimensions of the Choice philosophy.

Sarah Bashford speaking for PPI Monitor said "Choice is soaking up a lot of time and effort in the NHS. So far it has largely concentrated on reducing waiting times for elective procedures. Now as people think about expanding choice, more challenging issues come to the fore".

To date, patients have been given a choice of hospitals, under the Choice pilots, if they have been waiting longer than six months, in an attempt to reduce the number of six-month waiters. According to Bashford "this is clearly a relatively straightforward choice. The real challenge is thinking about how to extend choice to areas outside the acute sector, such as mental health and long-term conditions. It is vital to engage patients and the public in thinking through how we do this."

Early in March, "Treat me as if I matter", a conference on Choice in mental health services considered some of the key issues. Keynote speaker Liz Main is a mental health consultant and a user who sat on the Patient Choice Mental Health Task Group. She said "What makes Choice in mental health difficult is that the biggest choice of all – freedom, can be taken away. People therefore assume that there can't be any choice and that's an assumption they must not make".

She urged PPI forums to look closely at the information that is available to users of mental health services "people involved in PPI can help to decide what form information takes. This is vital in creating informed choice for example about medication".

Later in the month "Whose Choice?" looked at Choice in children's services and how to give children a voice (see also this month's Editorial Comment). Maria Shortis spelled out some of the difficult issues "Young people really seem to have a difficult time around transition of services. There was a recent case where adult services won't see a young person until they are at least 16 years old".

She added "What happens if you are booked into their system 2 days before your 16th birthday and have been waiting for 6 months for the appointment? Two days before the appointment you receive a message saying it has been cancelled due to the fact you are not 16. You are then told you will have to wait another 17 weeks before you can be seen. You ask the sensible question – 'why didn't you make the appointment two days after my 16th birthday', the reply is 'we can't answer that'".

Choice for children and young people will throw up a number of difficult issues. According to Shortis, "transition of services is the biggest nightmare scenario, although there are some excellent examples of best practice, they are singular and based on intelligent thinking and organisation".

Towards the end of the month, PPI Monitor considered Long Term Conditions looking at the issues affecting people who will have to manage their condition for a long time.

INSIDE THIS ISSUE

Identify what type and level of Involvement is appropriate for different issues with a unique "Policy into Practice tool" for Public Involvement.

Dr Jane Martin, Executive Director, at The Centre for Public Scrutiny explains how the new power of local authority overview and scrutiny committees to scrutinise health should be regarded as a constructive opportunity for local authorities and health service providers to work together to improve the health of local people

Case Studies. NHS Direct, East Somerset NHS Trust and the Shaw Trust, a Forum Support Organisation share their practice and learning in Patient and Public Involvement.

Jargon, in-house language, professional speak? Trevor Gay argues for common sense and reality about the way we speak to our customers: patients, carers and the public.

Jill Brunt, Head of the new Patient, Public and Community Involvement Unit at the NHSU outlines their strategy for PPI.

The Operating Theatre sets out innovative and successful methods to engage patients and the public into health related topics and issues using drama and the power of stories and fiction.

And much more.....

Conference notes for all three events are available priced £49 each, plus P&P from notes@bearhunt.org.uk

Voodoo Child

Me? I love a bit of mystery. Things that don't add up. Things that confuse. Things that challenge us to understand their meaning.

I've been reading about Haiti. Land of mystery, zombies and voodoo. There is a saying in Haiti "What you see, it's not what you think". People say it all the time. It explains the inexplicable and makes a mystery of the mundane.

It's not just what we see, but what we hear and what we feel. Very often, it's not what we think.

Recently, I became transfixed by a song that I kept hearing on the radio. It has to be some special song to get me to go into a 'record' shop. You can gather by my reference to black vinyl that it is some time since I last did it. But there was something about this girl. I found her mysterious. Somehow different. I went in search of her music. I imagined a supine black soul diva who fought her way out of New York's Bronx.

The lady at WH Smith's knew who I was searching for immediately. "The girl that sings 'Stronger Than Me'" I said. She took me to the CD rack. That supine black soul diva with the Bronx accent that I had seen in my head, stared out at me from the CD cover. Her name is Amy Winehouse. She's a white Jewish girl that grew up in a middle class family in North London.

What you see, it's not what you think.

Being that this was my first visit to a record shop for some time, and the fact that there was a 'Buy 2 Save £4' offer on, I scanned the shelves for a

bargain. Amy Winehouse, I concluded, would give me major street-cred with my children, so I went for an oldie to play in my car. A compilation of Stevie Wonder's greatest hits.

"Wait until you hear this" I said to the kids making out like I was chillin' with my homies, as I blasted Amy across the car. "What's that other CD dad?" I was asked. "Oh that's just an old blind guy".

Something mysterious happened. My children showed a total disregard for this hot new female, and bombarded me with questions about Little Stevie Wonder.

"Has he always been blind? What instruments can he play? How old was he when he started? Is he still alive? How does he know where the piano is? Has he got a guidedog?"

So much for my street cred. Every time I attempt to play Amy Winehouse it is greeted with groans. They demand to hear 20 and 30 year old songs. They have heard them so many times now that they are singing along.

That's not the way I saw it happening.

What you see, it's not what you think.

This Haitian philosophy is so relevant to those of us committed to designing and developing services which are more responsive to patients and the public. In particular, we should be careful when we imagine that we can second guess what goes on in the minds of children. It can, as my Stevie Wonder episode illustrates, be very different from what we see.

A study published by the Commission for Health Improvement (CHI) suggests that the NHS still has much to do if it is to adequately respond to the needs of young and teenage patients.

The report found that young patients think they are not sufficiently involved with the decision-making process and are unhappy with the lack of communication they get when treated in the NHS.

We need to listen more. We need to keep reminding ourselves that they see things differently, and we need to find ever more creative ways to get them to download their thoughts.

Helpfully, CHI has published comments from individual young patients, collected via oral interviews, questionnaires and interactive group sessions. This is a tremendous resource comprising more than 750 pieces of feedback. Whilst we may focus on other issues some children conclude that the best things about hospital were stickers, clown doctors and videos.

What you see, It's not what you think. We need to do much more with children to shape children's services.

My children have become smitten with their new found pop idol. I wonder if Stevie Wonder wonders how he came to have a burgeoning fan club of under 12's. It's a mystery.

Me? I love a bit of mystery.

EDITORIAL ADVISORY BOARD

Chris Dabbs

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

Nick Bosanquet

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

Zenna Atkins

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

of YSHIP, now First Base, a founder member of the Work Life Balance Trust and a mother of two.

Malcolm Stamp CBE, DCL, FRSA, MIHM, MMS

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

David Gilbert

David Gilbert is Senior Advisor Patient and Community Engagement at the National Health Service University, (NHSU). He was Head of Patient and 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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Independent Regulator authorises first NHS Foundation Trusts

Health Secretary John Reid welcomed the announcement by Bill Moyes, Chairman of the Independent Regulator of NHS Foundation Trusts, that ten NHS Trusts will be established as the first NHS Foundation Trusts from 1 April.

The NHS Trusts are:

- Basildon and Thurrock University Hospitals NHS Foundation Trust
- Bradford Teaching Hospitals NHS Foundation Trust
- Countess of Chester Hospital NHS Foundation Trust
- Doncaster and Bassetlaw Hospitals NHS Foundation Trust
- Homerton University Hospital NHS Foundation Trust
- Moorfields Eye Hospital NHS Foundation Trust

- Peterborough & Stamford Hospitals NHS Foundation Trust
- Royal Devon and Exeter NHS Foundation Trust
- The Royal Marsden NHS Foundation Trust
- Stockport NHS Foundation Trust

John Reid said:

"This is a very significant day for the NHS as it is a major step on the road to decentralisation and freeing up the NHS from day to day Whitehall control. These first NHS Foundation Trusts will be able to respond more quickly and directly to the needs of NHS patients and for the first time will give local people a say in how their local hospital is run.

"I am grateful to Bill Moyes for ensuring that each trust, which becomes an NHS Foundation Trust is ready and is in the

strongest possible position to benefit from this status.

"NHS Foundations Trusts will continue to be fully part of the NHS and treat patients free at the point of need. Our aim is for all NHS Trusts to be given the opportunity to become an NHS Foundation Trust in the next five years.

