

PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

Firm Foundations

New Government framework for community capacity building sets out plans for fully involving citizens and communities

A new report from the Home Office confirms the Government's ongoing commitment towards fully involving local people and communities, saying that it is the only way for the Government to achieve its objectives.

This is good news for everybody working in and around PPI. With the impending demise of the Commission for Patient and Public Involvement, some observers were concerned that there would be a softening of the Government position on involvement in health.

The report recognises the need to invest to build skills, abilities, knowledge and confidence within individuals and community groups, to enable them to take effective action and play leading roles in the development of their communities.

It also means expanding learning and development for public sector professionals, including the NHS, so that professionals, practitioners and policy-makers are better equipped to engage properly with citizens and communities.

The review recognises the importance of seeing communities not just as geographical entities – such as neighbourhoods, estates or parishes – but also as communities of people with common interest or identity.

Six principles will underpin Government action: -

- Adopt a community development approach
- Build on what exists
- Take a long term view – there are no quick fixes
- Ensure support at local level
- Accept learning as a key
- Embrace diversity – no 'one size fits all' approaches

In future editions of PPI Monitor we will be running a series of articles which look at each of these themes in the context of patient and public involvement in health. In the meantime, a full report is available at www.homeoffice.gov.uk/docs3/ho_firm_foundations0812.pdf

INSIDE THIS ISSUE

Mr Motivator – Just what is it that motivates people to get involved in health care issues. This is a big question and it's one that Johnston Birchall and Richard Simmons of Stirling University have been looking at.

Little acorns – The big focus of PPI is on urban issues, but rural health issues are important too. Herefordshire PCT won the NHS Alliance Acorn Award for PPI. Euan McPherson explains why.

Gobbledygook is everywhere, even though the NHS has tried hard to get rid of it. John Lister of the Plain English Campaign gives his top tips for written communication with patients and the public

Licence to innovate: Innovation in the NHS is not just about science and technology. Laura James shows how you can capitalise on PPI innovations

On the buses: It is an old chestnut, but transport issues are a big concern for patients and the public. Kath Tierney offers some ways to deal with these issues effectively

Welsh Rarebit: Wales is not behind the door when it comes to PPI. Val Doyle and Diane Henderson give insights into Signposts, their practical guide to PPI

Mr January

It sounds rather la-de-da. I'm writing a book, to be published in June – Bearhunt: How to earn your living by doing what you love.

By the sound of it, you may think it is a middle class book for middle class people. That's fair enough. Yet I have been keen to show that people from all walks of life can change their lives and the lives of the people around them.

It has taken me to two of Britain's most deprived neighbourhoods. Back to reality. To Benchill in Manchester, and to Bromley-by-Bow in East London. Two of the poorest, sickest, most run-down neighbourhoods in Britain as we came into the millennium.

What they have in common is that the 'authorities', the public services have ploughed on doing their own thing, whilst local people, out of a sense of pure frustration have taken their destinies into their own hands.

The results are The Bromley-by-Bow Healthy Living Centre and The United Estates of Wythenshawe Project. People, doing it for themselves. It's good that people take their

destinies in their own hands, but it's not good that they have to do it because public sector bodies are paying lip service to involvement.

Andrew Mawson who was instrumental in establishing the Bromley-by-Bow Centre explained how he soon became frustrated by the voluntary and public sectors who seemed to do a lot of talking, yet little to change the lives of local people. He says "I began to realise that if you really want to bring change into things, this idea of passing through on the three year Guardian advert is a complete waste of time. What you have to do is dig in or move out. Get to know the detail".

Similarly, Greg Davis in Benchill feels that the public services are so far removed from reality, they cannot possibly understand what it is like to live and survive on a run down estate. Last year, his project printed a calendar to raise funds. It was one of these where Mr Universe types from the projects gym were oiled-up and dressed as firemen, policemen, red Indians and so on, with only strategically placed dumbbells protecting their modesty.

When I asked him how it went, he replied

"not very well. Mr January is doing eight years for armed robbery and Mr October murdered someone". Despite the great work that he is doing from within, the reality is that life in our toughest neighbourhoods is just that. It is tough. Very tough. There are lots of pressures and lots of concerns.

We cannot understand what these are by keeping our distance. If we are to truly involve the public and patients from our most deprived communities, we must truly understand what their lives are really like.

How many of us actually do? How many of us take the time to go and find out? How many of us prefer to sit in the warmth of our offices and make judgements?

As Andrew Mawson points out, the answers are to be found in the micro. In the detail of people's everyday lives.

PPI could be seen as a micro input to get a macro output. Greg and Andrew have shown that micro inputs can have macro outputs.

If the answers are in the micro then PPI has to take to the streets. Are you doing enough to understand your most deprived people?

EDITORIAL ADVISORY BOARD

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

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

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

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

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

David Gilbert

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

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ISSN 1742-0407

a bearhunt publication



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News items

New action plan for race equality in mental health

The Government's response to the independent inquiry into the death of David Bennett is to introduce an action plan to run over five years and to be based on three 'building blocks':

1. Community engagement - delivered through healthier communities and by action to engage communities in planning services, supported by 500 new Community Development Workers;
2. More appropriate and responsive services - achieved through action to develop

organisations and the workforce, to improve clinical services and to improve services for specific groups, such as older people, asylum seekers and refugees, and children; and

3. Better information - from improved monitoring of ethnicity, better dissemination of information and good practice, and improved knowledge about effective services. This will include a new regular census of mental health patients.

By 2010 it is envisaged that there will be

a more active role for BME communities and BME service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services; and a workforce and organisation capable of delivering appropriate and responsive mental health services to BME communities.

The full report is at <http://www.dh.gov.uk/assetRoot/04/10/07/75/04100775.pdf>

Gr8 idea 4 txtting

People with long-term conditions like asthma could soon be receiving health information by text message or email.

They could even pick up advice on how to stay fit and healthy from their local barber.

These are just some of the ways in which the NHS could be helping people take care of their own well-being, according to Health Secretary John Reid.

His new document examines ways to improve the lives of the millions of people who are affected by long-term conditions like diabetes that can't currently be cured - but are controlled by medicines and other therapies.

About 17 million people in the UK suffer from at least one long-term condition.

The guidance will also enable the NHS to improve the lifestyles of other people in the wider community, helping them to lead healthier lifestyles or take better care of minor ailments.

John Reid said "Everybody is used to brushing their teeth regularly to keep the dentist at bay. We are looking to get more people to adopt this proactive approach towards their general healthcare."

The Department of Health document, Self care - A real choice: Self care support - A practical option, sets out the position on the DH's policy to support self-care. It is aimed at PCT, NHS trusts, SHA and social care management teams, as well as health and social care professionals and practitioners.

Experts Programme under microscope

National Evaluation of Expert Patients Programme: Assessing the Process of Embedding EPP in the NHS - describes the implementation of the Expert Patients Programme (EPP) pilot phase within NHS primary care organisations in England. The principal aim was to identify barriers to establishing functional self-management programmes in the NHS.

