

# PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

## Radio Days



What would you give for a communications infrastructure that got your messages out cheaply and effectively? Well if you are lucky to have a community radio station on your patch you might just be able to do just that and the good news is that more and more are on their way. Phil Korbel tells more ...

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**Bye Bye PPI:** This is the final edition of PPI Monitor. See this month's editorial for more details

**Travellers Rest:** Kath Tierney explains how a PCT has started to raise the travel information standard.

**Now I Feel Tall:** published by the Department of Health, encourages all NHS organisations to take a close look at how they deliver their service and to ask patients if their emotional needs are being met as well as their physical ones. Jenny de Ville explains.

**Rural Proofing:** Alice Earp and Lesley Jones introduce a new toolkit for primary care organisations in rural areas, including how PPI can be most effectively done in rural settings.

**Putting Health in Local Hands:** New governance arrangements are a cornerstone of NHS foundation trusts, including direct involvement of patients and the public. Lisa Hinton and Richard Lewis review the early experiences of Homerton Hospital NHS Foundation Trust.

**Volunteers Across the NHS:** The NHS has not always valued or made best use of volunteers. Sheila Hawkins introduces new guidelines to encourage greater consistency in how volunteers are managed.

...and much much more.

## Bye Bye PPI

All good things come to an end. Even great things sometimes come to an end. It's sad that we have to announce that this will be the final edition of PPI Monitor.

We set out to create a real tool for those working in PPI, and based on the feedback that we have had from readers, that's exactly what we have achieved. Real case studies, ideas, techniques, thought provoking insights have all been a part of a rich mix. A mix which has helped many of you to push back the boundaries of PPI.

So why has something so good reached the stage where it has to close? Partly, it's due to NHS reorganisation reducing the pool of people who will subscribe, and partly it's due to an almost wholesale lack of support from those organisations which are meant to be at the forefront of the patient end of PPI. Which has surprised us. We imagined that the real thirst for knowledge and understanding would be at this end of the market.

Even with these difficulties, we have constantly striven to produce a high quality tool, which as I look over the back issues has just been getting better and better.

We've enjoyed the ride, and we hope you have. We know that we have helped many of you to push forward the cause of PPI in the NHS. It is a cause that we strongly believe in and we wish you every success in your continued efforts to make the NHS more responsive to the needs of patients and the public.

Good luck!

For enquiries about subscription refunds please contact [s.naden-lamb@bearhunt.org.uk](mailto:s.naden-lamb@bearhunt.org.uk)

### EDITORIAL ADVISORY BOARD

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

#### 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

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

#### David Gilbert

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

#### Publisher/Editor

Malcolm McClean  
Six Kingsbury House, St Hilary's  
Park, Alderley Edge, Cheshire  
SK9 7DA  
[m.mcclean@bearhunt.org.uk](mailto:m.mcclean@bearhunt.org.uk)  
Tel: 01625 584448

#### Editor

Chris Dabbs - Features Editor  
[c.dabbs@bearhunt.org.uk](mailto:c.dabbs@bearhunt.org.uk)

#### Publication Coordinator

Shirley Naden-Lamb  
Tel: 01625 584448

#### Production and Design

Spirit Design  
[www.spirit-design.co.uk](http://www.spirit-design.co.uk)  
[patrhodes@spirit-design.co.uk](mailto:patrhodes@spirit-design.co.uk)  
Tel: 0161 430 7771

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# News items

## Guide for direct payments published

Direct Payments for People with Mental Health Problems: a guide to action, has been published by the National Institute for Mental Health in England (NIMHE). This guide sets out good practice in relation to making direct payments more accessible to people with mental health problems. It is intended to support the efforts that all local authorities, primary care trusts, mental health trusts and non-statutory providers

of mental health services and support will wish to make to ensure that direct payments become a standard option within mental health services.

The guide is specifically about the payments that are made to individuals who have been assessed as needing social care services in order that they can make their own arrangements to meet their needs. The number of people receiving direct payments

is currently a key performance assessment framework indicator (AO/C51) for local authorities.

The guide is available at [www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4131060&chk=7yvY37](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4131060&chk=7yvY37)

## Supporting people with long term conditions

**A new guide explains how health and social care services can support people with long-term conditions to self-care through an integrated package which includes information, self-monitoring devices, self-care skills education and training and self-care support networks.**

Improving care for people with a long-term

condition is one of the biggest challenges facing health and social care organisations and demands wholesale change in the way they think, train and deliver/design services. The role of self-care is crucial in people maintaining good health and taking care of their condition. Supporting self-care provides benefits all round.

The document, Supporting People with Long-Term Conditions to Self-Care. A guide to developing local strategies and good practice, is available at [www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4130725&chk=09VokD](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4130725&chk=09VokD)

## Nice work

**The National Institute for Health and Clinical Excellence (NICE) has in progress public health programme guidance in development on Community Engagement.**

This is an assessment of community engagement and community development approaches including the collaborative methodology and community champions. The Programme Development Group (PDG) oversees the development process.

The expected date of issue for the guidance is September 2007. The provisional timetable for the work is:

Provisional schedule:	
Consultation on draft scope by stakeholders	March/April 2006
Stakeholder meeting	March/April 2006
Final Scope published	May 2006
Consultation on evidence synopsis	March/April 2007
Consultation on draft recommendations	June/July 2007
Expected date of issue	September 2007

All enquiries to [communityengagement@nice.org.uk](mailto:communityengagement@nice.org.uk)

# News items

## Experts argue over user charges

**The reality of slowing economic growth, looming budget deficits and increased demand mean that the Government should consider introducing or extending user charges in key public services according to experts in a publication launched by the Social Market Foundation.**

Coming out on the day that the House of Commons Health Select Committee summonsed health ministers to give evidence on user charges, this timely collection of essays by leading academics considers the role user charges or co-payments have to play in delivering public services in the UK.

Charging Ahead? Spreading the costs of modern public services, edited by Jessica Asato, considers the future use of co-payments in higher education, healthcare and local government and includes case studies on road-user charging, home-school transport and for a new cervical cancer vaccine, presenting practical examples of ways in which co-payments could be used.

Prof. Peter C. Smith of York University considers user charges in healthcare and

suggests there are two uses for charges: to raise finance, and to dissuade patients from unnecessarily using healthcare. He argues that the increasing pace of technological innovation and rise in patient demand, requires a major rethink of the use of charges in healthcare. He advocates a system of healthcare which has a core of treatments paid for by the taxpayer, with charges levied on treatments falling outside this "statutory package". This would enable the NHS to provide health interventions and technologies which have not been approved by NICE.

Alissa Goodman, Institute for Fiscal Studies, defends the current system of top-up fees, arguing that it is more progressive than raising the same amount of revenue through general taxation. She argues, however, that the current cap on top-up fees will have to be lifted when it comes up for review in 2010 to more accurately reflect the personal benefit that graduates receive from their degree, and to enable universities to compete with each other through the use of differential fees.

Prof. Stephen Bailey from Glasgow Caledonian University argues that extending user charges in areas of local government could improve service quality and efficiency. He asserts that charging has a key role to play in encouraging people to use local services more responsibly. He proposes greater use of planning charges, road-user charges, charges on waste to encourage people to recycle more, and charges for extra policing in city centres to tackle anti-social behaviour.

Ann Rossiter, Director, Social Market Foundation said: "There may be further room for the use of co-payments in the UK, but equity must be the guiding principle when considering current charges or introducing new ones. The potential for raising additional revenue may be limited, therefore, because exemptions to safeguard equity may produce high administrative costs."

To order a copy of Charging Ahead? Spreading the costs of modern public services, please contact Jo Saunders on 020 7227 4402 or email [jsaunders@smf.co.uk](mailto:jsaunders@smf.co.uk)

## Doctors not expected to act like 'saints' but should always put patients first

**Traditional family doctors are fast becoming a thing of the past, as they face more time pressures and increased paperwork, according to a recent study carried out by leading health care research charity Picker Institute Europe on behalf of the General Medical Council (GMC). This is not, however, seen as a problem by the public, so long as their doctor is a good listener, makes their health care his or her first priority and keeps professional skills and knowledge up to date.**

The study set out to find the views of the public, including some traditionally hard-to-reach groups, and doctors on a revised draft

of Good Medical Practice, the GMC's core guidance for doctors which lays down the principles of good practice and the standards of care, competence and conduct expected of all doctors registered in the UK.

Dr John Jenkins, Chairman of the GMC's Standards and Ethics Committee says: "In reviewing Good Medical Practice, it was important for us to understand what patients and the public, as well as doctors, thought the right principles and standards were. We are very interested in the report's findings, including the broad consensus that the great majority of duties we have included in the

new version of Good Medical Practice are important, and will consider the full findings as we re-draft our guidance."

The GMC is in the process of reviewing its current guide and this study is the final part of a wide ranging consultation. The report is based on research into the views of a wide range of people, including urban and rural populations, older and minority ethnic and homeless groups. The outcomes of the consultation will inform the revised guidance, which will be published later this year.

# Hidden involvement - revealed

A variety of activities have established effective practical ways of involving patients and the public in sexual health services in Lincolnshire. Caroline Sherriff describes a winner at this year's NHS Alliance Acorn Awards.

## The project

Louth is an integrated sexual health service providing both family planning and genitourinary (GU) medicine services. The clinic is a drop-in clinic, which is open once a week and operates a triage system for people. A semi-structured interview schedule was devised using an audit toolkit produced by the London School of Tropical Medicine. It was refined in consultation with the staff members. Semi-structured questions are used in the interview schedule which allow people to say what they think about the service being provided in some depth and pursue any particular concerns. The interviewer assures people that nothing they say will be able to be linked to them.