"We are now almost half way through the ten year NHS Plan and the focus is shifting from national to local initiatives to make the system more responsive and patient centred. This is very much part of that. This represents a huge culture change, and the process is still underway. Modernisation won't happen overnight on 1 April, but the direction of travel is well-established, and the next steps are clear. We are entering the era of national standards, local delivery and patient choice."

CHI reports on inequalities in patient experience of NHS services

Inequalities in patients' experience of NHS care have been revealed in a report published by the independent health watchdog the Commission for Health Improvement (CHI). PPI Monitor presents the key findings:

The report considers the experiences of patients of different ages, gender, ethnic origin, educational status, level of health and deprivation. It is the first time a study to explore variations in patient experience has been carried out. The results come from 370,000 respondents to surveys of 480 NHS organisations providing inpatient, outpatient, A&E department and primary care services.

The results of the survey include:

- The age of the patient has a strong bearing on their perceptions of services. Older patients are more positive about the care they receive than younger people.
- Men generally respond more favourably

than women about the care they receive.

- White British and Irish respondents are more likely to respond favourably about their treatment than other ethnic groups. South Asian people (Indian, Pakistani and Bangladeshi) are the least satisfied with their care, with Bangladeshi respondents being the most dissatisfied.
- Caribbean, African and Chinese respondents are also less satisfied than white British and Irish respondents, as are white non British and mixed ethnic origin people.
- Respondents that completed full time education at an older age are more likely to comment negatively about the care they receive than those leaving school at 16 or earlier.
- The more sick the patient feels they are the more negative they are likely to be about the treatment they receive.

- Patients in areas of higher deprivation are more likely to be negative about the care they receive than those in more affluent areas.

Jocelyn Cornwell, CHI's Acting Chief Executive, said

"Understanding the variations in care from the patients' perspective is essential if policy makers, NHS Managers, clinicians and other staff are to address inequalities in health and improve the quality of services provided to patients. The information is intended to drive quality improvement in the NHS with a view to making services more patient centred."

The information will also inform CHI, and its successor the Commission For Healthcare Audit and Inspection (CHAI), in future assessments of services provided by NHS trusts.

'Ghost Town Britain' costing NHS £8.4 billion a year

NHS IGNORING ITS MOST VALUABLE ASSETS - PATIENTS AND FRONTLINE STAFF

A new report from the New Economics Foundation (nef) says that The National Health Service is wasting up to £8.4 billion a year by ignoring the potential of its most valuable assets. PPI Monitor summarises the key points below.

Towards an asset-based NHS says that experience in the UK shows neighbourhoods are the critical factor that is missing from both the public health debate and from NHS strategy. The loss of communities' services and involvement in public life is part of a wider phenomenon that nef has described as the rise of "Ghost Town Britain".

As the Minister for Health Alan Reid MP prepares to conduct another consultation on public health, the report recommends an 'asset based' approach which gives more responsibility to frontline staff, patients and their neighbours in the local community.

Current health policies misunderstand the potential of patient involvement, says the report. The Government is struggling to put a few professional representatives on powerless local boards, but ignoring the vital importance of a supportive neighbourhood if people are going to be healed and stay well.

As a result, re-admission rates to hospital are far too high, and powerful means of tackling chronic problems like long-term depression and loneliness are ignored - with serious cost implications.

The report proposes new systems of partnership between doctors, patients and neighbours that are capable of 'co-producing' health - using the pioneering experience of time banks and other forms of co-production in health in the UK and USA.

These allow patients to become partners in delivering health, by helping with small DIY



repairs, visiting, befriending, phone support, checking on hospital discharges and other small tasks that are vital for the efficiency of the NHS, but which are better provided by neighbours than by professionals. The report also calls for:

- A 'co-production' strategy that can measure and reward, and therefore tap into, the enormous resources of patient's time
- Devolution of initiative to frontline staff and an end to the target culture.
- A requirement that all health institutions have a strategy to involve patients as partners with professionals in the business of delivering health.
- Research into new public health solutions

that are more effective than 'education' campaigns and threatening people with serious disincentives.

"The asset-based approach is the key to making the NHS's vast resources start to work," says Sarah Burns, head of nef's public services programme. "Without a partnership in the actual delivery of services - which can transform people's condition just by the fact of involving them, as well as the support they receive - people have no meaningful stake in the NHS. Having a handful of local representatives on powerless boards is neither really participative nor likely to start to shift NHS fortunes"

"It is time that the Government realised there is more to public health than threats and scare tactics"

For more information or to obtain the full report contact nef on 020 7820 6300 or visit www.neweconomics.org

NHSU's strategy for patient and public involvement

The NHSU is the corporate university for the NHS. It has been set up to change and improve the services the NHS offers patients by giving everyone who works in health and social care opportunities to learn and develop, both personally and professionally: NHSU believes that developing individuals and developing the service go hand in hand.

PPI Monitor asked Gill Brunt, recently appointed head of NHSU's new Patient, Public and Community Involvement Unit to outline the NHSU strategy for Patient and Public Involvement.

The involvement of patients and the public in the design and delivery of NHSU's programmes and services has been valuable in ensuring its aim to improve patient care.

The Unit has three target areas for learning and development. The first is to work across NHSU, helping to embed the principles and practice of patient and community involvement in the way new learning programmes are developed. This area also aims to ensure that NHSU is involving patients and the public in the way it works, and also to make sure that every NHSU learning programme projects a consistent and helpful set of messages about involvement that will help service users and staff to embed it in their daily lives.

The second area of work for the Unit is to offer learning programmes that support health and social care staff who are specialists in involvement – for example, Patient and Public Involvement Leads at Trust and Strategic Health Authority level; Patient Advice and Liaison Services staff; and people working in the infrastructure that the Commission for Patient and Public Involvement in



Health is developing. "I'm particularly keen to work with existing forums, forum support organisations and the Commission for Patient and Public Involvement in Health, so that their staff are able to build on and share their existing knowledge and skills around involvement," says Jill Brunt.

The third area is to look at the broad concept of 'health citizenship'

Which would take in the wider determinants of health, health inequalities and well-being. A national core curriculum or 'learning framework' for health citizenship is planned to be fully developed over the course of time,

The Patient, Public and Community Involvement Unit, already has five staff, based in various locations around the country, and preliminary work has been done to establish 'Learning Labs' - groups of local stakeholders including NHS staff and specialists in learning and community engagement – in Aston, Brighton, Salford and North Tyneside. The Learning Labs have done some initial work to look at opportunities for patients and staff to learn together. The

Unit is now looking at what support will be needed over the next two years to develop those opportunities.

A theme for the Unit is raising the status of involvement as an area of study and practice taking into account many factors such as the history of community involvement, struggle and social change and understanding philosophical issues like ethics and genetics.

Jill Brunt sees a relationship between patient and community engagement. As an example of this, she is keen to link involvement with literature and creative writing such as patients' stories, writer workshops and community scripts.

"NHSU has an opportunity to widen the intellectual and academic location of involvement, as well as supporting people as they learn more about doing it in practice. If we get it right, people's health will improve – it's as simple as that!"

For further information on the Unit, contact Jill Brunt (jill.brunt@nhsu.org.uk) or Tris Benedict Taylor (tris.benedict-taylor@nhsu.org.uk).

Case Studies

Case study

The Shaw Trust

The Story so far.....

What have the first few months been like for the Forum Support Organisations? PPI Monitor asked Kirsty Regan who manages 12 Patient Forums for the Shaw Trust to tell us the story so far

What a frantic start for the Forum Support Organisation (FSO), getting all the forum inaugural meetings arranged and attended before Christmas, leading to an overdose of mince pies and bedtime reading. Forums are moving at a rapid rate of knots, raising issues on the way, both from the forums perspective and the NHS Trusts.

Where to start was the question on our lips as the FSO.

- Getting the forum working together, creating a unit, starting to assist the forum as to what they would consider for their work plan, focussing on small achievable targets, discussing that no one forum will change the NHS overnight.
- Assisting in forming a working relationship with all the Trusts involved. We have had several issues posed to us by the Trusts. Examples being:- how will the role of a forum member being a Non-Executive work?, How will the forums be more representative of their communities? and some Trusts have questioned the role of the Non-executive director as being the same as that of the Patient Forums.

To help with these partnerships the Shaw Trust met with every Trust Board to answer some of their concerns. This has had a very positive result by smoothing out any issues and encouraging a good working partnership with the Forums from the outset.