The report is available for download from the National Primary Care Research and Development Centre at <http://www.npcrdc.man.ac.uk/PublicationDetail.cfm?ID=105>

Health and Social Care Awards

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

There is a range of awards :

- Primary Care Professional of the Year Award
- Nurse or Midwife of the Year Award
- Hospital Doctor of the Year Award
- Allied Health Professional of the Year Award
- Manager of the Year Award
- Emergency Care Award
- Children's Care Award
- Queen Mother's Award for the Care of Older People
- Mental Health Award
- Social Care Award
- Long Term Conditions Award
- Patient Safety Award
- Improving Health and Reducing Inequalities Award
- Technology Award
- Health and Social Care Team of the Year Award
- NHS Live Award for Improvement and Innovation

For more information, see www.healthandsocialcareawards.org

What motivates patients and

Government policies aim to maximise the involvement of patients and the wider public in health care, but do people want to get involved? This is a big question, and it is surprising that so little academic attention has been paid to it. At Stirling University, we have been asking public service users (in housing and social care), and members of social enterprises (consumer and housing co-ops) what motivates them to participate or not to participate. While the context is bound to be different, we think the resulting 'Mutual Incentives Theory' also applies to health care.

First, we have to identify what we mean by participation. There are three ways patients can get involved. One is for individuals to exercise choice between different types of treatment, and over where and when to receive it. Whether or not they want choices is debatable, but at least it will not be difficult to get them to participate: people's own health is high on their list of priorities. The second type of involvement is in one-off events such as public meetings, forums or focus groups where individuals are asked to give their views. Again, it is not all that difficult to persuade enough people to participate: the offer has to be attractive enough for the personal benefits to outweigh the perceived costs of giving an hour or two of one's time. The costs are higher for those who are socially excluded and for ethnic minorities, but if necessary market research techniques can be used and they can even be paid for their time. The really difficult problem is how to persuade people to participate in the long-term, as members of advocacy groups, PPI forums or NHS foundation trusts, and it is this type of participation that our research is aimed at.

Academic theorists tend to start from the assumption that people are individualistic and will participate if the benefits outweigh the costs. The problem is that more people participate than their theory expects, so they have to add in factors such as altruism or collective benefits. We decided not to prejudge the issue but to ask a large number of active service users why they participate. They told us that personal costs were not significant, that there were personal benefits

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(such as enjoyment, a chance to have one's say, a sense of achievement), but that these were not why they took part. In fact, 80% of people said they would take part even if these benefits were taken away. They are motivated by more 'mutualistic' motivations, which we summarise as:

- shared goals
- shared values
- sense of community

The more people participate, the higher they score on these three factors. What happens is that in taking part they begin to see mutual rather than individual benefits, and so no longer think in an individualistic way. Their personal benefits become bound up with the benefits the group is seeking through collective action. Over time, the strength of these mutualistic motivations increases, and they build up commitment that makes it hard for them to quit. Only when the experience is particularly bad do they flip over to the more individualistic way of thinking, and begin to

calculate 'what's in it for me?'

How far do these findings apply in health care? We intend to find out as soon as we can get the funding for a new project, but we think they will be broadly similar. For people active in council estates and housing co-ops, the sense of community is based on a neighbourhood, while for social care it is based more on a type of need. We expect health participants to be motivated in some cases because they care about their neighbourhood, in others about a type of patient. They will easily find shared values in their common experience of illness, or of relying on the service of one general hospital or health centre. This means, however that they may not at first be motivated to see the wider viewpoint, and may come with what the professionals see as 'sectional' interests. They will easily identify shared goals in the need to improve the service, but their goals may not be those of service planners or politicians.

This is good news about the motivations of regular participants, but how do we encourage people to get started? First, people need the resources to participate: time, money, skills and confidence. They have to be convinced that these will be available, and will be encouraged by the offer of cost-effective meetings, travel expenses, training days and mentoring from more experienced participants. Second, they need opportunities – often those who complain the loudest that people do not participate are providing few opportunities for them to do so. Third, they need recruitment efforts. This means being asked, face-to-face, preferably by people they know and trust. It means making a good offer, on issues that they care about, and making it not once but again, because they may not be ready for it the first time.

What makes people give up? Participants are concerned with both process and outcome. They want to feel that their voice is being heard, their views taken into account, and that the exchange is an honest one, even if they do not always get their way. If they find the agenda has been fixed in advance, decisions have already been made or are being made elsewhere, then their motivation

And the public to get involved?

will weaken. If they find over time that their goals are not being achieved at least in part, this will also weaken their motivation to continue. They care about the quality of the relationship with service providers, but they also expect to see some action and get some collective reward for their efforts.

Do people vary in their attitudes towards participation? Through cluster analysis of our results, we found five types of participant. There are campaigners, who drive the group forward and are very strong on the 'mutualistic' motivations, foot soldiers who work hard to maintain the group, scrutineers, who are thinkers rather than doers, habitual participants who take part without thinking about it much, and marginal participants, who take part occasionally and may drop out.

What about those who do not take part? Are they all apathetic? We found that non-participants scored lower on our mutualistic motivations, but they were still positive – most people had some sense of community, shared values and goals on which recruitment efforts could be built. These motivations



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needed to be more strongly developed to tip the balance into participation. Non-participants also needed more reassurance that the costs of taking part were not too high, and that there would be personal benefits. We found three types of non-participant. There were marginals who were much like the marginal participants: they could be persuaded to join in but had not yet done so. There were alienated people who were cynical about the motives of service providers and needed to be convinced that the group could get things done. Then there were the really apathetic non-participants, who were simply uninterested. These made up only around a third of non-participants, suggesting that much can be done to get the marginal and the alienated involved.

What can health care providers do to increase participation? They need to have a joined-up strategy for mobilising people that includes providing resources, opportunities and active recruitment attempts. Then they need to provide an environment in which public and patient representatives can pursue mutual goals and strengthen their sense of community without becoming disillusioned

by lack of progress. They need to examine their own motivations, and be prepared to share the governance of the service. All of these elements are part of what we call the 'participation chain' – all the links need to be in place if the strategy is to work. There are now many opportunities to participate in health care at all levels from open meetings at the local health centre to service on a PPI forum and membership of a foundation trust, as well as autonomous action by self-help and advocacy groups. There is, however, no point providing opportunities if they are seen as being too costly, or some people have not been asked, or if the opportunity to share in governance is seen as not being genuine.

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Our recently published report, *User Power: The participation of users in public services*, published by the National Consumer Council, can be found at <http://www.ncc.org.uk/publications/>

From acorns come great oaks

Much of the national focus of PPI is urban – but how can it work in the most rural areas? Euan McPherson explains how Herefordshire PCT won the first NHS Alliance Acorn Award for PPI with a systematic approach across health and social care.

Herefordshire is a large rural county, covering 840 square miles; it has a population of approximately 170 000. The county's main population centre is Hereford City with a population of about 80 000. There are five market towns spread around the outskirts of the county and large sparsely populated areas.

Herefordshire Primary Care Trust (PCT) has had some success in patient and public involvement (PPI) over the last two years and has now developed a solid foundation on which to build a stronger culture of involvement. Although the PCT now hosts a small team dedicated to improving involvement across health and social care, the ideas that led to this arrangement started in early 2000.

Pre-NHS Plan (July 2000), Herefordshire Health Authority operated a Planning and Partnership Directorate, working across health and social care. This team recognised the need for a more consistent approach to service user, patient, public and carer involvement in service development and worked with the local community health council (CHC) to develop a model that supported future requirements.

At that time, there were two part-time posts within the Planning and Partnership Team that had some responsibility for engaging service users and carers. One focussed specifically on carers, the other on older people and people with physical disabilities. In addition, non-recurrent funding was made to two local user groups (mental health and learning disability) for them to carry out user involvement on behalf of the statutory agencies. Whilst in principle this could have provided a rich source of independent user feedback, in reality competing pressures for the organisations and lack of clarity about what was expected of them meant that it was ineffective. In addition, the arrangement left many groups without funding or support from an involvement worker.