20 people were interviewed over a two-month period, during which the clinic was visited four times. Many people are embarrassed about being interviewed, so participation is voluntary in nature. Sexual health still retains an enormous amount of stigma and people, generally speaking, do not want to be related to it in any way. Anonymity and confidentiality is therefore extremely important: no personal details are taken of anyone taking part in the interview.

The interview schedule breaks down into certain categories:

- about you
- convenience of the service
- staff
- organisation of the service
- awareness of services available
- experience of service

Results of the interviews

- People found it difficult to find the clinic with no clear signposting either outside or inside the building and no clear location of reception area.
- The reception area is one of the consulting rooms and doubles up as a room where both medical records and supplies are kept. A few people were concerned about

Louth is an integrated sexual health service providing both family planning and genitourinary (GU) medicine services.

other members of staff walking in the room when they were giving out personal details and there was recognition of the importance of the reception room being shut when someone was in there.

- The staff were found to be friendly, understanding and non-judgemental by all interviewees.
- The waiting time at the clinic was very variable with people waiting anything between 10 and 60 minutes. The majority thought the wait was OK but would have preferred 30 minutes or less.
- The timing of the clinic was very popular on a Thursday evening particularly for those who work because it meant that they did not have to take time off work.
- The service met people's needs 100%. 18 people were happy with the service and thought it confidential. GU patients were asked if they had used the system to ring in to hear their results: eight people had done so. Some people had been asked to come in again. Some people would prefer the clinic to ring them.
- Comments were received about the embarrassment of going to the toilet to

produce a urine sample and then having to bring it back through the waiting room for people to see.

- There were also comments about the size of the waiting room and people would prefer the waiting room to be less near the consulting rooms.

## Action plan

An action plan was produced to address the majority of concerns that patients had.

- To improve signs both inside and outside the clinic.
- Use of a leaflet to tell people of the process of what is likely to happen to them at the clinic.
- The receptionist has been moved to another room to improve confidentiality.
- Look at alternative procedures for urine sampling to save people the embarrassment of walking through the waiting room with their own samples.
- The clinic will offer a choice of results reporting i.e. face to face contact (using appointment system) or by telephone. Service users are still able to have the choice of being able to phone in themselves rather than be phoned by staff.

Since this action plan was produced, the receptionist has been moved, a shelf is being put in the toilet so that people can leave their urine samples in the toilet, a choice of results reporting is being offered to GU patients, signs have been put up both internally and externally to ensure speedy access to the clinic and the leaflet is being worked on.

The urine sample procedure has been raised countywide in sexual health services and is being discussed within the nurses' forum as it occurs in other clinics.

The patient experience audit led to service change within sexual health services in Lincolnshire for the benefit of the users of the service. Another audit of the service to review the situation is planned.

**Caroline Sherriff**

Patient and Public Involvement Officer  
Sexual Health Services  
East Lincolnshire Primary Care Trust  
tel.: 01775 720829  
email: caroline.sherriff@eastlincs-pct.nhs.uk

# What works in user involvement

Valerie Moore and Andrew Craig of the Moore Adamson Craig Partnership LLP shared this candid view of what they have learned about user involvement at the inaugural meeting of EDVANCE - the London network for user & carer involvement in health & social care education in November, 2005. They drew on four years of working with bodies in the field of PPI both nationally and locally in south-west London.

What we've done and for whom	What we've learned
– “Stronger Voice in Health in Wandsworth” community-based capacity building pilot project	Participants like “local” engagement; want to know how things (committees, agendas etc) work so they can influence them; have modest expectations of success despite widespread cynicism towards bureaucracy
Development work with Pilot Patient Forums – <ul style="list-style-type: none"> <li>■ Consultation – open “experience exchange” with no fixed agenda with stakeholders</li> <li>■ Development and capacity building - local training (Wandsworth and Camden);</li> <li>■ Research and evaluation - “recruiter and recruited” study</li> </ul>	Very open and unstructured events are productive – have confidence in the practitioner experience; clarifying values and beliefs about PPI the essential first step; a “pathway” capacity development approach works; penalty-free participation essential; training is valuable commodity even if serving on Forums is unrewarded; professional management and support valued; links and allies wanted; “recruitment” efforts by local Forums highly variable
PPI in Secondary Care Local Acute NHS Trust: 2002-03	Lots of existing activity involving users within large hospital, but not connected up; no learning drawn out to show PPI adds value; PPI progress and user/staff enthusiasm at risk from key senior staff changes
PPI awareness for Primary Care workshops on “involving patients in decision making to improve the user experience” and “managing patient expectations and experiences”	Front line primary care staff are largely “heads down” coping with work and many see PPI as creating “more work” and unrealistic patient expectations; they need help understanding how PPI can help them achieve targets and objectives within practices
Patient participation groups Group evaluation; outreach seminar for Wandsworth GP practices	patients like participation groups because make a bigger difference than as individuals; practices benefit too (IPQ, QOF, practice-based commissioning decisions etc); key person to get a group going is the practice manager; lots to learn about the practice that they don't know about as individual patients; local PCT needs to be supportive but not controlling. Participation in practices is a long term commitment
Patient and Public Involvement Forums and Forum Support Organisation in South West London	Local PPI forums were desperate for support and professional leadership; support organisation staff were enthusiastic but lacked experience and NHS knowledge; ineffective relationships between Forums and CPPIH created a flawed arrangement that training alone could not remedy.
Foundation Trust Governors Development programmes	NHS foundations trusts must be a big part of the future for user engagement and lay representation; huge and evolving area of governance and community participation; much confusion about role and power of Governors; hard work reconciling idea of social ownership, “membership” and engagement between Governors and Board; doesn't supplant existing PPI initiatives but will probably make PPI forums in NHS foundation trusts redundant as Governors expand their roles.

## To Sum Up - Our Rules of Engagement with PPI Projects

MAC Partnership's views on "what works in PPI" based on our national and local experience

### Recognise and appreciate what motivates lay people to become involved and stay involved

Don't make assumptions about motivation. Participation is always a choice for users and there are competing demands on their time. "Wanting to give something back" and "making sure others don't have the same experience I did" are both common. Understand what a "win" looks like and feels like from the user standpoint. Be ready to learn a lot. Your views about what's important will be challenged!

### Clarify values and beliefs about patient and public involvement

A fundamental joint process between providers and users. Evaluated pilot experiences showed a high degree of shared belief that enabling informed and empowered patients, carers, and members of the public to be "active citizens" is a good thing; affecting decisions about their health and health services is a moral good in itself. Translating beliefs into actions – the really hard part!

### Develop an organisational structure for user involvement

There has to be a rational organisational structure for PPI which identifies existing and anticipated relationships within and across organisations; it needs to be a managed function but not a "controlled" one.

### Recruit or identify staff to support the PPI work

Professional staff and well-supported lay members are indispensable at the core, but their role is to outreach and promote inclusion not to be a clique. Volunteers cannot shoulder the main responsibility for getting PPI work done.

### Identify potential patient/user/carer/public representatives

There is no ideal or easy approach to recruitment. Evaluations show that a broad and balanced approach reflecting the community is needed, but this has huge implications for access and ability levels.

Some schemes attract hundreds of potential members to events, but "hard to reach/under accessed groups" remain just that. There have to be intermediaries and proxies, as well as alternatives to "meetings" and use of non-health venues.

### Define initial training needs of user and lay representatives

Training has a key role in initiating and, more importantly, sustaining the engagement of lay people. Training should build perceptions of self-worth and identify existing transferable skills. Training as a recruitment incentive was used successfully by several pilot Patients' Forums. Accredited training and skills development can be used for career development and is appreciated as a valuable non-cash benefit. People like to see themselves succeeding at something.

### Define longer term development and support needs for user participants and support teams

Essential to prevent PPI initiative running out of steam once the initial enthusiasm wears off. Building capacity and sustaining interest is a continuous process. Individual service users may drift away or become unavailable for many different reasons. PPI structure has to be resilient enough to handle this. PPI staff can get in a rut. Lay reps and PPI Forum members experience increasing time demands with no compensating support. Burn out looms for both.

### Address perceived barriers around meetings, agendas and organisational processes and find alternative "ways in" for users

Working day meetings disadvantage participants who work, need to travel off peak, have carers' responsibilities, etc. Evening activities, telephone conferencing, email groups, "reading groups" to review papers in advance of meetings, advocates etc are all possible, but require significant resourcing and support. Cash reimbursement is needed for fares and out of pocket expenses. NHS paperwork imposes a penalty on participation.

### Create links with other agencies and find allies

Evaluations showed the importance of forging good personal and organisational

relationships from the outset, despite lack of clarity about the future. Make allies early not late.

### Disseminate information and generate feedback about your activity

Most initiatives we've studied had not progressed much beyond meetings and newsletters, but they see websites and email as attractive means to communicate. Gap rapidly closing between those who have online access and those who don't. Lay people of all ages keen to acquire IT skills to use these tools. Those without such skills will be left out. Realistic evaluation is always needed. Find out if people who are participating would recommend it to others – the best benchmark measure that they think it is worthwhile.

### Finally, the most important lesson of all – organisations get the PPI they deserve.

Contrast "angry and subversive; timorous and passive; uninvolved and absent"; with "passionate and direct; open and courageous; committed and present". Which would you and your organisation prefer? What can you do to get the best from involving users? There is a simple answer: Lose the Fear of PPI as "PPIB" – public pain in the bum.

The organisation that gets the most from PPI is the confident organisation in charge of its own future with the ability to welcome user/external views and a host of critical friends and then is able to DO SOMETHING WITH THEM. If you don't ACTION THAT INPUT then the rest is just tinsel on the tree.