Hopefully we have had the same sorts of issues as every other FSO:- forums and personality clashes, an abundance of paperwork, people deciding this is not for



them, the amount paid for the mileage rate etc.

Is it getting quieter – we would have to answer NO. We're talking to radio, local papers, presentations to Trusts, overview and scrutiny committees, voluntary groups, the list goes on. Forums researching and deciding work plans, public meetings and dare I say annual reports.

We still think information and access to information lies at the core of forum activities. If we support the forum rather than lead, the forum can break down peoples lack of trust, they will show they have the ability to engage directly with the Health service to influence change, they will be transparent, they can display their results, form good relationships, but most importantly, is for real people to be represented and have a say

As an FSO we still believe strongly in the agenda and remain enthusiastic and motivated for the future. The foundations are in place for worthwhile patient and public involvement. Aim for the sky with small, achievable steps as forums are the critical friend

Kirstine Regan
Area Manager PPI Forums
Shaw Trust

Case study

East Somerset NHS

Patient and Public Involve

User Involvement has long been a priority for East Somerset NHS Trust. There has been long-standing user input in Cancer Services, day hospital services, continuous quality improvement projects, identified from patient surveys and maternity care.

The enthusiasm of staff and users working together has fuelled the move forward with Patient and Public Involvement becoming a 'normal' and accepted next step in improving services and service delivery throughout our organisation.

East Somerset NHS Trust has been involved in a number of initiatives regarding Patient and Public Involvement and the following points are an overview of the areas that have been and are continuing to be developed.

- PPI Conference. A joint conference, with presentations from staff and users/carers of the service, was held in September 2003, which celebrated the benefits of working together for service development. A further half-day conference is being planned for late 2004, which is envisaged will be facilitated by the East Somerset NHS Trust User Group and supported by the Trust.
- PPI Strategy. The current PPI Strategy (2003-2005) was developed in direct partnership with the Trust User Group. This has ensured the vision for joint working plays an integral part in changing the culture of the organisation and moving the strategy forward.
- East Somerset NHS Trust User Group. The User Group held their first meeting in November 2003 and a lay representative was elected as Chair. The group has a Trust representative who helps facilitate the process. Terms of Reference have been agreed and the group's visible approach to joint working with the Trust is continually promoting the vision within the PPI Strategy.
- Patient Information Leaflets. All East Somerset NHS Trust Patient Information

Trust ment within East Somerset NHS Trust.

Leaflets are now available to order 'on-line' from the Internet. It is hoped this will help with access to information for our local population. An area encouraging responses from patients to make comments on any of the leaflets accessed through this method is also available. As part of the Trusts commitment to have patients and the public involved in clinical care, a member of the Trust's User Group was asked to review a significant number of Patient Information Leaflets from Outpatient and Day Theatre areas. The comments and suggested changes have been returned to the appropriate departments for actioning.

- User Group Involvement at Strategic Level. The Trust approached the User Group for representation on various strategic level committees to ensure the voice of the patient/carer is heard at all levels of the organisation. The committees currently having User representation are:
 - Clinical Governance Executive Committee (3 users)
 - Complaints and Compliments Group (2 members)
 - Trust Board open meetings (Chair of User group)
 - User Group Involvement at Service Delivery. Two members of the User Group are involved in a pilot project on Level 9 (2 Wards) within the Hospital. The project is based around promoting self-care for patients and carers and good communication between the patient and nurse with regard to the patient's emotional welfare. Evidence of identifying problems and problem solving is being gathered for both the Users and staff involved in the project with the aim of evaluating the findings together. It has been agreed that the Users will present the findings to the multidisciplinary team at a Trust Clinical Governance meeting, ensuring the sharing of good practice and that further development takes place throughout the whole organisation.
 - Patient Environmental Action Group (PEAG).

Following the resolution of a complaint, the complainant was offered a place on this group to allow an opportunity for user input for improving the patient's environment. This has been very successful and culminated with the User being present on the recent PEAT inspection.

- Development and Education. The FISH video, promoting public involvement, has been used to support the development and education of both staff and users. This video has been shown opportunistically in environments where staff and users have been present, as well as in individual departments within the hospital as part of developing the change in organisational culture.
- NHS Foundation Trust Application. Users from the PEAG Group and the Level 9 Project have supported the Trust's recent move toward NHS Foundation Trust Status by agreeing to be interviewed about their input into developing and improving services. The interviews have been used in the NHS Foundation Trust Consultation Document in an attempt to show members of the local community how they too can 'have a say' in their hospital and that they may also help develop and improve local services.
- NHS Foundation Trust Presentations. Members of the East Somerset NHS Trust User Group have supported the NHS Foundation Trust presentations by committing members to attend each public presentation. Many of the Users have participated in the presentations, thereby actively displaying the joint working that the Trust and the User Group are promoting.

Future Developments.

Peer Review

Future developments include seeking User representation on ward and department individual Peer Reviews. Presently each Ward or area completes its own quality monitoring systems within their area. A panel of Trust members then meet monthly to review the previous months findings where good practice is celebrated and areas for development are noted. Action points are made during the discussion to enable the ward or department opportunities to improve the areas identified for development. The Department of Health's Essence of Care programme (a quality benchmarking system for 'basic care' for patients) has been incorporated into the Peer Review process and the Trust is currently approaching the User Group for representation on these individual panels to promote a transparent and healthy process incorporating patients and carers views. All Peer Review Panel reports are then reviewed corporately for emerging themes, debated and actions identified to help improve service delivery throughout the organisation.

NSF for Older People

The Trust recently commissioned a working party from the multidisciplinary team to identify ways in which services to older people can be improved. The User Group is being approached to identify a representative to join this group.

What advice would East Somerset Trust give to other Trusts?

- Have a PPI Strategy that is realistic and up to date. It needs to be easy to understand for staff and users alike.
- Ensure that you have 'champions' of Patient Involvement within your PPI implementation group. This is a definite advantage when trying to change the culture in areas where Patient Involvement has not been a priority in the past.
- Have users involved at the planning stages of initiatives – not half way through the implementation. Users will soon realise how important their input is to your organisation
- When you make a date for meetings where users are involved, try not to change the dates without good reason – make sure that you let them know.

Contact Sue Hardy, Professional Development Lead, East Somerset NHS Trust - hardy@est.nhs.uk

Case Studies

Case study

NHS Direct Online scored a Rating 111 from CHI in Patient, service user, carer and public involvement. Here is how they achieved it.

NHS Direct Online is committed to involving patient, users, carers and the public in everything that it does. The assessment given by CHI was that 'NHS Direct Online has continually sought and used service users' views to develop and improve services.'

NHS Direct Online is committed to :

- developing services which are relevant and meaningful to users;
- producing content which is understandable and addresses issues which are important to users;
- using technologies which are accessible and usable by different sections of the population served.

Examples of the public involvement work reviewed by CHI included:

Consumer representation on key decision making bodies

NHS Direct Online's two key decision making bodies are the NHS Direct Online Board and the NHS Direct Online Editorial Board. These groups have a minimum of two service user representatives on each. NHS Direct Online approached major umbrella organisations for nominations including the Long Term Medical Conditions Alliance and the National Information Forum. When developing the NHS Direct Online Editorial Board, consumer representatives were invited from previous NHS Direct Online advisory groups.

Consumer feedback to the NHS Direct Online website

Our website has been constantly informed by user input received from an electronic feedback form available on the website. The form can be completed anonymously, but users can give their email address if they want a response to queries or feedback on comments and suggestions they've made. Comments and suggestions are fed into our processes to ensure their

relevance and accessibility is constantly monitored. Developments in feedback are outlined below.

Consumer pilot testing of new services

In response to user feedback, we launched an "Online Enquiry Service" in November 2001 which was developed and pilot tested with a number of different user groups, including older people and people with disabilities. Similarly, a new NHS Direct Online development - "My HealthSpace" a personal health organiser created in a secure environment on the internet - is being pilot tested with throughout its development and implementation.

Since the CHI review, there have been significant further developments in the organisation's public involvement work. CHI recommended that NHS Direct Online's systems for public involvement be carried out in a 'more robust, systematic way' as the service expands and that a specific online complaint form should be developed.