This team is known as 'The Involving People Team'. This title was pinched from elsewhere (so we can't take the credit), but it has really helped in clarifying the Team's purpose to health and social care professionals and members of the public. The Team has provided the resource needed to engage over 4000 local people in health and social care developments in its first year.

As a result, the Planning and Partnership Team and the CHC proposed a dedicated team with a remit to support and develop PPI across health and social care in Herefordshire. The proposal was discussed and consulted upon with local user groups and voluntary sector agencies. It was agreed that a central resource would provide greater equity to user groups and would be well placed to help drive a culture change within the statutory sector organisations. A central team working across statutory agencies would also be able to maintain an overview of involvement in the county, which would enable them to check that hard-to-reach groups, isolated

communities and individuals were being given appropriate opportunities to engage.

Financial support was made available from a health and social care partnership fund and the two existing part-time posts were realigned to the new team. After some debate about where the new team should be based, and the demise of the CHC, the PCT seemed the natural place alongside the new PALS. The team was expanded to include 2.5 whole-time equivalent posts, with managerial responsibility to the PALS Manager.

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This level of success has been achieved by targeted involvement and consultation, offering a range of involvement opportunities and mechanisms, and the development of an 'Involvement Network'. In addition, the support offered by the Team has encouraged local professionals to engage with service users, patient and carers, and to utilise their skills and knowledge in developing services.

The Team have targeted specific service user groups by working with the voluntary sector, with clinicians and social care professionals to make introductions, with looked after children's services and schools, and with local media to recruit local people. All of the people the Team have been in contact with are asked if they would sign up to the 'Involvement Network'. The Network is essentially a database of local people who are happy to be contacted about health and social care issues. They can specify what (e.g. doctor's surgery, social work or equipment) and how (e.g. by phone, face-to-face or in a group setting); they can also pick and choose when to get involved. This enables the Team to search the database for people with specific interests and distribute a newsletter with involvement opportunities and feedback, so that network members can choose to engage or not. The Network has been slow to develop, but now provides a

valuable contact list, although it still needs to be supported with this targeted approach.

Children and young people are offered a range of scenario-based and game-based workshops. This has helped obtain qualitative data on a range of issues, from sexual health to information available to young people entering 'looked after' services.

The Team staged an 'Involvement Day' in March 2004, which was designed to obtain the views of local people on how they wanted to engage with health and social care in the future. It also acted as the starting point of a new Involvement Strategy, which would be signed up to by all health and social care organisations in the county.

We started the morning with local radio coverage asking people NOT to attend unless they had booked as we had been inundated with people wanting to attend. There were close to 200 attendees with in excess of 50% lay people. The large response was due to good publicity through local groups, networks and the media. Publicity was planned well in advance and, along with posters and press releases; we had particular success with a professionally printed postcard that doubled as a response card.

Harry Cayton (Director for Patients and the Public at the Department of Health) agreed to support the day and provided an excellent introduction and summaries throughout. The main event was 'open space' style, which gave people the opportunity to move around during the day, but there were also music and art workshops for those who preferred those types of media. Although the music pool was aimed at young people (and supported by a local school), many others joined in throughout the day. At the end of the event, the young people came together and performed a rap about involvement that they had developed during the day. It proved a fitting end to what had been a very busy, noisy and productive day.

The day was hard work for the facilitators, but the feedback was positive (although excessive noise was an issue for some). Interestingly, the feedback also showed that people were keen to get involved and were aware of many of the key issues. The information gained on the day has been



It is always good to see involvement lead to a true win/win situation - of course, it often does. We believe that this type of success is as a result of fully engaging staff in the involvement process, rather than just carrying out involvement work and providing them with feedback.

developed into the new Involvement Strategy for Herefordshire.

The key to all involvement is to be able to show an improvement to services. One key area in which this has recently happened is in the service for people with Parkinson's Disease. The lead Specialist Nurse worked with the Involving People Team to actively engage patients in improving the service. She was under huge pressure and the current service could not be sustained, although patient satisfaction levels were high. Having worked with the patient group, she has taken on board a number of suggestions about the way she works and the number of appointments and follow-ups. She says that the end result has been a great improvement, not just for patients, but for her as well. It is always good to see involvement lead to a true win/win situation - of course, it often does. We believe that this type of success is as a result of fully engaging staff in the involvement process, rather than just carrying out involvement work and providing them with feedback.

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Sharpening Clinical Thinking

What has happened since July 2004?

Further progress is being made in Sheffield to engage patients in clinical audit. Emma Challans provides an update.

Introduction

In July 2004, PPI Monitor featured a case study regarding the creation of a clinical audit patient panel (CAPP) in Sheffield South West Primary Care Trust. The Panel was created after a CHI Clinical Governance Review in June 2003 where areas for improvement were highlighted. One area specifically was involving patients in how primary care services are delivered. This particular aspect seems to appear frequently in the CHI review for all Trusts.

Background

How do we know we are delivering the best care to a patient? We have evidence-based NICE technology appraisals and clinical guidelines as well as National Service Frameworks, but do we really know what the patient wants or expects from a service?

When involving patients it must be clear from the very start why the patient is involved and how they are expected to assist the service. Balogh et al. stated that users can be genuine collaborators, rather than merely sources of data. Clinical audit assists and develops services in improving patient care; therefore it appeared only logical to create a Clinical Audit Patient Panel (CAPP).

Involving patients is key to developing services. They can tell us a range of things: how to communicate, how we make them feel, how convenient the service is, how we respect them and their culture, whether we involve them in decisions and whether they trust us. When designing a patient questionnaire to find out how well patients think the service is, are we asking them the right questions, are we asking them things that are of no importance to them and what they actually feel is most relevant has never been asked? Would it be better for a member of staff to go through a patient questionnaire with a patient or for a patient to go through it with another patient? Recent projects indicate that a patient is more likely to tell

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another patient something that they would never mention to their health care provider.

The Trust had very few audits that involved patients, most of which had only token patient input. Since creation of the Panel, currently consisting of eight members, PCT services and independent contractors have had the opportunity to put forward audit projects with the possibility of involving a member of the Panel. This concept has been accepted widely resulting in all of the panel members currently working with staff on audit projects. The audit projects currently in existence are as follows:

- Older People's National Service Framework - standard 1, age discrimination

- Intermediate care services - effectiveness of service, patients perception (Department of Health policy and guidance)
- Expert Patients Programme (EPP)
- Therapy services - patient questionnaire redesigned and implemented
- Chronic Obstructive Pulmonary Disease care pathway - one-to-one discovery interviews carried out between health care professional, panel member and patient
- Free Nursing Care (Department of Health policy and guidance) - audit of new care records

The Panel has been available to advise, support and improve clinical audit activity within the Trust by supporting services and by enabling service users' and carers' perspectives to be included in evaluating quality and to identify opportunities for improvement. Each panel member has signed a confidentiality agreement, which has strengthened their accountability and reassured staff that all information is kept within highest confidence. Members of the Panel have been able to get involved with services at the very beginning of the project to support and advise right through to the final report stage.