**Valerie Moore and Andrew Craig**

Partners

The Moore Adamson Craig Partnership

tel.: 020 8670 0595

email: [andrew@agcraig.com](mailto:andrew@agcraig.com) and

[Valerie.Moore@btinternet.com](mailto:Valerie.Moore@btinternet.com)

We would welcome hearing from you about what has worked for you and continuing the debate on their website and blog – see [www.publicinvolvement.org.uk](http://www.publicinvolvement.org.uk) and our main site [www.mooreadamsoncraig.co.uk](http://www.mooreadamsoncraig.co.uk)

## PPI FM

**You're a health worker – you want to get more people to get better, stay well or help you to deliver your services better. What would you give for a communications infrastructure that got those messages out cheaply effectively and involved those same people in doing so? Well if you are lucky to have a community radio station on your patch you might just be able to do just that and the good news is that more and more are on their way. Phil Korbel tells more ...**

Effective communication is central to the task of creating effective patient and public involvement – that's a no brainer. You've tried leaflets and, well, you know what you do with unsolicited mail. You've tried press releases but then you are always at the mercy of the non-specialist and possibly lazy journalist even if your public do pick up the paper to read it. You've done public meetings but how do you get people to them in the first place?

Well, what would you do with your own radio station? What would you do with a broadcaster who didn't just interview you for three minutes but actually gave you the skills and the airtime to make your own programmes? Well, this is the promise of community radio.

We are in the midst of a broadcasting revolution. The Government has issued 84 five-year licences for community radio stations across the UK. Within a few months, we could see up to another 20 and the odd hundred more over the next three years. The stations are as varied geographically as they are in format. They range from the Scilly Isles via most major conurbations to the Orkneys. Some simply cover their given five kilometre radius whereas others focus on communities of interest – from ethnic, to age and religious groupings.

Community radio is not a small version of the existing forms of radio – it is something distinct and all the stronger for it. The fledgling sector took what it felt defined it to the Government, asked them to enshrine that in legislation and that was fairly much what happened. So community radio is defined by the Community Radio Order of 2004 as low-power, non-profit, community-based and focussed on the delivery of 'social gain'. In effect, a whole media sector has just been created purely to deliver community benefits.



Radio Regen ([www.radioregen.org](http://www.radioregen.org)) was the largest project within the 'Access Radio Pilot Scheme' – which the Government used to test the concept of community radio before the current roll-out. Our project consisted of two radio stations in very different areas – ALLFM ([www.allfm.org](http://www.allfm.org)) in Manchester's multi-cultural inner city and WythenshaweFM ([www.wfmradio.org](http://www.wfmradio.org)) in what was a huge council estate pretty much at the end of the runway of Manchester Airport. The two stations received five-year licences on 1 January, ALLFM as an independent social enterprise and WFM as part of the charity.

As well as those stations, the charity runs accredited training at its city centre HQ and various development projects to explore the application of community radio to the fields of the arts, youth work, refugee integration and volunteer recruitment. It worked for three years to develop the new and independent community radio station in Salford and on fledgling stations in Burnley and Bolton. It is also the instigator of the new Greater Manchester Community Radio Network.

Such was the volume of new and pioneering work undertaken by Radio Regen that the charity felt it ought to try to capture the experience it had gained for use by others. To that end it was commissioned by the Department for Culture, Media & Sport to write the Community Radio Toolkit ([www.communityradiotoolkit.net](http://www.communityradiotoolkit.net)). Radio Regen also works with the Sheffield-based Community Media Association ([www.commedia.org.uk](http://www.commedia.org.uk)) to run national and regional events for the sector. The organisation's current strategic priority is to establish a national centre for expertise for community radio to deliver professional development courses to the sector and its many partners.

Radio Regen has worked with many arms of the health service. On its first temporary broadcast in south Manchester, two community nurses made their radio debut to talk about the services they delivered. They came across as skilled, well informed and passionate professionals – people you could have confidence in – which is the sort of 'soft' PR that a swift consultation at the

surgery could only rarely deliver. ALLFM has used its non-English output to deliver health messages to the Pakistani and Somali communities. The temporary station Radio Regen ran in Moss Side worked closely with the enthusiastic staff of the area's community health network – 'Bloom' – and ran items to promote black and minority ethnic involvement in the various PPI mechanisms.

In Wythenshawe, the South Manchester Healthy Living Network supported a weekly hour-long 'Good Life Show'. This involved South Manchester volunteers reporting on and discussing the whole gamut of health issues that affect an area which, in parts, suffers great multiple disadvantage. Youth health issues were tackled head on by the young people attending the local 'Signpost' youth centre who also produced a hard hitting soap opera – 'Sex and Drugs and Tequila Slammers'.

Radio Regen is not alone amongst community radio organisations in working with health agencies. The excellent Bradford Community Broadcasting runs many projects with that city's PCT. In Hull, the long running 'RadioActive' project was established by the PCT there. In north Manchester, the pioneering health and arts charity, Lime, runs a radio project for people with mental health problems. The list is a long one but very little, if any, strategic work has been done to survey the range of UK activity in this sphere and assess its effectiveness.

To fully assess the potential of community radio as a tool to promote PPI, we must return to the idea of such stations being way more than 'media'. At one of Radio Regen's Community FM conferences the South African community radio pioneer Zane Ibrahim ([www.bushradio.org.za](http://www.bushradio.org.za)) was asked what proportion of the field was 'radio' and what 'community'. He quickly retorted "90% community!" and this was greeted with applause by the delegates. This gives you an idea of how small a priority the actual radio programme is to most community radio projects. Which is not to say the programme is unimportant – more that the process of its creation and its impact in the community are more so and resources follow this priority.

If the PPI process starts with communication and moves on to active engagement, then community radio can actually deliver on both of these. An imaginative PPI worker could not



only get the public on board but also use the radio to stage involvement events.

For example – your PPI forum wants to consult beyond its members. Using a community radio station, the members and their support team could be trained to make radio programmes that not only outline the subjects at hand but also directly engage the public in discussion of them. You know how much people are interested in their health issues and – I'm guessing here – the barrier is to get them to actually express their views. The joy of radio is that there are few blocks – such as literacy or confidence – all you are doing is asking people to talk.

In case you think that you have to do some sort of current affairs heavyweight programme – it really is as easy as chatting. Of course you have some sort of structure in mind, but no one requires you to be Jeremy Paxman – unwrap a subject until it becomes clear to the listener. You also have to bear in mind that you will have some specialist knowledge – which you must attempt to effectively shed if you are going to get the issue across effectively. This latter factor also increases the need to involve lay people in the production of your programmes.

Sometimes, when agencies come to Radio Regen, and we start a project to get them on air, they think that it is enough to get members of their team on air. At this point we gently suggest that the effectiveness of the project can be enhanced by the inclusion of 'lay' volunteers in their programme. Not only is this ethical practise within community

media but it also provides the listeners with someone like them to 'mediate' specialist information from the experts. So, if you are in this situation and your 'lay' participant asks 'What do you mean?', just take this as part of the interpretive process that is leading to more effective communication.

In any communication task, there is a real danger in getting too close to a subject. You might be embedded in the complexities of committee minutes and output monitoring – but your task in making a community radio show is to not just communicate your subject but excite the audience with it. As a presenter, taking on a certain level of naivety is useful and what better way to ensure that you're talking at the right level than to partner up with a lay member of the public – who might be a regular volunteer at the station. And talking of excitement – there should be a fundamental excitement that the health services are handing over a degree of control to the public. Don't forget to transmit this, as it might get lost in the minutiae of the PPI subject material.

There is also a raft of more 'creative' tools at your disposal in community radio. The use of drama can bring a subject alive like no other and commissioning community radio volunteers to make public service announcements can reap great rewards.

A note of caution must be sounded. The vast majority of community radio stations will be working with the least possible resources. 'Small' radio stations were recently officially defined as having under 20 employees; our stations have four each and are considered as well supported. So, when approaching your local station to explore partnership working, be aware of this and be prepared to bring some funding to the table.

Community radio stands ready to provide the most extraordinary level of effective communication with local populations. The platform and the will are there – the barriers are likely – as ever – to be skills and resources. We at Radio Regen hope to be able to help on the former but the former will be down to you and your marketing budget. Good luck!

**Phil Korbel**

Director  
Radio Regen  
tel.: 0161 237 5454  
email: [phil@radioregen.org](mailto:phil@radioregen.org)

# Listening to the priorities of service

In 2005, TwoCan Associates undertook a project for Macmillan Cancer Relief to find out how other health organisations listen and respond to the priorities of service users.

## Finding out about users' views

The three methods that have been used most frequently within the voluntary health sector to find out about users' views are:

### Surveys

Surveys can be cheap to carry out, and provide quantitative data based on large numbers of people that is considered to be robust. However, they also come under the greatest criticism for lack of depth, and for failing to allow people to develop an informed view about an issue.

In 2002, the **RNID's** Technology Department carried out a survey to help set priorities for the future. They chose a survey because they wanted a large number of responses. The survey was sent to the RNID's 30,000 members. Over 10,000 people responded. The information gained has been used in different ways by different teams within RNID – and staff are still using the data.

### Group discussions

Group discussions enable people to share experiences, and to develop a consensus. However, success is very dependent on the skills of the facilitators. There may also be problems of 'generalisability', and of power imbalances within a group.

The **Cancer Care Research Centre** in Stirling wanted to look at people's priorities for improving cancer care, and their priorities for cancer care research. In 2004 they set up over ten local advisory groups across Scotland, some of which are co-facilitated by people affected by cancer. There is good geographical spread, and the researchers have tried to listen to involve people who are often marginalised. Some ideas generated by the groups have already been developed into research projects, and some group members are working with health professionals to improve services and training.

Bec Hanley summarises the findings and gives examples of methods that different organisations use.