Following on from this, NHS Direct Online has created, as part of it's new executive structure, a Public Involvement Division. A Public Involvement Strategy has been developed which aims to ensure NHS Direct Online's work is both relevant and accessible to patients and the public, carers, NHS staff, and partners in the voluntary and other sectors. The strategy is being delivered through four inter-related programmes: Consumer Relations (customer care, equality and access, marketing and communications,); Consumer Involvement (including a readers' panel, consultations, surveys and product testing); Information Partners (delivering the NHS Information Partner and NHS Approved kitemarking); and Research and Effectiveness (collaborative working with research establishments, research governance and a research interest group).

Examples of work already undertaken by the new Public Involvement Division include:

A redesign of the website's feedback arrangements.

The newly named 'Contact Us' section offers users four new services:

- NHS Direct Online PALS - a virtual Patient Advice and Liaison Service where users can get help and advice on using the website;
- 'Comments and Suggestions';
- 'How to make a complaint';
- 'How you can get involved'.

Development of a Readers' Panel

Users can get involved in the website through joining a new 'Readers' Panel' which is an online community of lay users who agree to review, evaluate and comment on content being produced or revised by the editorial team for the website. There are also a range of other user involvement opportunities including, for example, taking part in product testing.

NHS Information Partner accreditation system

An NHS Information Partner accreditation system for providers of health information is being developed. This aims to help patients and the public identify quality assured, evidence-based health information; encourage and endorse best practice in health information; and share experience amongst organisations who produce health information. Health information partners who meet the 8 quality standards or steps, will be able to apply the NHS brand to their print and web-based resources.

Research and Effectiveness

An NHS Direct Online Research Strategy is being developed, which includes plans to work with partner organisations on research collaborations. In addition, a Research Interest Group has been established for NHS Direct Online staff which aims to promote good practice in the application of research findings in the workplace.

Contact: Bette Baldwin, Head of Public Involvement
bette.baldwin@online.nhsdirect.nhs.uk

Promoting Active Citizenship

Ruth Turner is Director of Vision 21 and co-founder and former Chairman of the Big Issue in the North and a founding Trustee of its charity. Vision 21 set up the first ever Citizens Council for the National Institute of Clinical Excellence.

I'll never forget 19th August 2002. At 6.30 that morning, I got into the office much earlier than usual to try to get a few things done before the phones started ringing on what I knew would be a busy day. As I unlocked the office door, my ears were deafened. All 12 lines were ringing insistently. Grabbing one, I heard the first of what would turn out to be tens of thousands of people ask: "Hello, can I have a say in the NHS?"

Let me explain. Vision 21 is a social research and community consultation company. Set up about 5 years ago, we specialise in public involvement and working with people who are often excluded from decision-making. Promoting active citizenship and finding meaningful opportunities to include people in deciding public policy is a personal pre-occupation as well as a professional calling for founders and staff.

In the summer of 2002, we'd won a tender to set up and run the first ever Citizens Council for the National Institute for Clinical Excellence. Having already established significant and impressively transparent structures to include partners, patients, clinicians and industry in their decision-making, NICE now wanted to bring the voice of the general public into their discussions about the social and value judgements that underlie those clinical decisions.

The model adopted was a variation on the citizens jury – a deliberative assembly of 30 people, which would meet twice a year for up to three days at a time to debate these dilemmas. Some characteristics marked it out from earlier models – it would be a standing panel, although 10 members would retire and be replaced every year to bring a balance of continuity and fresh perspective. At 30 people, it would be about twice the normal size. As an experiment in deliberative democracy, we have taken aspects of many techniques used in public involvement and social research and facilitation, and adapted them to suit. There is guidance and best practice available, but no road map to follow.



The brief was to find people who had never really thought of doing this kind of thing before, but who, as a group of 30, reflected the demographics of the population of England and Wales. They would be paid £150 per day for attending, to try to ensure that neither poverty nor self-employment, for example, was a barrier to taking part. As we all know, too often the only people who are able to take part in these kind of exercises are those who are retired, unemployed, or with unusually understanding (often large public sector) employers. It was thought important to make sure that people who were either time poor or cash poor would be able to take part this time.

So how did we get these people? Instead of asking people who had experience of committees and consultations, we wanted to recruit Council members based on their level of interest; their potential to contribute to discussions; and their differences from each other in terms of their life experience. The members should not be people who had any special interest in the NHS or private healthcare, or who were already 'committee people'. We needed a wide variety of people to come forward, but we also needed to set up the Council to a fairly tight deadline.

Working with Nexus Structured Communications, we came up with a plan to generate public interest. Nexus organised a huge level of TV, radio and newspaper coverage – achieving a real coup by getting

the Citizens Council to be the lead item on all BBC TV and radio channels for 24 hours. Sky, ITV and independent radio stations joined in too. All the national papers ran stories, as did hundreds of local papers.

Vision 21 negotiated big discounts on adverts in 60 publications the length and breath of England and Wales, to catch people who read local papers rather than following national news. We also thought that some people might feel more confident in answering a local advert rather than a national one. We advertised in a number of ethnic minority papers. We sent posters to every CAB, and to hundreds of local community centres. We contacted over 190 organisations and networks – from disability charities to the Youth Council to the Federation of Small Business to regeneration partnerships – asking them to help us spread the word.

We produced the application packs in English and Welsh, large print, Braille and on tape and arranged sign language interpretation and text phone facilities where needed. We provided individual assistance on the phone for people who had literacy difficulties. Every night we took sackloads of application packs to the post office to send out first class; they were also available for people to download directly from NICE's website; and we responded to around 13,000 individual emailed requests asking for us to email an application form back. Throughout this time, the phones kept ringing – requests

Promoting Active Citizenship (cont)

for packs, requests for support or queries about how it would work, and every now and then one of our other clients trying to get through.

Approximately 4,500 people returned their applications.

We constructed a framework so that, using a mixture of methods, we were able to create a shortlist of 350 people. After a series of phone discussions – rather than formal interviews – we had our 30. In virtually every respect – from age, gender, disability, ethnicity, social class, location – the group reflected those proportions in the population of England and Wales. But most importantly as far as we were concerned, each of the 30 hold quite different views, attitudes, experiences, values and personalities. We wanted lively debates, and we've got them.

At the start of November 2002 we held an Induction in London, and our first meeting was held at the end of that month in Salford, to discuss the topic of 'clinical need'. Since then we've held a two part meeting – in Cardiff in May 2003 and then three further days in Sheffield in November 2003 – to discuss 'age' and clinical and cost effectiveness. The first 10 people to retire have had their farewell dinner, and we'll be joined by a new 10 members of the Council at the next meeting in Brighton in May. Work is now underway to embed the decisions and the thinking from the Council meetings into NICE's work at all levels. The Citizens Council project is being independently evaluated by the Open University, and many lessons are being learned as we go along about how it runs in practice.

But even at this early stage, a few things are clear. The Council meetings are held mostly

Grabbing a phone, I heard the first of what would turn out to be tens of thousands of people ask: "Hello, can I have a say in the NHS?"

in public, which makes it quite different from some other consultation techniques – not only are their individual identities published, but they are asked to express their views

in public – and to float ideas, discuss openly, change their minds, and at times say unpopular things.

We are asking for a huge amount from Citizens Council members: a level of honesty, bravery, self-awareness, and a level of articulacy that we rarely ask of anyone. Many people don't know what they think about tricky social or moral issues. Not only do we want Citizens Council members to tell us what their views are, but more ... we also want them to work out WHY they think what they think.

Take your hats off to them: the job they have been given is not easy, any way you look at it. This demands more of the public than has been demanded before ... but look closely, because some of this could be the future of "intelligent democracy" and a new, more mature relationship between the public and those with power.

And whenever anyone says that the public isn't interested in active citizenship or taking part in public life, I hear a ringing in my ears. Perhaps it's simply an echo of the phones going all hours of the day and night at Vision 21 back in August 2002 – but I know for a fact just how much people really do want to have their say, and just how well they rise to the challenge when they get their chance to do it.

Ruth Turner, Vision 21

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Want to write an article?

Do you have a burning issue you would like to write about or maybe a success story to tell? Perhaps you have a comment to make on something happening in the PPI field? PPI Monitor welcomes editorial submissions and here are a few tips and guidelines to help you along.

- About 700-800 words is the minimum requirement to make up one page.
- Make it relevant to the audience. PPI Monitor readers are all those working in Patient and Public Involvement including Pals and PPI Managers in Hospital and Primary Care Trusts, Patient Forum Leads and Members, Local Authority Health Scrutiny Officers, ICAS, CPPIH Commissioners and Regional staff.
- Illustrate your points with real examples or experiences as much as possible. Real life case studies are well read.
- Do you have any supporting artwork such as graphs, charts, research or diagrams? If so attach these as well.
- Provide tips and practical advice for others. What works and what doesn't work?