Where users are involved in audit projects, careful thought needs to be given to issues of access, preparation and support (Kelson, 1998). All panel members have received clinical audit training to gain a basic knowledge and understanding of clinical audit, how audits are done, why they are done and what audit can achieve if done properly. Since setting up the Panel, the process for identification of audit projects is that a member of staff identifies an audit and requests for a panel member to be involved. The Clinical Effectiveness Manager reviews the project criteria and makes the decision to involve a patient on: is it audit (not data collection); why a panel member should be involved; how a panel member should be involved; and, if acceptable, identify a panel

member to be part of the audit project. Once a panel member(s) has agreed to be involved in the project, an initial meeting will be set up for them to meet the project lead and any other relevant staff. The Clinical Effectiveness Manager attends the first meeting and others thereafter if the panel member or service requests this.

The audit projects currently running may have one or more panel members working on the project, depending totally on the preference of the panel member. Some prefer to work in pairs. It is expected that panel members will work in pairs until their confidence and experience has grown, after which they will work alone with services where appropriate. Various presentations and information regarding the Panel has been shared with; Department of Health; Healthcare Commission; National Audit and Governance Group (NAGG); and with other colleagues via National Primary Care Trust



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and Development Programme (NatPaCT). Further presentations will be delivered at Clinical Audit 2005 and a joint presentation with a panel member at the Patient Involvement, Empowerment and Information conference in May.

Both panel members and staff have made comments after working together on audit projects:

Staff

- 'Can see how patient involvement can really help'
- 'Will not hesitate in involving patients again'
- 'Feel very positive'
- 'Member has seen possible drawbacks which we did not see'

Panel members

- 'Really useful'
- 'Allows end users to have input into care'
- 'Feel like I'm making a difference'

In October 2004 the CAPP had its first general meeting, where all members were able to meet each other. An agenda was prepared in advance with panel member input. Items discussed included: terms of reference; operational issues; chair of the group; and representation on the Trust Evidence-Based Practice Group. Standing agenda items were agreed for future meetings and these included feedback from each panel member relating to their audit project, including experiences of what worked well and what did not and identifying areas of improvement. The group agreed to meet twice yearly.

To date, six more patients have expressed an interest in being part of the Panel. A training and information event for new members will take place in March 2005.

Involving patients in clinical audit will help the trust take forward patient-driven services and to do this effectively we have taken the first steps in giving patients a real opportunity to help us rather than what has often been a mere token.

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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.

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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.

Involve to innovate

What do Newham PCT and the team get?

Innovation in the NHS is not just about science and technology. As Laura James shows, practical innovations arising from PPI can also gain support – and produce returns for those involved.

The NHS is the largest employer in Britain and the principal employer of graduates in the UK. It also invests a billion pounds every year in research and development. This vast, highly skilled workforce has made innovation innate to the NHS but, until recently, the wider benefits of innovation were lost as no formal channels through which to exploit healthcare innovations existed. This ultimately resulted in new ideas and inventions leaking out of the NHS, returning no financial rewards for the effort spent in developing the innovation.

NHS Innovations was set up by the Department of Health in order to fill this gap in the innovation pipeline. A network of nine regional hubs has been established to facilitate interaction and partnership between local NHS trusts, commercial enterprises and universities for identifying, protecting and exploiting healthcare innovations.

The East London Innovations Hub (EL!H) works with all 14 trusts within the North East London Strategic Health Authority. EL!H's mission is to take healthcare innovations and product-based research through to its adoption across the NHS and wider healthcare network. In order to identify new healthcare innovations, EL!H routinely carries out audits within its partner trusts. Innovations cover a broad spectrum from 'high tech' research to more practical healthcare improvements, each with potential value. An excellent example of a healthcare improvement innovation is the Diabetes Information Pack that was disclosed during an audit carried out at Newham Primary Care Trust (PCT).

The 'My Diabetes' Information and Resource Pack was developed by a group of diabetes experts and patient representatives based at Newham PCT in east London. EL!H felt it had the potential to create value after the development team mentioned the phenomenal interest it generated at the National Diabetes Conference.

EL!H worked with the team to discuss how best to progress with the pack and an exploitation plan was agreed. Hunter Lodge, a publishing company from Rickmansworth, was brought on board as a licensee to produce and efficiently market and sell the product. It was also able to offer a print-on-demand service, making the pack even more desirable and valuable to the end user. Print-on-demand enables information contained in the pack to be personalised for the area in which the patient lives, providing pertinent local information. There is also a hand-held record within the pack, which is used to record and monitor the individual diabetes sufferer's needs. A major benefit of the 'My Diabetes' pack is that it allows sufferers to take an active role in managing their condition.

The 'My Diabetes' Information and Resource Pack has been tremendously successful with 27 000 copies being sold to date. It has also been translated into Bengali, Gujarati, Punjabi, Tamil and Urdu and is currently

The NHS is the largest employer in Britain and the principal employer of graduates in the UK. It also invests a billion pounds every year in research and development. This vast, highly skilled workforce has made innovation innate to the NHS but, until recently, the wider benefits of innovation were lost as no formal channels through which to exploit healthcare innovations existed.



being assessed by the NHS Purchasing and Supplies Agency with a view to it becoming a national standard within the NHS.

What do Newham PCT and the team get?

The Department of Health suggested royalty-sharing scheme is shown in the table below:

Net Total Cumulative Income Inventors

Net total cumulative income	Investors Share %	Trust Share %
£0 – 5 000	85	15
£5 000 – 25 000	75	25
£25 000 – 100 000	50	50
£100 000 +	30	70

For the 'My Diabetes' pack, EL!H negotiated the licence deal with Hunter Lodge on behalf of Newham PCT, resulting in the Trust receiving a percentage return on sales. The team then receive a proportion of this return through a royalty-sharing scheme adopted by the Trust. In this instance, the team decided to invest their royalty share in the department enabling further improvements in the service for patients.

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To find out which NHS Innovation Hub covers your trust, visit www.innovations.nhs.uk

Great care - but how do we g

Much PPI work on health services swiftly broaches transport issues. Kath Tierney offers some ways to address these effectively with patients and the public.

When NHS services are reconfigured, there are winners and losers: some people find it easier, and others more difficult, to get there. Equally, some patients and their supporters experience difficulties getting to existing facilities. Experience suggests coming up with good workable transport solutions in the NHS is about painstaking attention to detail, which patients – if asked – can supply in spades.

But policy makers are faced with many difficult choices when it comes to determining the location of NHS facilities. Faced with the choice of having the best care the NHS offer located 20 miles away, or middling-to-awful care just round the corner, most people would prefer the former. Too often, politicians and senior NHS managers appear reluctant to engage with patients in an adult manner about these choices, shying away from dealing with the transport and travel consequences of NHS planning decisions.

Yet developments in health care provision are leading to many acute facilities being concentrated at fewer sites. Similarly, post-Shipman and following extensive estates reviews by PCTs, single-handed GPs are disappearing fast and many smaller GP practices are being grouped together. The transport consequences are straightforward in both settings: more patients are likely to want to get there by car. The NHS is not responsible for how society as a whole plans and organises transport, so only strong partnerships with other stakeholders will lead to good universal access to healthcare.

Another major difficulty for NHS planners is that the sites with the best access in terms of the road network, public transport, and proximity to the catchment population, tend to be more expensive to acquire.

In 2003, the Social Exclusion Unit published *Making the Connections: Report on Transport and Social Exclusion*. Its findings make salutary reading for anyone involved in healthcare provision. 31% of people without a car have difficulties in travelling to their local hospital, compared with 17% of people with a car. Over 1.4 million people say they have, missed, turned down or chosen not to seek

medical help in the past 12 months because of transport problems.