### Panels and advisory groups

These can be of varying sizes but are usually large so they can be thought of as representative of a wider group. Some panels can be long-standing, whilst others brought together to discuss a specific issue. Panels can be resource-intensive to maintain. New panel members may need to be recruited on a regular basis and this can be expensive and difficult if the panel needs to be representative.

The **Disability Rights Commission** has two advisory groups - the Learning Disability Action Group and the Mental Health Advisory Group. These groups are made up of users who are representatives of other user-led organisations or self-help groups. Having user representatives is a big advantage, since group members have easy access to wider networks and different communities. Both groups are fully integrated into the organisational structure. They each have a clear role and an established link with the main committee that makes decisions about future work. It is very clear to all involved how these groups influence the work of the organisation.

## Making users' views count

The different methods we identified to ensure users' views count include:

### Involvement in governance structures

Some organisations have chosen to involve users and carers in governance structures. This usually means that a number of places are set aside on each committee responsible for governance, at local, regional and/or national level.

**Rethink** (which aims to improve the lives of everyone affected by severe mental illness) has eight regions. Each region has a Regional Reference Group, made up of 12 Rethink members and supported by a user and carer involvement officer.

Each Regional Reference Group nominates one person to sit on Rethink's Board of Trustees. There are two further places on the Board reserved for service users, and the terms of reference for the Board of Trustees states that the majority of trustees must be service users or carers.

### Asking users for their views about priorities

Other organisations have chosen to involve users in groups that make decisions about priorities outside the formal governance structure. This might include planning meetings and advisory groups making decisions at lower levels in the organisation. These may or may not report to the Board.

Some organisations have chosen to ask groups of users and carers to set priorities. Sometimes their conclusions are fed into decision-making at the level of the Board or at another appropriate level in the organisation. However, some groups are seen as advisory only and their advice may be sidelined or ignored if it does not fit with other agendas.

At the **Parkinson's Disease Society's** AGM in 2004, people were asked to take part in an interactive session. Questions were shown on a large screen, and people were asked to press a button on a handset to vote. Results were then shown on the screen.

One of the questions asked was: Thinking about the group you represent, which are the most important priorities to improve in 2005 and beyond? The top five priorities were adopted as the Society's campaign priorities for the coming year.

### General lessons

There are a number of general lessons for organisations thinking about how best to listen and respond to the views of service users and carers:

- To be able to select the most appropriate method, it is essential to adopt a strategic approach. This means being clear about what information is needed, when, why, who it is for and how much it will cost.
- The involvement of service users and carers as co-researchers improves the quality and quantity of the evidence that is gathered. It is important to involve users as partners in the development and selection of methods as well.

The **Macmillan Listening Study** asked people affected by cancer about their research priorities. Users were involved in a range of ways, including as co-researchers. User co-researchers ran focus groups extremely well and were particularly good at attending to the needs of participants. Feedback from participants was very positive. They seemed to feel more comfortable about speaking their minds, and had more confidence that something would be done with the results

- Accessibility is an important feature of any method used to seek users' views. But not every method will be accessible to everyone. So it is important to use a range of methods that will enable everyone in the target group to have their say.
- 'Representativeness' may not be important if what is required is a detailed picture of users' perspectives – in which

In Ashton, Leigh and Wigan (ALW), a series of new NHS LIFT centres is being built, mostly in locations with which patients are unfamiliar.

case seeking a diversity of views may become more important than seeking views from a representative sample.

- Whatever method is used to ensure users' views count, it must be transparent and accountable – and both users and staff should receive feedback about any action taken (or a decision not to take action) in response to their views.
- People we interviewed for this project thought there was only one clear way to make users' views count - to integrate users into decision-making structures. If users are involved at all relevant levels where priorities are agreed within an organisation, they can ensure that users' views are translated into priorities for action.

**Bec Hanley**

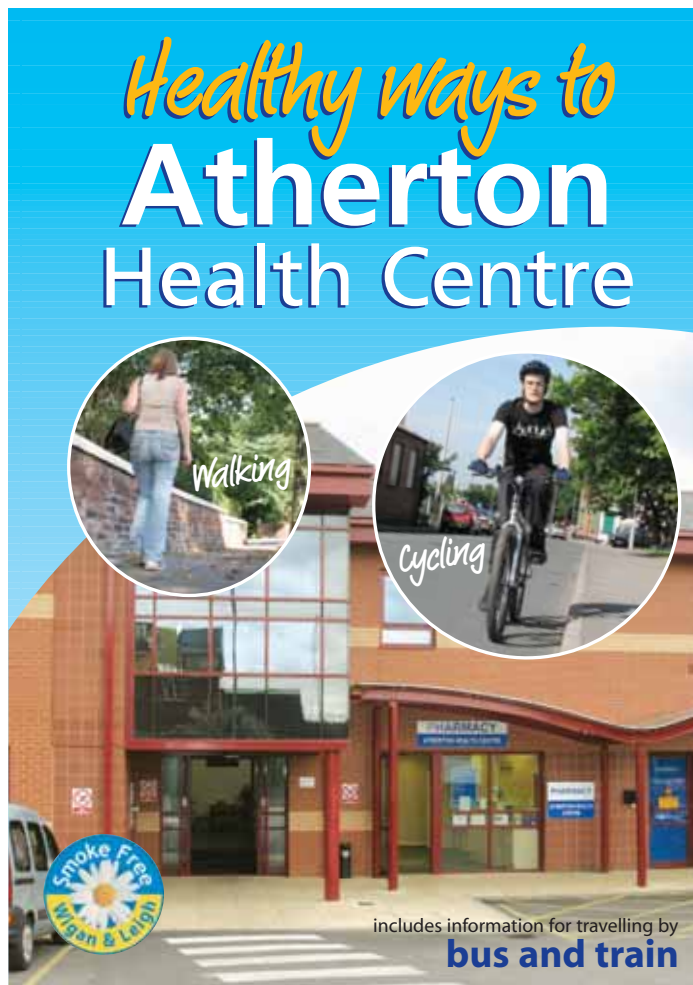
TwoCan Associates

tel.: 01273 831043

email: Bec@twocanassociates.co.uk

www.twocanassociates.co.uk

# Raising the travel information



Ashton, Leigh and Wigan PCT has a significant NHS Local Improvement Finance Trust (LIFT) building programme. Recently, its first LIFT centre opened, with its own bespoke travel information leaflet. Kath Tierney explains how a PCT has started to raise the travel information standard.

In Ashton, Leigh and Wigan (ALW), a series of new NHS LIFT centres is being built, mostly in locations with which patients are unfamiliar. They are also going to be attracting patients from a wider catchment area than most of the GP surgeries they are replacing. So, patients are going to be travelling to a new location, and some of them are going to be travelling further. ALW PCT's Director of Public Health, Julie Hotchkiss, is keen that the Trust helps reduce the adverse environmental impact of health-related travel. At the same time, she wanted to make it as easy and straightforward as possible for patients to get to the excellent new facilities and improved services that are being built.

## Travel information standard

Sustainable travel consultants have assisted the PCT with the development of its Travel Information Standard. This supports the PCT's Travel and Transport Strategy, which aims to:

- reduce unnecessary travel to PCT Sites and on PCT business;
- encourage the use of public transport, walking and cycling wherever possible;
- encourage car sharing, where car travel cannot be avoided.

Over time, the intention is that all PCT sites will have a

site specific travel and transport information sheet or leaflet for patients and visitors. It will contain:

- a map of the area around the site, showing bus stops (with bus service route numbers), railway station (if appropriate), pedestrian crossing points, and car parking locations
- for larger sites, the map will show health-promoting local sites (e.g. leisure centres, swimming pools, community centres), schools, opticians, dentists, pharmacies, bus or rail routes and cycle paths
- public transport timetable and costs
- taxi phone numbers, and the approximate cost of a taxi from the rail station (if appropriate)
- car parking costs.

In future, this information will be prepared in-house by a Trust HQ staff member, who will also ensure the material goes on to the Trust's website.

In addition, each site will have an information leaflet rack containing:

- local bus timetables, with an arrangement with Greater Manchester Passenger Transport Executive (GMPTE) to get replacements and updates
- leaflets about the Hospital Travel Costs Scheme (available free from the Free Publications Unit at Wetherby Telephone: 0870 122 6236)
- walking for health leaflets
- leaflets promoting cycling.

The Trust website will include:

- travel information for each site available as a downloadable pdf
- link to the GMPTE journey planner
- link to National Rail journey planner
- link to Transport Direct journey planner.
- a telephone number and textphone number through which a member of the public can make general enquiries to the Trust.

## Preparing travel information leaflets

The Trust's travel information will be prepared by a staff member with personal experience of using public transport. During the research process, the different travel and mobility needs of the Trust's patients will be taken into account. This is a six-stage process:

### Public transport information

Identify all current direct travel links to the site. Find out what public transport information is available, such as leaflets, bus timetables, travel websites, and existing travel information provided by the Trust.

### Site visit

Undertake a visit to the site, 'mystery shopper' style.

### Travel information text

Prepare the text for the site information sheet or leaflet, and circulate it for comment to key stakeholders.

### Maps and artwork

Commission, as required, maps and leaflet artwork, and circulate proof copies for comment.

## standard

In Ashton, Leigh and Wigan (ALW), a series of new NHS LIFT centres is being built, mostly in locations with which patients are unfamiliar.

### Dissemination

Print and distribute the leaflets, put the information on the Trust's website, and make sure relevant sites have links to these pages.

### Check and refresh

Check and refresh the Trust's travel information on a regular basis. It is expected that like most things in life, we expect this process will get easier to do as we go along, and get more practice. In fact, we want it to become a standard that is 'second nature'.

### Site visit

This starts with travel by public transport to and from the site, preferably using more than one of the transport services likely to be most used by patients. If patients are likely to arrive at a rail or bus station these interchanges should also be visited.