If you are interested or would like to talk about an idea please contact Sarah Bashford on 0161 266 1978 or email s.bashford@bearhunt.org.uk

Use Stories, Drama and Writing to assist learning on health matters

PPI Monitor is always on the look out for innovative and successful ways to capture attention and engage patients and the public into health related topics and issues. The Operating Theatre is a great example of using drama and the power of stories and fiction to help facilitate discussions.

Operating Theatre is a group of actors, writers, health care professionals and educators who use stories, drama and writing to assist learning on health matters. We particularly focus on areas of learning where there may be complex emotional issues or communication hurdles both for patients and health care professionals. Operating Theatre has existed for nearly three years and we are now a registered charity based within the School of Population and Health Sciences at Newcastle University. Our ultimate aims are lofty as our mission statement outlines: Operating Theatre exists to explore the natural drama of medical encounters so that empathy and understanding can be engendered between health practitioners, students and patients.

We feel that educating by using stories to communicate complex and emotive ideas is well tried and tested: fables, fairy tales, Greek myths and parables are just a few examples. If you have not had direct personal experience of a health problem it can be really difficult to understand the impact that it might have on your day-to-day existence and how it might make you feel about yourself and your world. Well told stories can almost take you there, and in a safe way for a limited time while the lights are down and you are watching, you can climb inside the skin of a character and see the world through their eyes, feeling their fear, their elation, their relief and their despair. Similarly a story can give you insight into the experiences people have just engaging with health services, such as the difficulties of expressing yourself clearly to a doctor or the rehearsals we all go through in our minds whilst sitting in the waiting room. The feelings we have as audience members watching this sort of drama are real feelings even though the scenarios are fictional and it is for this reason that this method of learning can be so vivid and powerful.

We feel that the power of stories and fiction,

whilst long recognised, is underutilised in medical education. Yann Martell, in his introduction to 'Life of Pi' explains the power of stories well when he explains that fiction is about the selective transformation of reality and that it is this twisting that can bring out the essence of reality. This is why we feel drama can offer something over and above the case presentation or clinical anecdote.

The project started as an experimental exploration into how drama might be usefully used in the education of health professionals and students, by running a series of workshops at Live Theatre on Newcastle's quayside. We were fortunate enough to have the talents of professional writers Carol Clewlow and Julia Darling from the outset of the project and we have continued to work with them as well as a number of the region's actors.

Our work is in two main areas. Firstly, we run and evaluate drama workshops for a number of groups from medical students at Newcastle Medical School to health tutors from multiple disciplines at Northumbria University. Workshops are generally around a specific health topic and often start with a piece of performed work that is then followed by discussion, facilitated creative writing and finally some short performance of work created during the workshop. We have looked at how we use language and metaphors to describe pain, we have looked at the inner voices of patients and doctors in consultation scenarios, we have looked at the things and people that subconsciously influence our actions in health settings as well as very many other areas. These workshops have proved very enjoyable and participants have given very positive feedback as to how illuminating this method of working can be. Some of the writing produced by participants has been of very high calibre. Some have even been inspired to continue writing material themselves.

Our second area of work is in writing short pieces of commissioned drama on health-related issues or topics. These can be used both as focus pieces or case studies by tutors, or as pieces for public performance to stimulate discussion on subjects by wider audiences. Our aim from the start has been to produce drama that is not only educational and informative but that is entertaining



and first-rate contemporary theatre. We have been fortunate to be able to work with professional writers, actors and theatre groups. In so doing, we hope to produce a standard of work that can stand alone as theatre. We also feel that the power of a story lies in part in how it is told and for this reason feel it is important to collaborate with those that are involved with this art at a professional level.

Currently we have a number of projects on the go, including work with drama students at Sunderland University on producing a piece on young people's health to be subsequently used in workshops for health professionals involved in this area. We also have ongoing projects with Northumbria University and Newcastle Medical School. We are in discussion with Live Theatre for involvement in a new play they have commissioned with a health theme and we have a project proposal to use Operating Theatre's methods to explore opportunities and barriers in interdisciplinary learning (where different health professionals such as nurses and doctors can be trained simultaneously when there are common themes).

If you would be interested to learn more about what Operating Theatre is doing or are interested in us running a workshop or writing and/or performing a piece for you please see our website: www.operatingtheatre.org.uk e-mail d.f.Slowie@ncl.ac.uk or telephone Alison Etherington at Newcastle Medical School on 0191 222 7382.

Martel, Y. (2001) Life of Pi Canongate Books, Edinburgh.

Policy into practice

PPI Tool

by Jessie Cunnett - Pals and Public Involvement Manager, Adur, Arun and Worthing PCT.

I didn't know it at the time, but I came to the world of patient and public involvement some eight years ago after experiencing the NHS as a fit and healthy adult going through pregnancy and childbirth for the first time. I was shocked at the lack of respect I was afforded by health care providers. I was the last person in any communication loop, and my thoughts, feelings and opinions seemed to carry little weight or importance in relation to the care of myself and my then un-born baby.

Having been a rather too-often resting actor for some time, I had some spare energy and enthusiasm that I dedicated to finding out more about this strange relationship between health service providers and users. I became involved in a Maternity Services Liaison Committee. It was an effective avenue to affect some change and a good place to learn. I was interested in why health care providers didn't seem to recognise the value of working in partnership (adult to adult) with service users, why was the value of a persons' knowledge about themselves and their experiences not utilised?

All things PPI have come a long way in the last eight years, to the point where in the right circles it is almost fashionable! But perhaps the most poignant difference I can see is a growing recognition of the value of involving patients and the public in decisions about their own health and care.

In my current role as PALS and Public Involvement Manager for Adur Arun and Worthing Teaching PCT, keeping abreast of the fast evolving PPI agenda has been at the top of my list of priorities; even the most stalwart of PPI resisters can't fail to notice that patients and the public are beginning



to get their say. However, embracing the need to involve and consult is one thing, practically doing it, and showing that you are doing it is another thing entirely.

With the introduction of legislation many staff began to approach me for help and support in looking at how to involve their service users. What appeared to be the most common concern for staff teams was the question of, "where do we start?" With already busy and demanding schedules, many staff were concerned about how to manage PPI, and saw it as an extra burden. What they wanted was practical solutions and suggestions. There was certainly no shortage of information, and to start off with I was sending people away with a few trees worth of pearls of wisdom. Instead of being helpful it had the opposite effect, I think people took one look at all the reading and ran a mile.