Transport is an important determinant in healthcare choices for a significant part of the population. For the NHS to succeed in narrowing health inequalities, making it easier for all patients to get to healthcare sites is going to be crucial. One problem is whether healthcare changes are being made at the expense of the most vulnerable people in society, those most likely to find it difficult to get to new out-of-town or edge-of-town locations? If so, what can we do to ensure everyone has access to the new and improved healthcare services the NHS is providing?

Let's improve the bus service

Many people will say the answer is a better bus service to the local hospital or primary care centre. Unfortunately, this is not as easy as it sounds nor is it always the right solution.

When NHS services are reconfigured, there are winners and losers: some people find it easier, and others more difficult, to get there. Equally, some patients and their supporters experience difficulties getting to existing facilities.

The 1985 Transport Act introduced deregulation of buses (outside London). It is now difficult to make significant bus service changes, unless there is a strong commercial case. Over 85% of bus services are now decided on the basis of hard economics: if the service is not going to pay, it will not run. Unless, of course, the local transport authority (or some other public body, like Cambridge University Hospitals NHS Foundation Trust is doing at Addenbrooke's Hospital) provides a subsidy. Such financial support is limited, most of it already committed to existing services. To get a new subsidised service at new NHS sites, a very strong case has to be made early in the planning process.

Yet more and better buses may not be the answer, in some areas and for some individuals. For example, in a rural area, where the nearest hospitals are merging into a new larger Trust, some acute healthcare services may be more than 20 miles away: getting to an early morning appointment or back home after a later afternoon visit can be impractical by public transport.

Who can help?

The good news is that the local council with responsibility for transport, with other partners (including the PCT), now has to look at accessibility to all key services, including access to healthcare. See, for example, government guidance on the preparation of the second Local Transport Plan (www.dft.gov.uk), and the Department of Health Inequalities Unit's *Accessibility Planning: An Introduction for the NHS* (September 2004).

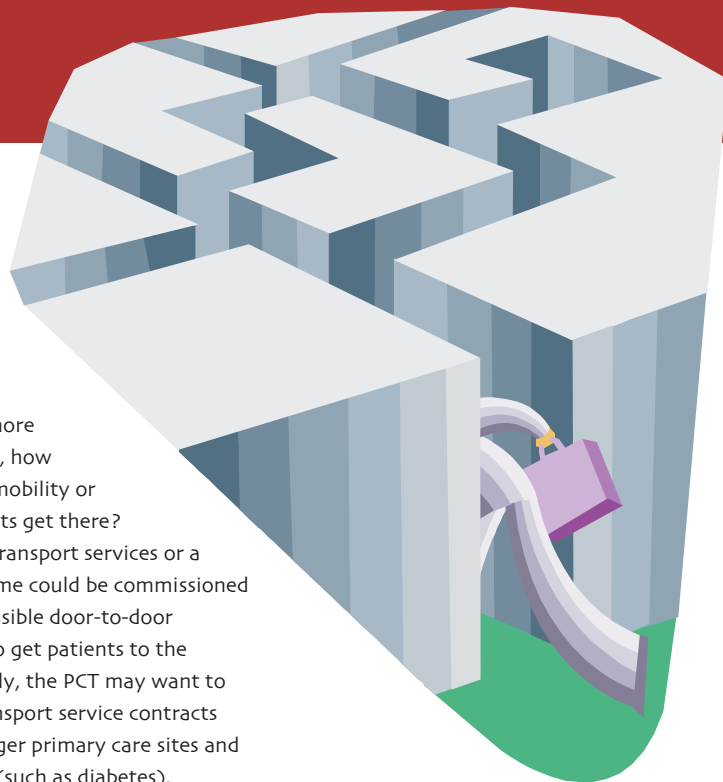
This increases the pressure on everyone to plan effectively and moves accessibility higher up the local agenda. The development of local strategic partnerships and community plans can provide a mechanism to bring voluntary sector and private sector partners into the process.

Working together to find the solution

One of the three core principles in *Keeping the NHS Local*: a new direction of travel is: developing options for change with people, not for them, starting from the patient experience and our commitment to improve choice, and working with staff to develop new ways of delivering services.

No one knows their area better than the

et there?



people who live there. They have a lot of the information that NHS planners, local transport planners and highways authorities need to choose good locations for new services and identify potential problems.

Today, there is a well-developed consultation toolkit at the disposal of public involvement specialists, ranging from 'planning for real' exercises, to focus groups, market research techniques, citizens' juries, and interactive exhibition formats.

Take, for example, a community planning day examining site options for a primary care resource centre. This can be an active, fun, drop-in activity, with opportunities for local people to identify the potential risks and benefits of each site option. A crèche is in operation and youth workers are on hand to work with local children and young people to gather information about their needs. Young adults are unlikely to want to bump into their neighbours when they are looking for contraceptive advice, so how do the proposed sites deal with this? Once the site has been chosen, have a detailed look - with the local community - at road safety, public transport, and the cycling and walking options. A site visit will identify the potential for conflicts between the needs of the NHS site and the local environment, such as on-street parking outside residents' homes, parking on pavements making them impassable for pedestrians, traffic travelling too fast where pedestrians want to cross the road to the NHS unit, and so on.

Working together, in an open partnership, where information is shared and decision-making is based on community needs, harnesses the positive views of the 'silent majority'. To achieve this, it is vital to provide feedback from events and surveys, to show where and how community views have influenced decision-making and build confidence. If a bus stop is relocated, a new pedestrian crossing is put in, a short cut provided or the street lighting improved as a result of problems identified by the community, make sure this is well publicised.

Factoring transport into healthcare decisions

The establishment of primary care centres offering a full range of primary care services, and access to some services that have traditionally been provided at hospitals, should encourage PCTs to think about

transport and access in wider terms.

For instance, if the PCT is going to provide more services locally, including more specialised services, how will patients with mobility or sensory impairments get there? Local community transport services or a voluntary car scheme could be commissioned to provide an accessible door-to-door transport service to get patients to the centre. Alternatively, the PCT may want to extend patient transport service contracts to include their larger primary care sites and trips to key clinics (such as diabetes).

Larger GP centres may find it more cost-effective to use a practice car with paid driver to bring some patients in for their appointment with the GP or other healthcare professional, rather than increase the number of domiciliary visits made by the practice.

In 2003, the Social Exclusion Unit published *Making the Connections: Report on Transport and Social Exclusion*. Its findings make salutary reading for anyone involved in healthcare provision.

Health centres may decide to offer a range of additional services locally - such as green nappy washing services, healthy food cooperatives, healthy cooking for babies and young children, benefits and debt advice surgeries - bringing patients into contact with health professionals in a more informal setting, particularly in areas of high levels of deprivation, where access to shops and services is limited. Some of these activities can be undertaken in partnership with other agencies, such as Sure Start.

At all key NHS sites, patients and visitors (and staff!) should, as a matter of course, be provided with high quality, up-to-date travel information and journey planning advice should be available on an individual basis. Patients can of course, provide some of this to patients.

At all points in the actions outlined above - from the planning process through to the development of local primary healthcare services - it is practical and sensible to involve local healthcare service users in ascertaining whether transport (or the lack of it) is excluding some people from accessing healthcare services when they need them.

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RATC works extensively in the NHS on all aspects of transport and health.

Better Health Information

Help is at hand to ensure high-quality health information. Tom Hain describes the work of the Centre for Health Information Quality and some evaluated resources.

