

PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

Superbug Targeted

PPI forums set their sights on MRSA superbug amidst concerns that lay people may be out of their depth

MRSA, the so-called superbug, now responsible for 800 deaths a year, is a prime target for newly-established local bodies for involving the public in health - Patient and Public Involvement (PPI) Forums. The bug, which killed only 53 people ten 10 years ago, is now a key concern.

PPI Forum members, supported by the Commission for Patient and Public Involvement in Health, welcomed Health Secretary John Reid's new action plan to beat MRSA.

But there are concerns that the ability of lay volunteers to shoulder this important work is limited, and that expert support is needed.

Chair of the Commission for Patient & Public Involvement (CPPIH) Sharon Grant said "Our forum members are volunteers and there are limits to what they can do – without extensive training and extra support. Some also have concerns that lay people are being asked to carry out technical work."

Despite these concerns forums from Ellesmere Port to Somerset have already flagged up serious concerns over hospital hygiene. In many areas they are working with staff to draw up action plans to protect fellow patients by helping medical staff in the war against killer infections.

A survey at The Countess of Chester Hospital last year highlighted the fact that a small, yet significant percentage of staff were observed to treat different patients without washing their hands. On a recent visit, forum members saw this happen on a ward on which there was a confirmed case of MRSA infection.

The Countess, which is now an NHS foundation trust, has an infection control record ranked in the bottom six of hospitals in a recent survey. Now its PPI forum is carrying out a detailed survey during the summer to check on improvements.

As checks on MRSA become almost as contagious as the bug itself, other Patient and Public Involvement Forums are also running bug checks including: -

- East Somerset ; Salisbury Healthcare; Somerset Coast ; Weston Hospital ;
- University Hospital Birmingham, ranked the fourth worst specialist hospital in the country, and the PPI Forum there and at North Birmingham are looking into practices to prevent instances of MRSA and cross-infection.
- Barnet and Chase Farm Hospitals NHS Trust PPI Forum members in London are now actively involved with local MPs in highlighting hygiene issues that need to be addressed through regular inspection, and monitoring progress, in response to patient concerns.

In a cautious welcome towards this activity, Sharon Grant added "MRSA is already high on the workplans of many forums and we all strongly welcome the Government's move to make beating it a priority. We all need to encourage greater awareness of ways that infection can be spread unwittingly on wards – such as the shared use of mobile phones. People do not realise that a patient may be contaminated simply by a visitor passing them a phone to speak to a relative."

More forums will no doubt be considering what action they might want to take following an appeal from Health Secretary Dr John Reid for them to join the fight against the superbug MRSA, resistant to most antibiotics.

INSIDE THIS ISSUE

Sex and the City may be the TV programme that everybody is talking about, but getting people to talk about their experiences of sexual health services is not quite so easy. Caroline Davey offers some tips.

We need to value the opinions of our service users, not just by saying that we'll listen but also by enabling them. Arrianna Walker shares some ideas for getting and keeping people involved.

Barnsley PCT has developed its own toolkit, in an attempt to 'nail down' PPI. Val Cole explains how it emerged and what it does.

Viki Cooke and Graeme Trayner report on their new research which identifies trusted people within communities as The New Persuaders. Here's how to recruit and engage these 'protagonists'.

Many organisations engaged in PPI are set up for people; less common are organisations of people. Fran Branfield introduces the work of Shaping Our Lives: the national user network.

Research and development are very influential in health and social care, but have been dominated by professionals and academics. Helen Hayes introduces the national focus for public involvement in R&D.

Puffing Billy

The man sitting at the bar looked out of place. It seemed somehow odd to see a tattooed, overweight Mancunian, in this idyllic, top of the range Cheshire village pub.

As the weeks went by, he began to blend in. First with the barmaids. They seemed to share a mutual fascination with mixers, beer pumps and staff tip distribution methodologies.

Those of us that had built up a degree of resilience to the guttural screech of Mancunian, either through our upbringing or sheer bravery, began to exchange pleasantries with the stranger.

According to the barmaids he was in the trade. Of course. What else does a pub landlord do on his night off? He goes to the pub of course. The Mancunian mein host was called Billy. He seemed to be a walking advert for all that is unhealthy. Tattoos, beer gut, smoking like a chimney, his friendly but downbeat demeanour didn't have us rushing to find out where his pub was.

After some weeks, Billy ceased to be an object of our curiosity, and simply became 'Tuesday night Billy'. He began to blend into the background.

Now, I have something that I do on my journey to and from work. You might call them habits. For instance, in Wilmslow, it is quite common for ladies to wear golden slippers, even in the rain. As I drive along, each time I see one of these ladies, I have a compulsion to say out loud "goldenshoes". I am sure that there is a name for this condition. And so my journey goes, punctuated by little

comments as I pass the women's prison, the airport and the country park.

Where I grew up, one of our neighbourhood pubs was called The King William. It was always known as The King Billy. Whenever I see a King William pub, I feel obliged, as if to set the record straight, to say "The King Billy". As I pass Wilmslow's King William every day, this is a heavy burden that I have to bear.