The Public Involvement Levels: Policy Into Practice Tool, was developed in

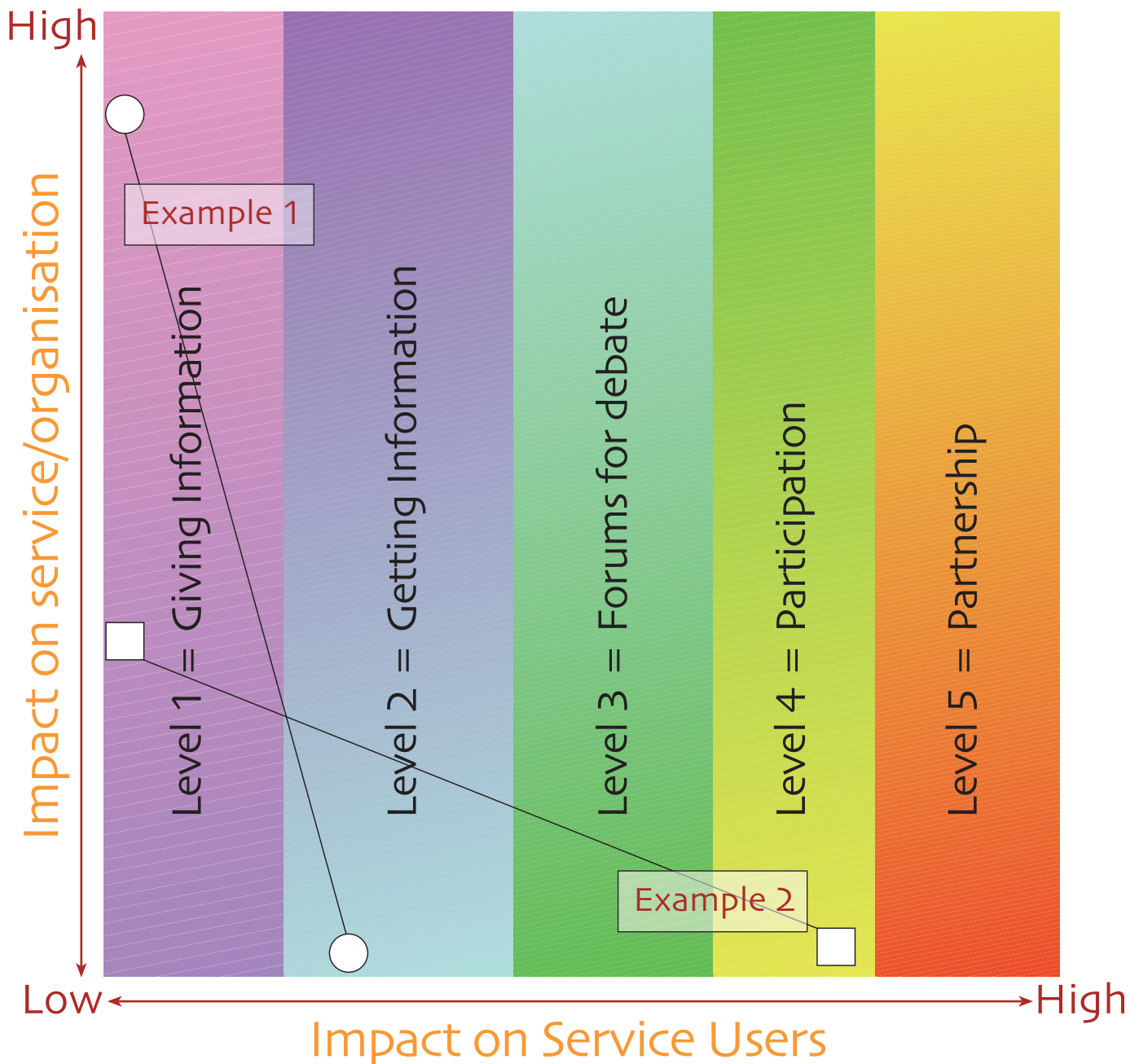
order to make PPI something accessible, something that staff needn't feel afraid of, and something that was achievable. Strengthening Accountability Practice Guidance 10 is really useful and used by staff. The Policy into Practice Tool is an extension of that guidance, to help people identify what type and level of involvement is appropriate. The tool is not scientific and needs to be used as a guide rather than a definitive solution.

I will shortly be moving on to work for the Commission for Patient and Public Involvement in Health, and am keen to introduce the tool as a way that Patient and Public Involvement Forums, can work together with PCTs and Trusts to identify a mutual understanding of meaningful and realistic patient and public involvement. I am confident that the NHS is welcoming the involvement of patients and the public and am optimistic that we are working towards an NHS which puts patients at it's heart.

Public Involvement Levels – Policy into Practice

The best outcome can be achieved by using this tool in conjunction with Strengthening Accountability Practice Guidance 10.

In order to gauge what level of public involvement you should be looking at regarding a particular project or change, assess the impact on the service against the impact on service users. Example 1: the relocation of PCT head office, the impact on service users is relatively low, but the impact on the service/organisation is high, if you draw a line between the two, the levels through which the line passes gives an indication of what levels of involvement should be considered. Example 2: the provision of a piece of equipment is being considered, the impact on the service is relatively low, but the impact on service users using the equipment is high. NB: This measure should only be used as a guide, and not a fool-proof measure of levels of involvement.



Developed from a diagram developed by Bedfordshire Health Authority

The Centre for Public Scrutiny highlights its role in Health



PPI Monitor asked Dr Jane Martin, Executive Director, The Centre for Public Scrutiny to explain the role and powers of local authority health overview and scrutiny committees and to share any specific learning from her experience at the Centre for Public Scrutiny.

The new power of local authority overview and scrutiny committees to scrutinise health, established under the Health and Social Care Act 2001, should be regarded as a constructive opportunity for local authorities and health service providers to work together to improve the health of local people. It is a power which is entirely consistent with the new core duty of the local authority under the Local Government Act 2000 to promote community well-being. Could this be a case of joined-up government?

All the signs so far are positive. Many local authorities have begun by building constructive relationships with local health services to work up the new agenda in partnership with local primary care trusts and the strategic health authority. But all acknowledge that there are concerns about how this new power will be put into practice, given the gaps in knowledge and differences in organisational cultures between all the partners. As with most statutorily imposed processes, it will be the people engaging in them which actually make them work, so positive relationship building which

reinforces the mutual benefits of the exercise must be the first step.

The real potential of health scrutiny, as in other areas of 'external' scrutiny by the local authority, is the opportunity to improve the quality of a public service through constructive public challenge informed by a dialogue with the public. A challenge which has real democratic legitimacy since it is mounted on behalf of the public by their elected representatives on the local council. A challenge which will also be informed directly by the public as users of services.

One of the CfPS four principles of effective scrutiny¹ is that it should 'reflect the voice and concerns of the public and its communities'. This message was most recently reinforced by the Chair of the Commission for Healthcare Audit and Inspection (CHAI), Sir Ian Kennedy. Speaking at the CfPS annual lecture in January, he said scrutiny must be driven by the public perspective and scrutineers should engage with patients and the public through a number of different routes. Local authority overview and scrutiny committees will, of course, draw upon their own networks at ward and local authority level. But increasingly they will also need to consult with local PPI forums, members of boards of NHS trusts, other local authorities and strategic health authorities. In the same way as parliamentary select committees, local authority scrutiny reviews should be informed by evidence from the public – in written submissions, as witnesses in oral hearings, and as collected by inspectors and regulators. CHAI should be a good source of information in this process.

The role of the overview and scrutiny committee is investigative. Effective consultation procedures and protocols, and efficient information flows are critical. At the local level all parties need to invest time to establish what works effectively.² Elected representatives on overview and scrutiny understand the need for increased direct engagement with the public and are getting out into the community, being innovative about where and when meetings are held

and gauging the user perspective with 'reality check' visits.

Health scrutiny will be concerned with the patient experience and the patient journey, but its real value will be its focus on local public health concerns and how to tackle them across the local public sector. Significantly, this does not mean performance management of the NHS – it means ensuring the better health and well-being of local communities by local authorities and health service providers working together, not only to scrutinise the problems but to put in place the solutions. Solutions which may require action by the executive of the local authority in terms of education, housing or other environmental issues, just as much as the primary and acute care providers of the NHS. Scrutiny reviews of health will be concerned with what makes you sick in the first place as well as what makes you better. This will include social care as part of the health improvement agenda

This is already beginning to happen. Local authority health scrutiny reviews carried out to date include children's therapy services in Stockport, children's and women's services in Kirklees, tuberculosis in Newham, teenage pregnancy in Ealing and patient and public involvement in health in Middlesbrough.³

The Centre's health scrutiny programme⁴ aims to reinforce the distinct role of local authority health scrutiny in reflecting the public voice whilst recognising that it is also part of a bigger picture. Through a number of elements of research, guidance, training and practical support we hope we can shape a new agenda resulting in effective health scrutiny which is a well-informed and proportionate joint enterprise taking into account, and seeking to address, health inequalities as well as proposing local action and delivery to meet local problems and concerns.

For more information on the Centre for Public Scrutiny please visit our website at www.cfps.org.uk where you can also register online on our scrutiny champions network to receive our monthly bulletin. Or telephone us on 0207 296 6835.

Footnotes

- 1 See CfPS 'The Good Scrutiny Guide' 2003
- 2 The Local Government Association has established a national framework protocol with the Commission for Patient and Public Involvement in Health (CPPIH)
- 3 For a full list of scrutiny reviews see the CfPS database at www.cfps.org.uk
- 4 CfPS will be running a three-year support programme for local authority scrutiny of health funded by the Department of Health commencing April 2004.

A patient-centred NHS

The benefits of joint working are obvious when you look at the progress being made in Middlesbrough as explained by Tim Gilling, Health Scrutiny Officer.

The Government's strategy for a patient-centred NHS provides a number of ways for the views of local people to be fed in to the planning and delivery of health services:

- Scrutiny of health issues by elected Councillors serving on an Overview and Scrutiny Committee (OSC). This has become commonly known as "health scrutiny".
- Patient and Public Involvement (PPI) Forums
- Patient Advice and Liaison Services (PALS)

A fourth, perhaps less understood mechanism, will be the "Member constituencies" of Foundation Trusts.