Using the site visit audit checklist, observations will be made during the site visit. Some of these should be shared with other local strategic partnership members such as Wigan Council, which has direct responsibility for highways, signage and other amenities, where they could contribute to making the Trust's patients' journeys easier.

The person carrying out the site visit is asked to imagine what would the journey be like if you are elderly, or disabled, or accompanied by young children, or are pushing a child in a buggy, or are unfamiliar with the area?

Examples of what to look out for are provide, such as:

- Is the health centre visible from the bus stop? If not, are there any signs to help you find the centre?
- Are there dropped kerbs in place to make it easier for wheelchair users and parents with buggies to cross the road to the centre?
- Is there a shelter and a seat at the bus stop? Is there real-time information or bus timetables for all services on display at the stop?
- Are there suitable crossing points between the bus stop and the health centre?
- When you get to the health centre, is there any travel information available at reception or on display?

### Text preparation, design and distribution

The standard has a useful list of things to include in the text of the site travel information leaflet, and a suggested distribution list for when the leaflet has been completed.

It is expected that a draft of the text and map should be distributed widely for comment, and taken to the management meeting of the health centre to check all of the local detail and ensure it is correct.

Over time, the material will need to be regularly checked and refreshed. Web-based downloadable information should be updated immediately. Printed leaflets should be updated before each order for a leaflet re-print, but the information on all leaflets should be checked at least annually.

### Kath Tierney

Senior Travel Planner

Richard Armitage Transport Consultancy

tel.: 0161 368 6603

email: kath@ratransport.co.uk

For further information, please contact Julie Hotchkiss or Glen Berry, Ashton Leigh and Wigan PCT; tel. 01942 481703 or email glen.berry@alwpct.nhs.uk

# Rural proof for health

Alice Earp and Lesley Jones introduce a new toolkit for primary care organisations in rural areas, including how PPI can be most effectively done in rural settings.

**Rural Proofing for Health is a project designed to provide a resource for primary care organisations (PCOs) to help them to consider the needs of people living in rural communities in order that all health care services are rurally sensitive and that there are no inequities in access to care.**

The House of Commons was the prestigious venue for the launch of this important tool in the armoury of resources designed to ensure that the needs of rural communities are fully considered in health planning at a local level. Jim Knight, MP, Minister for Rural Affairs, Landscape and Biodiversity, gave an address at the reception of Lords, MPs, primary care trust (PCT) chief executives and invited guests which officially launched the Rural Proofing for Health Toolkit.

A modern and dependable NHS in the United Kingdom is based upon the premise that all citizens have equity of access to services that are appropriate to their needs and free at the point of delivery. However, people who live in rural areas often do not have the same geographical accessibility to as broad a range of services as their counterparts in urban Britain, and inequalities in health and inequity in health service provision continue to persist.

To focus attention on people in rural areas the Institute of Rural Health (IRH) developed the Rural Proofing for Health Toolkit with funding support from the Department of Health (DH) and the Department for the Environment, Food and Rural Affairs (Defra). The Toolkit has been designed to act as an aide memoire for PCOs, and to suggest ways in which they can ensure that health service delivery is patient-focused and appropriate for the needs of everyone.

The Toolkit has sections on access to services and transport, primary care, community care, specialist services, hospital services and patient and public involvement. Each section has questions about current service provision, solutions to address shortfalls, and one or two examples of good practice.

The initial approach adopted by the IRH was defined by detailed research into previously published research material and data

collection with rural PCTs on the constraints they experience in the delivery of health care in rural areas. Forty rural PCTs collaborated with the project and the data collected from them underlined the interest and the gravity attached to fair and appropriate provision of services in rural areas. Three English PCTs - South Worcestershire, Mendip and Morecambe Bay - collaborated further and took part in detailed consultation with the IRH as the Toolkit was developed.

The Rural Proofing for Health Toolkit has been issued to all English PCTs. Local Health Boards in Wales have also expressed an interest in the document, which the IRH believes will be useful to all rural service providers. The web site also provides access to an online database of good practice, a valuable source of information for all UK organisations with an interest in rural health and well-being. The database was developed by the IRH as part of the Rural Proofing for Health Project and aims to provide stimulus to others by showing actual examples of innovative practice.

The final phase of the project, which is being funded by Defra, will see IRH researchers encourage the implementation of the Toolkit approach and evaluate the Toolkit in use. This

is taking place at an important juncture in the design of services to populations in England as it coincides with a radical reorganisation of PCTs in England. One element of the reorganisation will be the merging of PCTs which cover predominately rural areas with those that have historically covered largely urban areas. There is a consequent risk that the rural dimension in service configuration may be lost as England's rural areas are enveloped into new larger PCTs.

At this time of change it is as important as ever that the Patient Advocacy and Liaison Services (PALS) in each PCT and NHS Trust ensure that they are aware of the rural communities within their area, and use the Rural Proofing for Health Toolkit to help to make the case to their PCT or Strategic Health Authority for considering the rural dimension when planning and delivering health services, in order to reduce disadvantage and ensure equity of access to services for all people.

The public and patient involvement framework needs to develop into a long-term inclusive partnership between agencies, the voluntary sector, patients and the public to ensure that health service delivery is patient focused and appropriate for the needs of everyone including rural and isolated communities.

**Alice Earp and Lesley Jones**

Rural Proofing for Health Project  
Institute of Rural Health  
tel.: 01686 650800  
email [alice@irh.ac.uk](mailto:alice@irh.ac.uk)

Based at Gregynog in mid-Wales, the Institute of Rural Health is an organisation dedicated to optimising health and well being in rural communities across the UK. An academic centre of excellence, the IRH works to identify and address issues related to rural health and to disseminate good practice through its research, education and policy work.

The Rural Proofing for Health Toolkit can be found at [www.ruralhealthgoodpractice.org.uk/index.php?page\\_name=toolkit\\_menu](http://www.ruralhealthgoodpractice.org.uk/index.php?page_name=toolkit_menu)

A modern and dependable NHS in the United Kingdom is based upon the premise that all citizens have equity of access to services that are appropriate to their needs and free at the point of delivery.

# Volunteers across the NHS

**Sheila Hawkins introduces new guidelines to encourage greater consistency in how volunteers are managed.**



The guidelines, Volunteers

Across the NHS: Improving the Patient Experience and Creating a Patient-Led Service, have just been published by Volunteering England in response to the identified need to create consistency in involving volunteers in all roles across the NHS.

There is a long tradition of volunteering in the NHS, with roles such as

- befriending schemes, taking library trolleys round hospital wards, etc.
- supporting professional staff working in the community by preparing rooms and providing refreshments

The Orthopaedic Outpatients Service Improvement Manager at Stockport Foundation NHS Trust identified 11 points during a typical patient pathway in which volunteers contributed to that patient's experience.

There are also a number of newer initiatives which are usually separately managed but nevertheless are ways in which volunteers support the NHS. These include

- delivering services such as the Expert Patients' Programme
- people involved in governance and service or policy development
- members of patient and public involvement fora

At present there is some inconsistency in the way that volunteers in traditional roles are recruited and deployed in the NHS; there is awareness that individual hospitals and primary care trusts may have different arrangements, for example in requiring references, payment of expenses, access to training and so on. This becomes even more apparent when the more recent initiatives are included, as they have often been set up separately to existing volunteering schemes. This was highlighted by research carried out by the Institute of Volunteering Research from December 2004 to January 2005 which showed:

"Seventy-nine per cent reported that they always reimbursed volunteers' expenses.

Seventeen per cent reimbursed expenses only for some volunteer roles, while 4% did not pay any expenses to volunteers."

There were also large differences in the rate of expenses between neighbouring NHS trusts, or between volunteers in different roles, which obviously have the potential for causing unnecessary confusion and potential conflict, and could have the effect of putting off some volunteers.

"Others chose to prioritise the allocation of expenses, for instance by giving them only to disabled people."

These inconsistencies in approach across the NHS could be interpreted as one trust valuing the contribution of volunteers more highly than a neighbouring trust. By highlighting good practice, it is intended to support a more equal and consistent approach to the support offered to volunteers throughout the NHS.

The guidelines can also be used by anyone who is thinking of setting up any programme to involve volunteers or members of the public and include:

- the value of volunteering to the NHS
- legal position of volunteers
- volunteer policy and procedures
- expenses
- volunteer agreement
- volunteer roles
- recruitment/screening
- induction
- training
- support and supervision
- equal opportunities/diversity
- data protection/Freedom of Information Act
- health and safety
- employees as volunteers
- moving on from volunteering

## Consultation

More than 200 individuals from 25 strategic health authorities took part in the consultation which took place between May and August 2005. There were responses from individuals in a variety of roles involved with volunteers, such as PPI leads, voluntary service managers and Expert Patients' Programme trainers and lay tutors. Volunteering England has also been supported in this work by several individuals from a variety of NHS and voluntary and community organisations who have been part of the Project Advisory Group or acted as critical readers to the project. This work has been sponsored by the Department of Health through the Home Office funded Change Up programme, and reflects the importance of working with volunteers in NHS settings.

### Sheila Hawkins

Head of Volunteering (Health and Social Care)  
Volunteering England  
tel.: 020 7520 8951  
sheila.hawkins@volunteeringengland.org

Volunteering England will be distributing copies of 'Across the NHS' to all PPI Leads; if you would like copies, please request them through the Volunteering England website at [www.volunteering.org.uk/hsc](http://www.volunteering.org.uk/hsc)

The Department of Health has also recently published 'Reward and Recognition', good practice guidance on the payment and reimbursement of services users involved in service improvement for health and social care. This could apply to those who

- present at conferences, leading workshops
- deliver training
- are involved on selection panels
- participate in research, focus groups, interviews
- chair or attend meetings
- act as Quality and Outcomes Framework assessors

'Reward and Recognition' and 'Across the NHS' have been written to complement each other, recognising that there are areas of overlap between service user involvement and volunteers, and the need to have a consistent approach across and between NHS Trusts.