Recently, whilst in the process of setting the record straight, I noticed a small sign in the window of The King Billy. Each day I was able to glimpse another word on this sign, and after several days I was able to piece it together. It said "This is a non-smoking area".

Having just returned from a research visit to look at New York's smoke free legislation, I felt a fact finding mission coming on. Surely, smoking was an essential feature of a traditional pub like The King Billy. My hypothesis was that they had made a small alcove into a non-smoking area.

I ordered the first of my fact finding pints of lager and asked to see the landlord. "I'll be out in a minute" he shouted. There was a familiarity about the Mancunian bluntness. And then Billy emerged. Yes, I know it seems unlikely, but Billy really does run a pub called The King Billy.

Having given up smoking, he took the bold decision to ban it from his pub. Not just from an alcove in the corner. There is a total ban on smoking. He says that he and the staff feel better for it, and there has been no adverse effect on the takings.

It's interesting that the CPPIH found that PPI forums have identified the issue of banning smoking in public places as a key priority. It may well feature in legislation very soon.

In the meantime, The Chief Medical Officer has published his Annual Report. In it he recommends that the NHS should lead by example and make its premises smoke free by the end of 2004. Billy will confirm what I found out in New York. Even though we know it makes sense, there will be resistance. The issue of involving patients and the public in managing the change to smoke free status is an important one. If people feel involved, they are more likely to understand and accept change. Moreover, the NHS will need to think about the issue of enforcement. If someone refuses to comply, the NHS cannot just get a hardcase Mancunian to use his powers of persuasion.

In October, The Smoke Free City conference will link Liverpool to New York live by satellite, so that the lessons of implementing Smoke Free policies can be transferred. It's an important event, because all the signs suggest that implementing smoke free policies will be an issue for all of us soon. We must make sure that patients and the public are engaged.

If you do feel a fact finding mission coming on, The King Billy can be found on the northern edge of Wilmslow, but don't tell Billy that I referred to him as overweight. Please!

For details of The Smoke Free City see www.smokefreeliverpool.com

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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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Confidence, Connection and Contribution

At last Patient & Public Involvement (PPI) is coming of age. It is seen as a key component in the White Paper on Public Health. According to Derek Wanless who authored two reports leading up to the White Paper, the level of public engagement will be the key determinant of the nation's health and the quality of services provided.

Yet those working in PPI face a range of challenges. Many are in the process of building confidence, both in the process, and amongst patients and the public; Others are striving to build connection between people, agencies, ideas and services; whilst all of us want to get to grips with how we can make PPI even more effective in making a massive sustained contribution to health.

These are the themes of this year's **PPI Monitor Annual Conference – Confidence, Connection and Contribution.**

This is a not to be missed event for anyone determined to take ever more heightened action to make PPI central to health. It is not just another conference. We are aiming to inspire you, motivate you, provide you with new insights and connect you to a nationwide PPI community.

Importantly, you will be able to network with PPI people from all walks of life, from all over the country. If you are serious about taking massive and sustained action to make PPI central to health – you will use the inspiration from this day for a long time to come.

Put this in your diary now and watch for further details. If you want to take advantage of the **special discount 30%** for **PPI Monitor** subscribers then you can pre-register using the form below.

Yes I am interested in attending the PPI Monitor annual conference in November. Please send me a full conference programme.

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Patient Power in the

Patient Power in the NHS

New book assesses the impact of patient choice by 2010

The New Health Network has published a collection of short essays from eleven health professionals on what health services might look like in 2010. Contributors include Rt Hon Dr John Reid MP, Secretary of State for Health; Dr Michael Dixon GP, Chair of the NHS Alliance and; Professor Carol Black, President of the Royal College of Physicians.

The book is aimed at anyone interested in the future NHS. Taken together, these individual perspectives paint a broad picture of an NHS shaped by citizens' choices and preferences - where patients feel in control of their care and the concept of choice is embedded in NHS culture.

Commenting on the book Dr Tom Coffey GP and chair of The New Health Network said "The centrality of General Practitioners is common throughout these perspectives and their role remains pivotal to the delivery, commissioning and signposting of health services."

Margaret Mythen, Chief Executive of The New Health Network added "These essays confirm that patient choice is about much more than hospital operations and has great potential to improve health and health care, but only if:

- particular attention is paid to supporting those who could benefit most from increased choice – the elderly and people with long term conditions;
- all healthcare staff are fully engaged and;
- appropriate information is collected and made available to patients and staff"

The book, 'Patient Power – the impact of patient choice on the future NHS' edited by Margaret Mythen and Dr Tom Coffey GP is priced £15 and is available from The New Health Network on 0207 7407 1618.

New cash boost for scrutiny projects

Pioneering health scrutiny projects have been awarded £180,000 to share learning among local authority scrutineers and improve well-being in local communities.

Nine local authorities have each been awarded up to £20,000 to carry out innovative action learning projects in the field of health scrutiny.

One authority from each English region has been selected to scrutinise a topic that impacts on the health and well-being of their local community, whilst also testing and evaluating new health scrutiny processes and sharing lessons learned with councils across the country.