These replace Community Health Councils. Health OSCs have inherited the role of statutory consultee on substantial service changes and can require information from the NHS and the attendance of senior staff at meetings. PPI Forums have become the day to day "eyes and ears" in Trusts and PCTs and can refer issues to OSCs.

Getting started with health scrutiny
In Middlesbrough, we created a Health Panel and began to build relationships with our Strategic Health Authority, PCT and Hospitals Trust. Our local District General Hospital is also a specialist centre for cancer care and heart services and we recognised early on that we would need to work jointly to scrutinise the wider aspects of its work and wider public health issues.

We ran a successful "summit" for Councillors and NHS colleagues from across Teesside that informed the development of our local work programme. In partnership with the PCT we ran an innovative public consultation around the programme in Boots the Chemists and we've gone on to look at District Hospital Services, Strengthening Accountability, Appropriate Hospital Care for Older People, Patient Choice and Dental Health. The aim is to tackle health inequalities and we try

to address PPI and equality of access and outcomes in all we do.

Working Jointly

Because our PCT also covers part of Redcar and Cleveland, we produced a protocol for joint scrutiny and are currently examining Sexual Health. Middlesbrough also developed a protocol for sub-regional health scrutiny and a Tees Valley Health Scrutiny Joint Committee was created with 15 members (3 from each Council). The Committee is a "clearing house" for sharing plans and outcomes from local reviews to ensure that scrutiny is efficient. This approach was the favoured of two options for regional and specialist scrutiny and we were keen to act early to avoid a "direction" from the Secretary of State. Our foresight was rewarded in June 2003, when the Strategic Health Authority launched a Tees-wide review of primary and secondary care services with four workstreams and four cross-cutting themes. Clearly, we would have preferred something less complex for the Joint Committee's first review! The aim of the Review is to ensure sustainable solutions to managing service demand, delivery of NHS Plan targets and modernisation, while taking account of the need to maintain services, now and in the future. The Chair of the Committee was present at the launch and was able to brief the media about the role of the Committee.

The Committee met early on with the Chair of the PPI workstream to understand how PPI was to be taken forward during the Review. It is interesting to realise that in previous health service reviews meetings like this just didn't happen! Progress was made locally on hospital transport issues to not only feed in to the Tees Review but to inform the development of Local Transport Plans. The Committee also met the Chair of the Transport workstream. The Committee picked PPI and transport as its first priorities because these themes were highlighted by the Independent Reconfiguration Panel (IRP) in its first report about service changes in East Kent. The IRP is the body that advises

the Secretary of State when OSCs contest proposals for service changes.

Our neighbours in Durham and North Yorkshire, some of whose residents access services in Tees, were briefed on the Review and we will welcome our colleagues on to the Committee during the statutory consultation.

The Committee has also found time to consider "out of hours" provision following on from the Carson review of GP out of hours services and the new GP contract. A visit to the local NHS Direct call-centre is planned.

On 30 March, the NHS shared draft proposals from the Review with the Committee in front of a wider invited audience of patient and public representatives.

Challenges

So what have been the challenges of joint working? Firstly, I've been struck by the difference in cultures between the NHS and local government. Secondly, joint working requires recognition of political realities but at the same time avoiding "second bites of the cherry" by containing discussion within the Joint Committee. Thirdly, there's the challenge of matching the resources of the NHS in the review process. How can OSCs meaningfully engage in wide ranging health reviews? Finally. There's the challenge of contesting proposals for change. How will that work? Watch this space.....

For more information
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A CUP OF COFFEE WITH...

Alan Pringle, Health Lecturer, School of Nursing at the University of Nottingham

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

McCarthy Glen is one of those identikit designer outlet parks on the edge of Mansfield.

Here you can get any amount of Adidas leftovers. It helps though if you are large or XL. The outlet bookshop piles them high too. In Mansfield the diary of Billy Connelly does not seem to have sold too well.

I came here to find Starbucks and to talk about diaries. Alan Pringle is a health lecturer from the School of Nursing at the University of Nottingham. I was interested in the way he has involved the public in a health issue using diaries, and what lessons could be learned.

His now softened Scots accent hardly reflects his tough Glaswegian origins. Like most Glaswegians, he is intensely proud of his roots and points out immediately that he was raised in Drumchapel. "It's the place that Billy Connelly comes from", he says.

Mindful of the pile of Connelly diaries in the bookshop I begin to hope that the Pringle diaries offer more promise than those of the Big Yin.

He says "We seemed to play football all the time in Drumchapel. My mother was a single parent who went out to work. We didn't have child minders, and much of our time was spent on the street. With Rangers and Celtic and street football, it was a real footballing environment".

He trained as a nurse and in 1987 left Glasgow for Mansfield. The Millbrook Unit was a brand new psychiatric unit. He says "I found myself growing up in a culture that was evidence based and innovative".

A year later something happened in the world of football that was to influence the future focus of his career. Scottish football fans rioted and invaded the pitch at Wembley, famously returning home with the goalposts. Pringle observes "Between 1978 and 1988

something interesting happened. The reputation of Scots football fans changed. There was a redefinition away from the hooligan ethos towards an ethos of 'carnival' – The Tartan Army"

Looking at the statistics he noted that in one year there were 3000 arrests in England & Wales for violence at football matches, yet 26 million people went through the turnstiles. "In mental health we get irate when generalisations are made, and issues are blown up. Yet there was so much coverage of football hooliganism. We are always talking

He trained as a nurse and in 1987 left Glasgow for Mansfield. The Millbrook Unit was a brand new psychiatric unit. He says "I found myself growing up in a culture that was evidence based and innovative".

about the terrible effects of stigma. If all schizophrenics are labelled murderers just because one kills someone we get very upset. Yet we are doing the same to football fans"

He began to think about the near 26 million non-violent fans and asked what do they get out of it?

At this time in Mansfield, pits were closing. Male oriented job and life roles were at risk. Men need to express their difficulties, but

don't. "I noticed that when they went to a football match they could 'explode' in a safe environment, and wanted to investigate whether this had any impact upon their mental health".

He did this through a two stage process. Asking Mansfield Town fans to keep diaries of their feeling and experiences before, during and after matches. These were followed by in-depth interviews.

Through his analysis, he has concluded that win or lose, going to the match is good for your mental health. He says "People report a sense of involvement and belonging. In a world of rapid change this is a stabilising factor. Even though the teams change, the history belongs to the fans. Men are actively using the match as a discharge – frustration comes out in a way that would be unacceptable should they do it on a Friday night in the pub".

Using diaries and interviews was a simple and effective way to gain an insight into the experiences of everyday people and their impact upon health. According to Pringle "It produces richer data than questionnaires. You get more information given with more thought and people do it when it suits them. They are alone so they are not putting on a performance. The downside is that you can't get away from a degree of subjectivity when interpreting the results".

Diaries can be a useful tool for involving patients and the public in health issues. "People have got questionnaire fatigue", says Pringle "There are other ways which give us richer insights as long as we do it well".

Dong it well has convinced Pringle that, for men in particular, the football match is good for your mental health – even if you do support Scotland.

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alan.pringle@nottingham.ac.uk

User Engagement

Ron Poponis, a Mental Health Service Development Champion argues that real User Engagement is not just about involvement but also information, training and support .

It will be frustrating for many professionals who have worked hard to achieve some level of user involvement; to be told, this is only one part of the larger goal to achieve user engagement. The old give'm an inch and they'll take a mile scenario. Users are only just waking up to the need for a more total engagement. Involvement is only one element of user engagement. Information, Training and Support are the other elements. There is no order of importance, but there is an order of occurrence. Information is first, followed by involvement and training, which all need support.