# Putting health in local hands

**New governance arrangements are a cornerstone of NHS foundation trusts, including direct involvement of patients and the public. Lisa Hinton and Richard Lewis review the early experiences of Homerton Hospital NHS Foundation Trust.**

The new community-oriented governance arrangements are a central plank of the Government's foundation trust policy. They represent a new departure for public accountability in health services, although such an approach has been trialed in other public services – most notably the introduction of parent governors to schools.

The Government is convinced that the NHS, with all its complexity, cannot be satisfactorily managed from Whitehall. The key to success in the reform agenda for the NHS is believed now to be leadership by local communities and frontline health care professionals. Optimistic claims for mutuality in health services have been advanced: improved and responsive services; greater efficiency; and even better community health as a by-product of empowerment.

## But how does this work in practice?

The King's Fund spent a year on the ground researching the implementation of these new governance arrangements at one of the first foundation trusts to "go live", the Homerton University Hospital NHS Foundation Trust in east London. The focus of the research was the emerging role of trust members and governors and the relationship that formed with the trust Board of Directors. In particular, the research explored the key questions:

- What role or roles have been adopted by the Homerton governors?
- To what extent have foundation trust governors shared power within the decision-making structures of the Homerton Hospital?
- What impact, if any, have governors had on the management of the Homerton Hospital?

## What are the governors there to do?

The Department of Health envisaged three types of role for governors: advisory, guardianship and strategic (Department of Health 2004). However, during the

first year of operation the governors and directors at Homerton Hospital found these ideas to be ambiguous and open to multiple interpretations.

The gap between the vision and the practice was significant. Although some governors had the clear idea at the beginning of the process that they would be "tongues of the community", monitoring and scrutinising the work of the hospital, how that actually worked in practice produced both confusion and discussion.

"When we started, people expected to be told what to do by the hospital but the hospital didn't know exactly what to expect or what the role is, so it has been a journey for them too." (public governor)

Through interviews, a number of potential different roles of governors were conceptualised. These sought to create a range of broad role definitions that would prove useful in identifying and exploring the multi-faceted role of the foundation trust governor. By the end of the first year, a degree of consensus had emerged about what governors should be doing in some areas, although the methods of practice were not always clear.

All roles, bar that of operational manager, found a degree of support among governors

and directors. Most governors saw acting as a community barometer as central to their role, although most felt that it was not a role that they were adequately fulfilling by the end of the first year. Governors felt that they had enjoyed greater success with the ambassadorial role, which was seen as crucial. The Open Day in April 2005 provided a good opportunity to exercise this role and governors pointed to this as evidence of their success.

A number of governors felt that they were able to make a particularly valuable contribution through the select committee member role: they reported back their involvement in trust activities to the full council. However, concern was evident regarding the extent to which governors are able to scrutinise effectively the work of the board of directors.

"I struggle with the notion and role of scrutiny. Accountability is a much clearer role – that we can be accountable – but I can't think they are ever able to function as a scrutiny body, simply because they don't have the time [and] they don't have the knowledge." (director)

The concept of the elected constituency representative proved to be the most contentious. There was much debate

**"I very unclear about what I can actually do to make a difference."**  
(staff governor)

### Roles played by a foundation trust governor

<b>Community Barometer</b>	Providing a ready source of community views to inform the work of the board
<b>Conscience</b>	Ensuring that the board acts in accordance with NHS values
<b>Ambassador</b>	Promoting the work of the hospital to the community and other stakeholders
<b>Select Committee Member</b>	Providing independent scrutiny of the work of the board and hospital
<b>Elected constituency representative</b>	Handling, monitoring and promoting individual members concerns
<b>Operational manager</b>	Taking an active role in the management of day-to-day issues and concerns
<b>Strategic player</b>	Taking an active role in shaping the corporate strategy of the hospital

## GOVERNOR AND MEMBER INVOLVEMENT IN 2004-2005

### Governors sit on the following committees:

- Public and Patient Involvement
- Membership Development
- Nominations and Remuneration
- Clinical Governance
- Open Day Steering

### Governors have been involved in:

- Clinical Practices Ethics Forum
- PPI Forum inspections and recommendations
- Essence of Care training (as a case study)
- open days and awareness days
- Members' Forums
- establishing Member Surgeries
- Healthcare Commission inspection
- presentation at conference with Chief Executive to give governor perspective on Foundation Trust status

### Members have been involved in:

- volunteer working groups
- volunteering to help run the Open Day in April 2005
- Member's Forum on 'Giving Patients a Choice'
- Patient Environment Action Team
- Monthly awareness talks
- Essence of Care training (as a case study)
- readers' groups to develop hospital publications

and some division among governors and directors throughout the year about whether governors should be championing individual cases or working purely at a strategic level. This has been played out in extensive discussions over whether to hold surgeries.

While directors were clear from an early stage that governors could provide valuable input into the work of the hospital to improve what was termed the "patient experience", most governors saw their remit as also engaging with far wider issues relating to the hospital and its strategic future. However, in practice this was not straightforward. It proved difficult to develop a single, corporate view within a large council of diverse views and diverse backgrounds. It was also questioned whether governors, with their limited time and experience, would ever have enough grasp of the complexities of hospital management to make a valuable contribution in this area.

### What changed?

Even after a year, governors were still feeling their way. In some areas they were relatively

clear what they should be doing (for example, communicating with members). However, there remained a lack of clarity in the minds of both governors and directors about their contribution to scrutiny and strategy.

The Government is convinced that the NHS, with all its complexity, cannot be satisfactorily managed from Whitehall.

It was clear from our study that in the first year the council of governors made little tangible impact on the running of the hospital. Yet it would perhaps have been unrealistic to expect that it would. The impact of the governors will, in part at least, be determined by their knowledge, skills and experience. These are still developing.

All stakeholders accepted that they were entering into an experiment where few ground rules had been set. The confusion experienced in the first year of foundation trust status can, to an extent, be explained by teething troubles and was broadly tolerated although frustration was evident. There was little clarity in government when the system was set up and that now seems to be reflected in practice. Governors, from the experience of the Homerton Hospital, seemed to be struggling to make it work and get to grips with the new arrangements.

That said, the experience of the Homerton Hospital shows that foundation trust status can galvanise local communities to become more involved in their hospitals. More than 300 members attended the Trust's annual meeting in September 2004, compared with only a handful before foundation trust status. The trust directors felt that even after a year the existence of members and governors served to strengthen their sense of accountability to the community.

This is only a single case study, although there are indications that it could be reflected elsewhere. A national workshop organised by the King's Fund in January 2005, which brought together 14 of the 20 'first wave' foundation trusts to gauge their views on the new governance arrangements, revealed that less than half the governors had a clear understanding of their role and less than a third felt that they had made a difference. However, 70% felt that confident that they would make a difference in the future.

**Lisa Hinton – Visiting Researcher**

Richard Lewis – Senior Fellow (Health Policy)  
The King's Fund  
tel.: 020 7307 2657  
email: r.lewis@kingsfund.org.uk

The report, Putting Health in Local Hands. Early experiences of Homerton University Hospital NHS Foundation Trust, can be obtained at [www.kingsfund.org.uk/resources/publications/putting\\_health\\_1.html](http://www.kingsfund.org.uk/resources/publications/putting_health_1.html)

# Putting people in control?

**The new White Paper on health and social care has much to welcome, but it also leaves many unanswered questions about PPI, says regular columnist Ian Hayes**

The publication of the White Paper, *Our Health, Our Care, Our Say*, heralds yet another set of far reaching changes to the way our health services are organised and delivered. Its proposals are to be welcomed – most patients would want to see more services delivered in primary care settings and longer opening hours in GP surgeries.

Greater integration of health and social care services will be welcome to anyone who has ever felt in danger of “falling into the gap” between them. A greater role for the “third sector” may well make services more responsive to the needs of the people who receive them.

The White Paper promises a future in which a diversity of services, commissioned from a range of providers, will provide real choices. These choices will have significantly more meaning to most users of health services, particularly to those with long-term conditions, than the choices for non-urgent inpatient treatment currently being offered.

The commitment to an explicit transfer of resources from hospital care to primary care, a transfer that will amount to £2.4 billion in budget terms, backs these aspirations in an impressive way. It is difficult to see how such a change can be cost neutral given the predominance of fixed costs in hospital budgets. Those of us who remember previous attempts to transfer acute service resources to “priority services” outside the sector may doubt whether it will actually happen, but nonetheless it is an impressive commitment.

Achievement of the changes envisaged will go a long way towards creating a modernised “patient-centred” service. I would like to think that one reason for this is that the proposals result from an extensive public consultation. The White Paper itself, and the publicity which surrounded its release, puts great emphasis on this consultation, the numbers involved, the national listening events and the role of the Citizens’ Panel. Although it is easy to criticise these efforts for their tight timescales, the questions asked and the number of participants who were NHS employees, the fact is that the consultations, which attempted to involve as

The White Paper promises a future in which a diversity of services, commissioned from a range of providers, will provide real choices.

many people as possible, did take place and the views expressed resulted in real policy proposals. However flawed the process, few White Papers in the past have been based on this level of consultation and those of us who value patient and public involvement should welcome this.

Against this backdrop, however, the lack of any detail about the future of PPI in the White Paper or in any other announcements is disappointing. Involvement is not just about consultation as part of policy development. It is as important for involvement to be strong during the planning and implementation phases, and in evaluating whether the policy has been successful. Without this continuing involvement there is every possibility that the good work of the initial consultation will be undone and that the aspirations of the people involved will not be met. Not surprisingly, I believe that this role could be played by strengthened and reorganised system of public and patient involvement forums.