Centre for Health Information Quality (CHIQ).

CHIQ was established in 1997 with funding from the Department of Health, as part of an independent charity, the Help for Health Trust. The Centre acts as a clearing house for the NHS and others, playing a lead role in evaluating health information for the public. CHIQ also provides training and support for producers.

CHIQ considers three key elements to the quality of information, relating to relevance, accuracy and clarity. These quality criteria are directly concerned with those involved in the production of health information. That is:

- where members of the target audience have been involved, the information is more likely to demonstrate relevance
- where experts in the topic area have been involved, the information is more likely to demonstrate accuracy
- where a skilled health communicator has been involved, the information is more likely to demonstrate clarity

Additional indicators of quality can be assessed through appraisal, once a piece of information has been produced. A combined assessment of the above provides a comprehensive appraisal of the quality of any health information resource.

The CHIQ Triangle Mark (a blue triangle on a white background) indicates that a skilled appraiser has tested information in the manner described above, and that it meets minimum criteria for quality.

Evaluated resources.

A number of organisations work with CHIQ to ensure information produced is independently evaluated. Discovery Health was the first organisation to be awarded Partner status, in January 2002.

In the process of becoming a Partner, the producer's editorial processes are subject to an initial assessment by an expert appraiser. The next step is a review the resource, from which the appraiser makes a report indicating which quality criteria are met

and which need further attention to meet minimum standards. The producer makes any alterations required and re-submits the resource. Producers of resources that meet the minimum requirements are immediately confirmed as CHIQ Partners. Some of the Partners' services (details as of 4 August, 2004) include:

- The Alzheimer's Society provides fact sheets and web site information for people with dementia, their families and carers. <http://www.alzheimers.org.uk>
- The Brain and Spine Foundation has published 27 booklets on a variety of neurological conditions and procedures. A related helpline service was launched in 1998 and has since responded to more than 18 000 calls, and a web site receives more than 3 000 users a month. <http://www.brainandspine.org.uk>
- BUPA (British United Provident Association) produces a wide range of health information resources for consumers, including fact sheets, healthy living articles and topical news items. <http://www.bupa.co.uk>
- Discovery Health provides a range of services, including games and features, news headlines, and a television guide which complements an interactive TV service. There are different sections, including those for both men's health and women's health. <http://www.discoveryhealth.co.uk>
- EIDO Healthcare produces procedure-specific medico-legal documents and patient information to support the process for informed consent. EIDO works with consultant specialists, patient representative groups and the Plain English Campaign supporting more than 150 hospitals. <http://www.eidohealthcare.com>
- Headway provides support and services including information leaflets and a web site, for people with a brain injury, their family and carers. <http://www.headway.org.uk>
- The Healthpoint Touch Screen system gives access to over 3 400 health topics with advice on diet, complementary medicine, vitamins and medical conditions. Many topics have educational videos and still pictures. More than 320 kiosks are installed across the British

Isles. <http://www.healthpointtech.com>

- Macmillan Cancer Relief, together with CHIQ, has recently produced annual editions of the Directory of Information Materials for People with Cancer. All entries to the Directory have been tested using an assortment of appraisal tools. <http://www.chiq.org/macmillan>
- Medicdirect, hosted by medical consultants, provides a range of web-based information services, including a sports section. <http://www.medicdirect.co.uk>
- The Migraine Trust offers information for sufferers of migraine and headache. <http://www.migrainetrust.org>
- Patient UK has over 600 condition leaflets many with diagrams, details of nearly 2 000 UK patient support organisations, 800 drug information leaflets and an extensive directory of health-related websites. This is free to access 24 hours per day. <http://www.patient.co.uk>



Tip

When searching for high-quality health information on the Internet, it is increasingly a simple case of adding 'CHIQ' in your search enquiry. For example, when searching for information about asthma, type 'asthma chiq'. As more Internet information is evaluated by CHIQ, more information will be available in this way.

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Notes:

- For more details about CHIQ, visit: <http://www.chiq.org/chiq>
- For details about how to become a CHIQ Partner, visit <http://www.chiq.org/chiq/partners>

All together now

Patient and public involvement forums often have shared interests and concerns. Astrid Adams describes how joint working is being made effective north of the Tyne.

North of Tyne Patients' Voice is a Forum Support Organisation for eight PPI forums in the north of Tyne region. We are one of the few organisations (certainly within this region) that has been set up specifically to support PPI forums. A not-for-profit company, we achieved charitable status earlier this year. As we were setting up, we tried to involve community and voluntary organisations, inviting them to become members of the company or to take a place on the management group. In a sense, this allowed us to be more inclusive as a wide range of people had input into our original aims and objectives. We continue to welcome individuals and groups to become members of the company and charge a minimal subscription.

There were two pilot patient forums in the area, set up by the Community Health Council (CHC). Many members of these have become members of the new PPI forums, bringing previous knowledge and experience with them.

With a core of staff from a CHC background, we now have a full staff team in two office sites, including four full-time equivalent Development Officers and a Knowledge and Information Officer. Her job includes doing one-to-one or group training with forum members and staff on the Knowledge Management System (KMS). She also produces a weekly bulletin for staff showing key web sites and is working to establish a resource centre for staff and PPI forum members. She co-ordinates the input of Forum papers and reports on KMS. Together with members, she is developing separate information leaflets for each of the eight PPI forums which, together with CPPH leaflets, we can use to publicise their work. She has also developed a 'generic' PowerPoint presentation that forum members can amend and use if they are going out to talk to local groups.

With the PPI forum members, we quickly identified the need for allowing time outside meetings to get to know each other and to start developing work priorities and action plans. Most of our forums have had one or two half-day sessions to help establish

effective team working and have found them invaluable. Staff have been involved in setting up and providing training for forum members, including a session on managing meetings.

Several issues have arisen locally that cross NHS trust boundaries. It is becoming clear that there are very few issues that affect just one trust, so joint working across forums is an obvious way forward. Our response has been to set up cross-forum working groups. Using working groups on single-issue concerns and inviting appropriate people – including members of local authority health scrutiny committees, NHS staff and people from the voluntary sector – to bring their expertise to the groups will allow forums to see issues through to a conclusion.

One example is a working group to monitor a review of maternity services across the huge Strategic Health Authority area. The forums involved are working with the Primary Care Trust to set up a series of public meetings that will allow local people to be involved in the consultation.

We hope to run in the near future a cross-forum workshop to work through a new toolkit for engaging children and young people and finding out their views on health issues. The toolkit, Young Voices/Real Choices, has been developed locally, with young people delivering the training. We

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hope to establish a core of forum members who have used the toolkit and are able to work with children and young people to get their views on health, to widen the perspective of the forums.

In October, we are holding an event for all our forum members. The agenda is being set by forum members to address issues of concern to them. The day will take the form of a number of small workshops where forum members can share experiences, learn from each other and develop new ways of working. It will be an opportunity for them to network and also to celebrate their successes. Dr. Stephen Singleton, the Director of Public Health at the Strategic Health Authority will be the keynote speaker to close the day.

With some PPI forums having low numbers and several inactive members, there are concerns about the volume of work coming their way. They need to be able to prioritise and learn to say 'no' when they feel that an increased workload will stretch the forum too much.

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Improving PPI: as easy as AB

Patient experience knowledge is as important as theoretical and practice knowledge, say Tony Warne and Susan McAndrew. So how can this make a real difference in nurse education and training?