INFORMATION

Only three things matter about information, it must be; Accurate, Relevant and Accessible. Omit any one of these three features and information is useless. The majority of information being provided for users is missing one of these three features. You can't limp along with only two, you must have all three. Unless your information goal is to provide something different. Example; I was in a user group office some time ago and saw thousands of tri-fold leaflets in a cupboard. They had not been sent out because there weren't enough people to stuff the envelopes or enough funds for the postage. However, they honestly answered yes to the lottery board question, **"Did you produce information about your groups' activities"?**

INVOLVEMENT

I am often asked, "Who should be involved". The simple rule is; All Appropriate Parties. Especially users, but carers, staff, management, clinicians and a slew of interested parties as well. This rule needs to be applied with some wisdom and judgement. For example; is it appropriate to involve a user with only personal experience of depression in the planning and develop of a personality disorder service? A depressed user is preferable to none, but a user with experience of personality disorder is more appropriate. Who would you seek to advise

on the development of a mother and baby unit in a medium secure unit? Surely not the 99.9% male population, of which a majority have been transferred from the prison service. My point is that involvement should no longer be seen as a tick the box exercise. There must be some intelligent thinking in order to achieve appropriate involvement that can produce realistic outcomes.

TRAINING

All aspects of training need to meet the Lowest Common Denominator rule. This rule states that all training 'must not' be beyond the lowest level of understanding and capability of any participant. Believe me, this is much lower than anyone may think. Unless everyone learns, the educational process as a whole has been less than successful. Although I believe some learning always occurs. The goal must be to produce knowledgeable participants capable of achieving appropriate outcomes through their involvement.

SUPPORT

Support is the one element that needs to be Omni-Present. It must underpin all the other elements. It must be provided from the beginning to the end and in sufficient amounts and forms to ensure the other elements achieve their full potential. Support should be provided in several forms; financial, administrative, human and emotional, just to mention the big four. Others will add; transportation, childcare, carer, language, hearing, sight, etc. The important thing about support, is that the level and differing types need to constantly be adjusted to meet the needs of all those involved. Be in no doubt, professionals need support as well.

True user engagement is anything but simple. Just a look at the short explanation of the four elements above, will show that. There is a bright spot on the horizon. Once user engagement is achieved it is almost self sustaining due to the number of involved



individuals and the support that must be committed. The one great surprise that awaits organisations who achieve user engagement; is how much it saves in the long run. Personnel in planning start planning more realistic services due to contact with users Example; there was a poorly attended day centre in my area years ago. We all received a questionnaire from the trust. There were only two questions. Do you want the centre to open earlier than 10 o'clock? Do you want the centre to open later than 4 o'clock? I think they received less than a dozen replies to their 500 questionnaires. We all stopped going to the day centre because they were no longer providing a realistic service. Who wants to wait for the lady to answer the buzzer when its chucking it down and you are soaking wet. The bus station café started providing a cheaper lunch, the church drop-in put in a snooker table (everybody loved that), and the charity shop had a little place out the back where you could get a cup of tea and someone to talk to. No one cared what time the centre was open. This illustration points out one of the great truths of user engagement. Users vote with their feet. Thank you.

Ron Poponis
NIMHE Mental Health Service
Development Champion

Professional Speak...

Guaranteed Protection

Trevor Gay, Head of Communications at Torbay Primary Care Trust argues for common sense and reality about the way we speak to our customers: patients, carers and the public

When I was younger and less confident at work in healthcare, I played the game too. I too nodded approvingly at meetings when we discussed complex issues in our own language. I probably even appeared knowledgeable.

As years have passed I have come to realise that it is in fact a game. I now try hard to keep things simple. This is not because I want to score points over colleagues or appear non conformist. It is a straightforward realisation on my part that protectionism is one of the main reasons we use such language in work settings.

I guess there is, among like-minded professionals in an organisation as complex as the health care setting, an acceptable level of "in-house" language. I happen to believe this is also an effective method of communicating among peers. Where I part company with professional speak is when the audience includes those not in the "inner circle" – in the case of health care I mean patients and carers.

Group dynamics, peer pressure and "group norming" intrigue me. One thing that has become apparent to me is that when we engage in meetings with patients and carers the language protectionism needs to be exorcised if we are to have real and meaningful dialogue.

I am not suggesting patients and carers are unable to comprehend complex language – that assumption would be folly and indeed insulting to the patients and carers we serve. It is simple logic to conclude that patients and carers contain, among their number, equally academic and intelligent individuals as the people serving them.

Patients and carers have enough to contend with. By virtue of entering the health care sector – the patient is in need of support, advice and guidance. There is a health problem. That is often a stress provoking position. Support and care through that stressful period of life means it will hopefully pass. I am usually very re-assured in my discussions with patients and carers that health care professionals are very good at explaining things in language that is understood by the patient or carer. There is also the opportunity for the patient or carer to check the meaning in a one to one consultation.

So ... you might say ... what is the problem?

Something else seems to happen in meetings of managers with patients and carers.

This is a totally different setting to the one to one consultations. It can – at worst – become a stage or arena for the manager to show their prowess of mastering a language that leaves the patients and carers confused, as yet another acronym or buzz word or phrase

emerges from the lips of the well meaning manager. This is not intended to be either an insult to my colleagues in management – I am proud to be one of their number - or a patronising statement about the intellectual ability of patients and carers

It is simply my contention that "in-house" language should remain in house. The moment we engage in dialogue with patients and carers outside the "warmth" of our own health care environment, the language should change to what most people would call normal.

It is, perhaps, a sweeping generalisation, and one that I am confident will provoke challenge from readers, but I suspect that most patients and carers would rather hear plain language – similar to that used in everyday conversation.

This is not rocket science and I accept I am making a complex issue very simple. That is the whole point. I am simply asking for common sense and reality about the way we talk to our customers.

There are six buzzwords or phrases below that we could make a real start with. There will be numerous others that readers could easily identify. So why don't we make a start?

I know it takes longer to say the alternative – but maybe there is just a chance ordinary folks might understand what it is we are saying.

Professional Speak	Real world language
1. Intermediate Care	Care provided when you are too ill to be at home but not ill enough to be in a high-tech hospital. This could be, for instance, care provided in a community hospital, a Nursing Home, Residential home or even a package of care provided in the patients home
2. Integrated Care Network	Hospital staff, family doctors and community health staff working more closely together to ensure patients receive their care in the most appropriate place
3. Co-terminosity	Two or more organisations covering the same geographical area
4. Commissioning Care	Looking at the health service we buy for our population and ensuring it meets their needs and that we cannot do any better
5. Governance Framework	The rules and regulations by which we operate
6. Annual Accountability Agreement	The yearly agreement between health organisations about what will be done

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Last Word from Chris Dabbs



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

Dear Mrs. Buggins,

It is remarkable how often births and deaths occur close together, as they have recently done in several local families. This hit me more because of a book I have just finished.

"Tuesdays with Morrie" by Mitch Albom (an American sports journalist) is about his weekly discussions with a former college tutor that he had not seen for some 20 years. Morrie had a serious neurological condition similar to Stephen Hawking.

Over the final weeks of Morrie's life, they discuss death, family, emotions, fear of ageing, greed, love, marriage, culture, forgiveness and a meaningful life. The book is both funny and moving; its messages about life and living are striking.

One phrase stays with me: "Once you learn how to die, you learn how to live." More health care resources are used in the final year of people's lives than at any other time – even early childhood. Yet, how much do we know or ask about what preferences people have, let alone how to meet them?

Death is a part of health care, but one people tend not to want to consider. The NHS could do worse than finding ways to engage people in how to deal with dying and death. The work of the best hospices, which treat people as people (not as patients) with families and friends, has much to offer.

This is a real challenge for everyone engaged in involving and consulting patients, carers and the public. What information and advice is best? Who needs advocacy and for what? How might self-management help people take greater control over their own death? What does choice mean to those who are dying? How might trusts, PPI forums and local authority scrutiny committees

sensitively fulfil their roles so that we all manage death better?

Perhaps an even greater challenge is how we can better handle our own fears about dying. If we can do this, our dialogues will be more productive and enable departures from this world to be handled better, less traumatic and more dignified.

While Morrie's condition slowly progresses and weakens him physically, his spirit remains undiminished. In fact, in contemplating death and dying, Mitch and Morrie (and me) learn more about life and living. The challenge set is to do what some Buddhists do: every day, have a little bird on your shoulder that asks, "Is today the day? Am I ready? Am I doing all I need to do? Am I being the person I want to be?"

Mitch Albom calls Morrie his coach: perhaps if we find ways to listen better to those moving towards the end of their lives, they can coach us how to improve not only things for others in similar situations, but also the quality of life by focusing on what is really important.

Morrie concludes that a meaningful life means devoting yourself: to loving others; to your community around you; and to creating something that gives you purpose and meaning. Not a bad way of approaching patient and public involvement.

Keep well,

Chris.

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

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