Given that the implementation of the policies will be at local levels where PPI forums can have real value, the lack of a clear statement of the future arrangements for PPI is all the more regrettable. The White Paper has a whole chapter called “Ensuring Our Reforms Put People in Control”, but the vast majority of this is about changes to commissioning arrangements and developing the role of the “third sector”. There is relatively little relating to PPI, and what there is amounts to broad statements that:

- finding out what people want is a fundamental duty of commissioners and providers of services

- it is important to reach out to those whose voices are often least heard
- these voices need to be heard at a local level where spending decisions are made and priorities set.

It seems that these aims are to be met by an increased emphasis on public engagement in commissioning and a strengthening and enforcement of Section 11, with success in involving people forming part of an organisation’s overall performance rating. There may also be greater involvement of the public in overview and scrutiny committees and a greater role for individual councillors.

So, beyond broad goals everyone can agree with and some ideas for strengthening current responsibilities, there is little that indicates what the future PPI system will look like. The White Paper does accept this, it recognises that the details are still to be resolved and commits to “completing our existing fundamental review designed to strengthen the arrangements for ensuring a strong local voice in health and social care by April 2006.”

What is missing is any mention of a role for PPI forums. It is hard to see how this omission can be without significance. This will be disappointing for the thousands of people who have given freely of their time, working to ensure that PPI forums have begun to play a significant role in their communities. Particularly since they have recently received praise for their input into the recent health check process and for their contribution to consultations on the modernisation agenda.

It is also a missed opportunity to employ an established mechanism for independent involvement during the implementation of the reforms. Given the difficulty in establishing new involvement arrangements to tight timescales, would it not be better to support and continue the existing system allowing it to review the vast changes envisaged over the next few years before it itself is reviewed and revised to fit the new structures?

**Ian Hayes**

Trainer and Consultant  
Involving Patients Consultancy and  
Commissioner, Commission for  
Patient and Public Involvement in Health  
tel.: 07947 251752 and 01934 842479  
email: mail@ianhayes.com

## “Now I feel tall”

### What a patient-led NHS feels like.

**“Now I Feel Tall”, published by the Department of Health, encourages all NHS organisations to take a close look at how they deliver their service and to ask patients if their emotional needs are being met as well as their physical ones. Jenny de Ville explains.**

Patients often come into contact with the NHS when they are at their most vulnerable. Research and feedback shows that patients’ emotions and their negative feelings are heightened at these times. The NHS needs to have a better understanding of when and how it can improve how patients feel about their experiences of the NHS.

Not all patients ‘feel tall’ and their emotional needs are not always a high priority for the NHS. Current activity mostly relates to achieving financial balance and policy work tends to focus on the practical and physical aspects of patient care. There is relatively little understanding about patients’ emotional responses to their experiences, and little attention is paid to the expectations of patients at an emotional level.

What do we mean by a patient’s emotional experience? This is about how a patient feels about their experiences of using the NHS and what they value.

‘Now I feel tall’ deals with the emotional experience that patients have when they are in contact with health care providers. It gives moving examples of patients’ experiences and what it felt like when they were facing difficult times in their own lives. It shows how a number of NHS organisations have listened and responded to patients, how they have changed the way they deliver services and how patients feel about the improved services they are receiving.

The title – ‘Now I Feel Tall’ is taken from one of the examples. A carer of a patient with learning disabilities highlighted to the Patient Advice and Liaison Service (PALS) at South Manchester University Hospitals the problems around communication, getting consent and the treatment of patients with learning difficulties. PALS worked with Manchester People First (a self-advocacy group for people with learning disabilities) to organise a day to which people with learning disabilities could come to tell their stories.

Patients often come into contact with the NHS when they are at their most vulnerable.

Over 50 people attended and said they felt ignored, scared, bullied and uncared for. They said that:

- medical staff spoke about them, not to them
- staff did not listen to them
- staff were not explaining medical conditions or treatment in a way they could understand so they often left the hospital feeling worse, more frightened and confused
- it was hard to find their way around the hospital
- they often did not go to the doctor when they knew they should, as there seemed little point
- they sometimes felt bullied, emotionally and physically, into giving permission for treatment
- there were problems with the accident and emergency department and theatre, and these were particularly frightening places

They said they wanted explanations. “What an illness means, what needs to be done. You leave the hospital worrying and feeling more ill because you haven’t understood what is wrong with you, what it means or what to do!”

It emerged that people were finding the hospital experience so frightening that they were not going to appointments.

Following the day, PALS started to receive calls from carers to say that there were people with learning disabilities who were finding it just too frightening to come to the hospital. As a result of this, they began to invite people to the hospital for a coffee, followed by a walk around the hospital and

a visit to outpatients, x-ray, accident and emergency and other departments.

People First advised on the way forward. The PALS Manager met everyone to raise awareness and identify ‘champions’ – the champions were the Medical Director, the Head of Training, the Clinical Governance Manager and the Chief Nurse, and with their help changes began to be made.

Some of the changes they made were:

- pictorial guides to accident and emergency departments and theatre specifically created for people with learning disabilities
- changes to the hospital signs
- more time in outpatients for people with learning disabilities and support from PALS
- ‘protected admission’ for patients with complex needs, which means that these patients should have some protection in terms of their surgery not being cancelled
- quarterly visits around the hospital to accident and emergency, a ward, outpatients, x-ray and a theatre

The comments received show the difference these changes have made to the emotional experience of patients with learning disabilities who visit the hospital. One of these was “I am only small but now I feel tall.”

**Jenny de Ville**

Head of Patient and Public Involvement  
South-East London Strategic Health  
Authority  
email: Jenny.Deville@selondon.nhs.uk

Copies of ‘Now I Feel Tall’ are available from DH Publication Orderline, PO Box 777, London SE1 6XH. Tel. 08701 555 455 quote 271245/Now I feel tall. It is also available on the Department of Health web site at [www.dh.gov.uk/assetRoot/04/12/44/76/04124476.pdf](http://www.dh.gov.uk/assetRoot/04/12/44/76/04124476.pdf)

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# Making it happen: why we need

Jane South considers social entrepreneurship, how it works in practice, and its relevance and value as an approach for engaging people in primary health care.

Primary care trusts (PCTs) have a leading role in building relationships with their local communities. While community engagement is a fine phrase and one that commands support in the 21st Century, the big challenge is moving from rhetoric to reality. There have always been charismatic 'have a go' heroes in primary health care who are willing to work in different ways, supporting community action and developing local partnerships. Shifting the Balance of Power proposed that community involvement should no longer be on the periphery but part of the normal way of doing business [1]. In effect a cultural revolution: aiming to change not only what happens but the way it happens. One approach that offers a way to help health services work better with their local communities is social entrepreneurship.

## What is social entrepreneurship?

Social entrepreneurship is a way of working which is based on finding innovative and flexible solutions to social problems and bringing about change. Social entrepreneurs, as individuals or groups, use existing skills and resources flexibly and creatively.

Like entrepreneurs in the business world, they are not afraid to innovate or work 'outside of the box'. In his book 'The Rise of the Social Entrepreneur' [2], Charles Leadbeater contrasts social entrepreneurs with the way that welfare services normally operate. Where traditional services are often paternalistic, bureaucratic and slow to change, social entrepreneurs are innovative and 'transformatory'. He gives an example of the development of Bromley-by-Bow, one of the first healthy living centres, as an example of social entrepreneurship in action. Social entrepreneurship is not just about bringing qualities associated with the commercial sector into health services. It involves working with communities (and other stakeholders) in a dynamic, outward looking way, building networks and finding local solutions. Social entrepreneurship can foster social capital in communities and local people can be supported to become social entrepreneurs[3]. Social entrepreneurship is

Social entrepreneurship is a way of working which is based on finding innovative and flexible solutions to social problems and bringing about change.

not a set method; it is more a way of working and a willingness to explore opportunities for managing social change.

For those involved in implementing health policy, the concept of social entrepreneurship might appear too 'fuzzy' and it can be difficult to imagine what it would look like on the ground. Drawing on work taking place in Bradford, two case studies are now presented to illustrate how the approach can work in practice. In neither of these case studies did the people involved set out be 'social entrepreneurs' but both show the potential using such an approach.

## What can social entrepreneurship offer the NHS?

As these two case studies show, social entrepreneurship can offer a way of joining up NHS organisations with local communities. The first example shows

how strategic aims around community engagement in a group of PCTs could be met through a flexible, capacity building approach. Whereas the second example illustrates how capitalising on small opportunities could really move work forward in a neighbourhood and help the PCT connect with a 'hard-to-reach' group - disaffected and disadvantaged young people. Working to make and strengthen real-life connections should not substitute for participatory structures, however; it can improve access and flow of information between health and community sectors. Social entrepreneurship, because it is based on using existing opportunities and resources, can make community involvement more tangible and achievable for both health practitioners and people working in the community. Small successes can build trust and credibility and ultimately larger successes, as shown by the HAZ team. Hierarchical structures, cumbersome procedures and professional protectionism can all prevent effective community involvement. Social entrepreneurship, although not a universal panacea, can bypass some of the barriers and make the most of the opportunities out there. It is not, of course, an approach without risk and does require high-level commitment to support people prepared to work in this way. It also requires organisations and services to be outward looking, to seek out new opportunities and to foster mutual respect for the skills and resources to be found in any community. Anyone wanting to develop a social entrepreneurship approach in PCTs and primary health care might like to use the recommendations of the Bradford HAZ Community Involvement Team as a framework for action:

- Use all opportunities productively
- Work with champions and supporters to influence others
- Develop and maintain extensive networks
- Focus on realistic, achievable action plans and goals
- Build on successes

# d social entrepreneurs

- Maintain an autonomous profile outside of the management hierarchy

## Jane South

School of Health and Community Care  
Leeds Metropolitan University  
tel.: 0113 282 1957  
email: j.south@leedsmet.ac.uk

## References

1. Department of Health, Shifting the Balance of Power: the next steps. 2002, Department of Health: London.
2. Leadbeater, C., The rise of the social entrepreneur. 1997, London: Demos.
3. Catford, J., Social entrepreneurs are vital for health promotion - but they need supportive environments too. Health Promotion International, 1998. 13(2): p. 95-97.
4. Fawcett, B. and J. South, Community involvement and Primary Care Trusts: The case for social entrepreneurship. Critical Public Health, 2005. 15(2): p. 191-204.