Nearly two years ago, we decided to bring together the ideas and experiences of colleagues involved in developing new ways in which patients could become more involved with the education of nurses. Our aim was to produce a book that would effectively contribute to this important aspect of health and social care. Patient and public involvement (PPI) had already started to become an issue that many health and social care organisations were addressing, albeit perhaps only to ensure their clinical governance review went OK. However, such involvement seemed to us to be an 'after the event' approach rather than anything more proactive. Indeed in discussions in the classroom, often our students' would talk about the rhetoric of empowerment and involvement of patients in their health care when what they were really describing was simply more practitioner-driven intervention.

Coming from a mental health nursing background, we had long thought there might be a more effective way to redress the professional/patient power imbalance often experienced by patients, carers and families when they came into contact with mental health services. We are committed to the idea that one effective way of doing this might be to involve patients in the very processes that shape the healthcare professional; that is, in their education and training. Both of us had trained to become nurses at a time when, if you learned anything at all during the three years of training, it was from the patients you cared for rather than the tutors or ward staff. As a student nurse, you had to be proactive about your learning in order to get a tick in boxes A, B and C. Reflecting back on those heady days 30 years ago, it now seems that 'learning through doing' in this way was a very hit and miss affair. Many changes have occurred in nurse education since the late 1970s. Overall, there has been a move away from the apprenticeship approaches we experienced and a move towards embracing evidence and research-based approaches to knowledge and skill acquisition. Such educational approaches are firmly rooted in scientific and quantitative schools of thought. Whilst providing one view of the world, these

Our aim was to produce a book that would effectively contribute to this important aspect of health and social care

can, paradoxically, make it more difficult for individual patients to 'tell their stories' and in so doing create a different, but perhaps equally important view. The consequence of this is that a wealth of important experiences (the possible basis for knowledge generation) is lost to students, practitioners and teachers.

Of course, theoretically based knowledge and practice-based knowledge are important. We argue, however, that patient experience knowledge is equally important, but perhaps more difficult to get at and use in developing professional practice. Patient experience knowledge is different from the knowledge that is gained in grounding theoretical knowledge on practice knowledge – but it is part of both. Theoretical knowledge can help frame the view of the nurse in contact with the patient, but it is generally only what this knowledge dictates is important that is acted upon. We argue that it is through the use of patient experience knowledge (where patients are enabled to share their illness experience) that theoretical knowledge firmly grounded on practice knowledge is given a personal context and as such can become the basis for effective nursing practice. This rather simple argument is, however, difficult to put into action. For example, contemporary approaches to nurse education ensure that the student spends an equal amount of time in practice as well as in the university. So for 50% of their training they are immersed in a learning environment rich in patient experience. It appears that this experience does not have the same currency (in terms of what it might represent as knowledge) as when, for example, patients are invited to participate in formal learning opportunities within the university. We wonder what it is about the latter approach that 'legitimises' the experience in this way when students should be able to benefit from these learning opportunities as and when they occur in practice placements. One reason might be the ever increasing 'busy-ness' of many practice environments, which can make

it difficult for the student nurse to seek out effective learning that can be supervised by more experienced practitioners. Other reasons might reflect that the patient story is often ignored or at least goes unheard, because students are not equipped with the reflexive skills needed to treat such stories as 'evidence' or that their limited experience of hearing and responding to the story might be exposed.

It was these types of concerns that we sought to address in our book, *Using Patient Experience in Nurse Education*. The collective experiences described by the contributors to the book (which includes patient contributions) provide an exciting collection of stories, ideas and practical examples of how to improve PPI in nurse education. A number of important issues emerged which included:

- Improving the recruitment and selection processes of patients; for example, should we formally interview patients in the same way as prospective staff members?
- Finding better ways to pay for this involvement – should this include sick and holiday pay, will such payments adversely affect benefit payments?
- Developing support systems – for individuals who might experience some upset as a result of retelling their experience; for dealing with a group of truculent students? – perhaps difficult for the experienced teacher! and finally, support for lesson preparation and for ensuring learning outcomes are achieved.
- Ensuring a healthy respect is given for the person, not the 'patient group' the individual might represent?
- Managing organisational culture change – vital when dealing with professional perceptions of threats to jobs, the 'dumbing down' of educational process, and for developing and facilitating new forms of 'learning through doing' approaches to education and training.

Of course, we did not intend to write a book that provides all the 'off the shelf' answers to these issues! Some of the issues are very complex. For example, it will require real 'joined-up government' to deal with the benefits issue when trying to involve some groups of patients in this way. We do, however, make the following



EVENTS CALENDAR



recommendations, which might equally apply in a range of different contexts for improving PPI:

- Consider the need to invest in effective planning processes. The key is to ensure that potential patient involvement happens right from the start of any new initiative. As you as a professional sit down to think through a service improvement or change, you should be doing this with patients.
- Thinking about how as an organisation we can commit to learning from patient experience knowledge. In an educational context, this reflects an approach, based upon well-established principles of adult learning, perhaps most importantly, that these recognise the two-way learning that needs to occur.
- Promoting a greater sense of equality in organisations. Not all teachers are effective and when this is recognised support is provided to improve their skills. The same approach should apply to the patient educator.

Our book is about promoting different sorts of partnerships. This approach is not one based upon the desire to create a homogenous, universal type of partnership per se, but one that recognises and embraces difference. We believe that the patient can be viewed as an expert (in terms of their illness experience), in much the same way as the nurse or teacher can be recognised as being an expert in their field. We believe that in attempting to improve PPI, one effective way is to bring these 'experts' together. Whilst this may not be as simple as learning your ABC, it is possible. What is required is that all three experts start to learn how to learn together, and there is much to learn! Our aim was to produce a book that might help facilitate this. Time will tell how successful we have been.

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

19th Annual Health Services Research Lecture

London School of Hygiene & Tropical Medicine
Department of Public Health and Policy

The Autonomous Patient Revisited

Angela Coulter
Picker Institute Europe, Oxford
Tuesday 1st March 5.30pm Goldsmiths' Theatre
The London School of Hygiene & Tropical Medicine is located in Keppel Street, off Gower Street, London WC1.

EVERYONE WELCOME

A Practical Guide to Developing and Implementing Informed Consent

Thursday 14th April, One Great George Street, London
Contact Healthcare Events 020 8541 1399 Price £330+VAT

Health Co-operatives: An International Perspective....Lessons for UK Healthcare

Thursday 10th February, One greatGeorge Street, London
Contact 0161 246 2908 Price £250+VAT

Public Health and Consumerism: Will the White Paper work?

Friday 18th February, Sheffield - 10am to 4pm
Quaker Meeting House
10 St James Street , Sheffield S1 2EW

Main speakers:

Dr Geof Rayner, Visiting Research Fellow, City University, London, lately Chair, UKPHA:
Choosing health: the market, culture and the government.

Prof Chris Drinkwater Head of the Centre for Primary & Community Care Learning at the University of Northumbria: Public Health and Personal Choice

Prof Richard Wilkinson, Division of Epidemiology & Public Health, University of Nottingham Medical School, author of many publications on Income and Health: "Inequality, Social Differentiation and Health".

Janine Arnott, University of Manchester, will present a broad overview of the MMR controversy in the UK and will examine the questions raised by the case - what counts as evidence and whose evidence counts - in evidence based policy making.

Lunch provided.

Cost £90 for statutory and commercial organisations, £45 for voluntary organisations, CHCs and PPIFs, £25 for individuals, £20 SHA members.
Some free places for people on means tested benefits.