### Case study 1: A team connecting organisations and communities

Bradford Health Action Zone (HAZ) saw the creation of a dedicated Community Involvement Team which consisted of a manager and four members, one working in each of the local PCTs. Given its size, the team did not seek to do community involvement for the PCTs, but rather it focused on a capacity building approach enabling dialogue to take place[4]. On a day-to-day basis, team members were regularly involved in networking, creating and maintaining links between different community organisations and the PCTs. Sometimes the role was a reactive one, responding to requests for information and help from different groups and individuals. Other times, the team were proactive in trying to connect the two sectors. For example, bringing PCT support to healthy living centre bids or assisting voluntary sector projects to set up in general practices. An important part of the team's work was supporting the involvement of groups and individuals who were traditionally under-represented. They were often described by health managers and staff as an essential 'bridge' between communities and the PCT. A lot of work was done to secure resources for small community groups which were tackling health issues in localities. What characterised the team's approach was their ability to link different agendas, use policy levers and bring a community involvement dimension to other areas of work in the PCTs. Rather than applying a top down approach, they tended to work with allies in the PCT, build on strengths and use tangible examples of success to convince sceptical NHS staff.

### Case study 2: Joined up work with arts for health

A district initiative secured funding to run a series of small arts for health projects. One of the projects was run in a youth centre on a large housing estate and involved children aged 8-13 years in art workshops. The local PCT were involved as a funding agency and used the opportunity for developing public health work with young people. A local community association also became involved as they wanted to engage the young people as stakeholders in a new community centre. So from the beginning, what was a small amount of funding was used by the various individuals involved to bring different organisations together. Although each organisation had different objectives in becoming involved, they were able to seize the opportunities of working together. By the time the project ended, relationships had been strengthened and future plans for joint work had been identified. Young people were able to make a contribution to the community centre and their views were listened to. What was significant was that the arts project was used as a vehicle to foster links and develop local resources. People working in the area were clear that it would have been unlikely that anything with a health label on would have achieved the engagement of the young people in the same way. One person from the PCT said: 'We've always wanted to be part of the community, not seen as a separate outside organisation that just gets invited in for special occasions. We want people to come along and ask us and involve us in anything - I think this has helped'.

For those involved in implementing health policy, the concept of social entrepreneurship might appear too 'fuzzy' and it can be difficult to imagine what it would look like on the ground.

# Fighting gobbledygook

**When is a container not a container? When it's being described in legislation. John Lister explains the importance of Plain English – and what you can do about it.**

“Container’, in relation to an investigational medicinal product, means the bottle, jar, box, packet or other receptacle which contains or is to contain it, not being a capsule, cachet or other article in which the product is or is to be administered, and where any such receptacle is or is to be contained in another such receptacle, includes the former but does not include the latter receptacle.” (Medicines for Human Use (Clinical Trials) Regulations 2004).

This mouthful won one of our dreaded ‘Golden Bull’ awards last December and serves as a fine example of how not to communicate medical information. Fortunately everyday medical writing is not usually this bad, but health remains among the most important areas of our work.

Plain English is not about academic linguistic debates, but rather the way unclear language affects people’s lives. Our supporters consistently tell us they are most concerned about the language of the law, money, food – and health.

One example came last year when it became compulsory for doctors to give patients copies of any letters to other doctors about their case. We studied examples of existing letters and found that doctors risked bewildering and alienating patients unless they switched to a plain English style.

In another project, we tested a wide range of general practice leaflets. Among our testing panel of 100 people, aged between 17 and 80, almost a third struggled to comprehend many of the leaflets because of excessive medical jargon.

And we also heard of a case from one of our supporters, who had received an e-mail from a senior executive in an NHS trust. The e-mail, filled with management terminology had gone to every employee in the trust. Unfortunately, and unsurprisingly, the jargon appropriate for executives was not so effective with nurses and porters. Bureaucracy means many medical organisations are rife with management-speak, usually dealing in vague concepts rather than precise practicalities. At times it feels as if you can guess the number of

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(Medicines for Human Use (Clinical Trials) Regulations 2004).

layers of bureaucracy between a writer and a patient from the style of writing.

But it’s not all bad news. Most people working in health organisations, particularly those who deal directly with the public, recognise the need for clear communication. There are now 174 organisations with at least one Crystal Mark (Plain English Campaign’s seal of approval) for a medical-related document. There is so much interest that we now run training courses dealing specifically with clearer medical writing. And two years ago, the Patient Information Forum’s Jane Wilson earned an MBE for her work promoting plain English in the medical profession.

So how can you make your writing clearer and break down barriers of communication between medical professionals and patients? These tips should help – but remember, they are only guidelines, not unbreakable rules.

- Stop and think before you start writing. Make a note of the points you want to make in a logical order. You need a clear idea of what you are saying before you can say it clearly. And you need to know who your intended audience is before you can decide the most appropriate style.
- Prefer short words. Long words will not impress your readers or help your writing style.
- Use everyday English whenever possible. Avoid jargon and legalistic words, and

explain any technical terms you have to use.

- Try to avoid using too many abbreviations. But sometimes they are useful for saving space. The first time you use an abbreviation, write the name or phrase out in full and put the abbreviation in brackets.
- Keep your sentence length down to an average of 15 to 20 words. Try to stick to one main idea in a sentence. If a sentence involves a long list, break it up into a bullet-pointed list (just like this one). And don’t be afraid to vary the length of your sentences. If you try to make every sentence the same length, your writing will come across as forced.
- Use active verbs as much as possible. Say ‘we will do it’ rather than ‘it will be done by us’. Active verbs usually lead to shorter sentences, and they can reduce confusion over who is doing what.
- Don’t be afraid to use the same word more than once. The idea is to communicate, not to show off your vocabulary or your creative writing skills.
- Be concise.
- Imagine you are talking to your reader. Write sincerely, personally, in a style that is suitable and with the right tone of voice. Bear in mind what knowledge they will already have of your subject.

And always check that your writing is clear, helpful, human and polite.

**John Lister**

Plain English Campaign

tel.: 01663 744409

email: [info@plainenglish.co.uk](mailto:info@plainenglish.co.uk)

web site: [www.plainenglish.co.uk](http://www.plainenglish.co.uk)

Plain English Campaign is an independent pressure group formed in 1979 to fight gobbledygook and unclear public information. It has almost 8000 registered supporters in more than 80 countries. It funds itself through commercial activities including editing and training. The campaigning work includes annual awards for good use of plain English, and the infamous ‘Golden Bull’ booby prizes. The Campaign’s Crystal Mark seal of approval, which is based on rigorous testing on the public, now appears on more than 10000 documents.

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## Last Word from Chris Dabbs



### Dear Mrs. Buggins,

**I am getting worried – there is an awful lot of talk of not tolerating any discrimination in public services, and much preaching about equality.**

I think that there should always be discrimination in public services, such as the NHS.

Is it discrimination to run screening programmes that only cater for people of certain ages? Yes, of course, but it also makes them easier to run, and allows them to focus on those people most likely to have a particular condition, rather than dealing with “worried well” at little risk.

Is it not discrimination to guarantee only disabled people a job interview if they meet the key criteria? Yes, but this only serves to counteract discrimination that disabled people experience throughout their lives.

Having men-only or women-only clinics discriminates against one or other sex, but without them some services would be practically inaccessible for at least some people.

Ensuring that people of whichever faith are not given appointments on important religious days is also a form of discrimination. Yet it respects their beliefs – and also means that absence rates are reduced.

To some extent, any NHS charges discriminate against people on the grounds of income – particularly those just above the threshold applied for people on low incomes to get free treatment. They also breach the long-trumpeted principle of an NHS “free at the point of delivery”.

The smoking lobby complains that it is discrimination to refuse surgery to a person if they do not reduce or stop their smoking. They are right – it is discrimination. But it is justified if the smoking means that the

treatment will be ineffective. Why should the person go through the risk, staff time be used, and other citizens’ taxes be used for something that will not work?

It is strange that in all the shouts for no discrimination in the NHS, we seem content to continue to allow people from higher social classes and with higher incomes to have more GPs and better access to health services, although they have better health. Where is all the tough action and legislation for people at the bottom of the social ladder? Perhaps they deserve more discrimination in their favour – and, yes, some discrimination against those who are better off.

For those of us in patient and public involvement, this is no academic issue. Who do we actually engage and involve? Whose voices do we week out? Who actually gets heard and influences decisions? Who do we tend to ignore – perhaps people with dementia, young children, or travellers?

PPI has a role in discriminating in favour of engaging those people who are usually discriminated against. While there is much good work going on across the country with various groups, we need to constantly ask – who is not here, who is not being heard, who is being ignored?

If we are aiming for equity (fairness) rather than equality (treating everyone the same), then we need to discriminate all the time – just for positive reasons – and justify it when challenged.

Keep well

**Chris**

Chris chairs Passionately Curious Ltd, a social business that is working with diverse citizens and communities.

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For details contact  
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