Contact: Martin Rathfelder
Telephone: 0161 286 1926
E-Mail: admin@sochealth.co.uk

Climbing the ladder of involvement

North East Wales NHS Trust is no stranger to involving patients and the public, having been awarded Charter Mark, for the acute part of its services in 1995. In 2002, the Trust was chosen by the Welsh Assembly Government to act as a pathfinder site for the 'Signposts 1' initiative, a practical guide for developing, public and patient involvement in the NHS.

'Signposts' describes PPI as having three dimensions: giving information, receiving feedback, and enabling influence. A baseline assessment of the levels, range and structures of the Trust's PPI work showed that the Trust produced lots of information and used methods to gain feedback. However, despite a long history of involving the public, participation at the influence level was patchy. The Trust lacked an organisational approach to developing this area of participation.

Increasing PPI at the influence level became a key objective. Systems needed to be developed to encourage the public to become more involved in the Trust's corporate and directorate business, giving them a genuine opportunity to influence decisions. This was a tall order: to be involved in decision-making members of the public would need to be on a range of Trust committees and no single person could claim to be totally representative of the public. It was at this point that the Trust's PPI Committee came up with the idea of creating the voluntary role of 'Public Member'. A Public Member was envisaged as a person interested in learning more about the work of the Trust and influencing the decisions made by becoming an active member of committees, or groups.

The Trust's PPI Committee originally consisted of people from the voluntary sector, Trust staff, Local Health Boards, and the Community Health Council. In 2003, six Public Members were recruited to join this committee. They were asked to contribute to discussions and decisions made, and give a laypersons' perspective on plans or proposals. It was anticipated that these first recruits would pave the way for future Public Members, by helping to develop and extend the role.

The Public Members were soon offering us ideas on how the role could be further defined. Along with the definition of their role they requested criteria that identified our expectations of them. It was agreed

'Signposts' describes PPI as having three dimensions: giving information, receiving feedback, and enabling influence.

that the people best placed to develop these criteria were the members themselves. They clearly saw themselves as maintaining and developing effective patient and public involvement relationships in the Trust. However, this concept needed to be teased out; a working group was formed and criteria developed which were later used to form the basis of a policy for the recruitment and selection of public members (see box).

In 2004, the Trust decided the time was right to extend public membership to other corporate and directorate committees. Having members of the public influencing the decision making process at such a fundamental level was a new concept for some of these committees. This stage of the plan therefore needed careful facilitation. In particular it was important that good practice was being used when recruiting Public Members.

Using the criteria developed by the Public Members, policies and procedures were developed to standardise this recruitment process. As a result we believe we are the first Trust in Wales to introduce a policy that is solely dedicated to the recruitment of Public Members. The policy takes into account national guidance and in particular we ensured that it complies with Child Protection and Vulnerable Adults requirements. We are grateful to our Public Members for helping us to develop this policy, which has been well received by all stakeholders.

When we look back at the baseline assessment of 2002, we are pleased to see that we have climbed the ladder of participation. We believe that we have engaged with the public in a positive way, developed organisational systems and supported staff by developing policy and procedure to facilitate public influence within the Trust. Our Public Members, staff and partner organisations have guided us in this

- Contribute to maintaining and developing effective public and patient relationships in the Trust.
- Support, consider and review findings from studies carried out by the Trust.
- Develop contacts and good working relationships with organisations, patients and communities, which make up our local public.
- Provide a source of expert views in dealing with particular issues, which may arise.
- Provide guidance on the development and implementation of strategies for communicating and consulting on PPI with as wide a range as possible of patient, carer and other groups with an interest in involvement issues in the NHS.
- Reflect on the experiences of people as patients, service users and carers as well as their wider views of health and social care.
- Enable the voices of excluded and vulnerable people to be heard, and facilitate the involvement of people who are not part of traditional networks and groups.
- Work in a transparent way in all activities with clear accountability.
- Participate in other communities if able.

work. Our systems and approach will help us to link in with the English Trusts that surround our borders and the next stage of the work is to link in with some of the English PPI Forums.

We have found the whole experience very rewarding and enlightening. There is always potential to climb higher, and take the next step along this journey, and with the continued support of our Public Members, we know we can climb further.

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Last Word from Chris Dabbs



Dear Mrs. Buggins,

In the Ninth Century, Eric the Red led the Vikings to colonise Greenland. Their community grew over several generations to some 5000 people.

The Vikings maintained their lifestyle from Norway, slowly destroying their new environment by inappropriate forestry and grazing. They ended up eating their cattle literally down to their hooves. The bones of the pet dogs were left, covered with knife marks. The settlement collapsed and the Norse people starved to death in the 15th Century.

Yet, the neighbouring Inuit – apparently despised by the Vikings – not only survived but continued to sustain their community. What was the difference? Eating fish and burning seal blubber, which were in ample supply. The incomers did not, however, eat fish and continued their labour-intensive cattle rearing and hunting practices. These were part of what it meant to be Viking. Although it would have been easier to adapt to the new environment (and survive), the Vikings stuck to the old ways (and died out).

Persisting in collective behaviour is a frequent feature of human societies – whether or not it makes sense. See how western societies still maintain environmentally destructive practices, despite all the evidence about climate change (a process which may be irreversible within 10-20 years). We are repeating the foolishness of the Vikings.

Key in all this is the collective response to changing circumstances. The society or community that responds successfully to the social, economic, physical and political environments will, by definition, not collapse.

Some argue that the world's most pressing question is: how can we improve our response to changing circumstances? Even at a relatively small level, in health care, the same challenge can be put. The health service was designed for a society in which

preventable and curable diseases formed the greatest challenge. In conjunction with other economic, environmental and social policies, the NHS has largely succeeded in meeting this.

Now, however, there is a different environment, substantially created by the previous success. By far the greatest demand on all health services comes from people with long-term conditions, whether mental or physical. This is far more about managing conditions, of which the people who have them tend to have considerable knowledge and experience.

Yet, the NHS – and much of PPI – remains primarily focused on its longstanding objectives, ways and culture. If you doubt this, see how much time, money and targets are devoted to hospitals and acute care, not only by politicians and professionals, but also by the public.

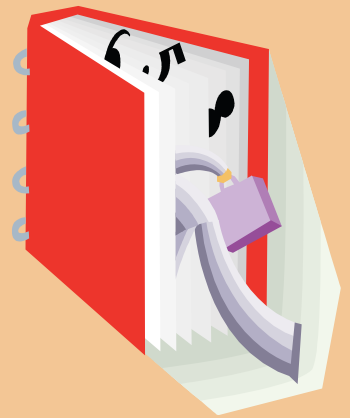
We hear the frustration of local people that those who make policies are often insulated from the consequences of their decisions. Likewise, those who are affected by these choices often lack an appropriate role in making them. This tends to blunt the sensitivity of responses to changing circumstances.

Those of us active in PPI must move the agenda forward – most especially in promoting self-management. If the NHS has not fundamentally changed within relatively few years, it could see its demise. We have a choice – to be like the Inuit or the Vikings.

Keep well

Chris

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



Contribute to PPI Monitor!

Do you want to
write an article
for PPI Monitor?

Everyone involved
in public and patient
involvement has a story
to tell, and we would like
you to tell us yours.

Have you approached
your own PPI in a new
and innovative way?

Do you have something
to share with other
readers about solving
problems and moving
forward?

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studies help someone
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Share your challenges
and successes with other
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