The awards are being made by the Centre for Public Scrutiny (CfPS) as part of their three-year Health Scrutiny Support Programme (HSSP), designed to increase capacity as non-executive members get to grips with their new powers to scrutinise health services.

The selected authorities and topics are:

- Bradford Metropolitan Borough Council - Obesity
- Cumbria County Council - Teenage Health
- Coventry City Council - Breastfeeding
- Darlington Borough Council - Breastfeeding
- Cornwall County Council - Patient Pathways for Older People
- London Borough of Bexley - Young Peoples' Health
- Norfolk County Council - Palliative care
- Oxfordshire County Council - Chronic Disease
- Derbyshire County Council - Sexual Health

The projects will commence by December 2004 and run for around 12 months. A second round of awards will be made in Summer 2005 and a final round in Summer 2006.

For further details contact Alex Hardy, Centre for Public Scrutiny, 020 7296 6211 alex.hardy@idea.gov.uk • www.cfps.org.uk

Academics work together for best practice in health improvement

Some of the best brains in the country will work together to strengthen intellectual and academic networks and promote best practice in public health. Nine new collaborating centres have been launched across England and Wales by the Health Development Agency.

Based mainly in the university sector, the centres will each have their own focus on gathering evidence on what works to improve health and reduce health inequalities and building on practice development in areas such as smoking cessation and drug prevention. They will help strengthen public health infrastructure by creating a network of organisations and institutions working together to further develop HDA evidence and promote good practice.

NHS



These centres will enhance and maintain the evidence base in areas such as childhood accidental injury, maternal and child nutrition, the promotion of physical activity, the prevention of obesity and drug misuse. Others will focus on the practical issues of smoking cessation and tobacco control, maternal and child nutrition and community engagement.

The collaborating centres are situated at Oxford University (in collaboration with Loughborough University), University of the West of England (Bristol) (in collaboration with the University of Newcastle and the Childhood Accident Prevention Trust), University of Teesside, University of Wales (College of Medicine), Liverpool John Moores University, Leeds University (in collaboration with the Universities of York and Coventry), Public Management Associates, Lancaster University and Queen Mary, University of London.

Could do better Ombudsman's verdict on NHS

In her latest annual report, Ann Abraham, the Health Service Ombudsman for England, highlights the key concerns raised by the public in the 4,700 complaints made to the Ombudsman's Office last year.

"We demand a lot from our NHS and sometimes it does not deliver. Perhaps this is not surprising but when it happens people rightly expect their concerns to be addressed and the Service to learn from its mistakes," says Ann Abraham. "The themes I highlight in my report demonstrate that there are areas where the NHS could do better."

One ongoing issue concerns NHS funding for the continuing care of older and disabled people. In February last year the Ombudsman published a report highlighting deficiencies in eligibility criteria and assessments which led to severe hardship in some cases. As a result the Government agreed to the Ombudsman's recommendation that strategic health authorities review all relevant cases dating back to 1996.

Other themes addressed by the annual report include difficulties in living up to a patient-centred approach and poor handling of complaints once things have gone wrong. The former is usually characterised by poor communications with patients and between health professionals, and poor co-ordination between services. The latter, meanwhile, is typified by delays in responding to complainants' concerns, poor communication with complainants and inadequate record-keeping. The report makes clear the Ombudsman's disappointment that the introduction of a more accessible, patient-centred, responsive and independent complaints system has been delayed, especially when local practice remains patchy.

The 4,700 new complaints to the Ombudsman between April 2003 and March 2004 represent an increase of 18% over the previous year. Most of the increase reflects a rise in complaints about continuing care assessments but overall there has been a steady increase in the number of complaints coming to the Ombudsman over the last ten years.

**The full report can be found at
www.ombudsman.org.uk**

User Friendly

It's easy to say that we want user involvement, but do we go out of our way to make sure that we get it? Arianna Walker shares some ideas for getting and keeping people involved

Imagine you are four months pregnant, you've got a two-year-old and your five-year-old is at school. You've been invited to go along to a Maternity Services Users' Forum, which you'd love to attend, if only to get out of the house for a while. The trouble is it's across the other side of town, there's no childcare and although you've been told that you can reclaim your bus fare, you're not sure if you can face the 45-minute ride with a screaming toddler. Then you discover that the meeting doesn't finish till 3 pm, which doesn't give you enough time to get back for your older one. Besides, you're worried that you might not have anything worthwhile to say. What if you don't know how to answer a question and look silly in front of all those doctors and midwives? Perhaps it'll be better not to go; they all get paid to be there but what's in it for you?

It's no wonder many of us struggle to get certain types of users involved in what we're trying to achieve. Sure, you can get the 'usual suspects', but to reach those whose voices are not usually heard, we need to put ourselves in their shoes.

One lesson I soon learned from running the Maternity Services User Involvement Project in Bradford are all too happy to get involved, if you make it easy for them. Childcare is a must. Being community-based also helps, which means I find out where the users are and go there. I have held forum meetings in baby clinics, community centres, Sure Start projects, and many other community-based locations.

On the odd occasion that I've needed to recruit users to attend an event at the maternity unit, taxi fares have been paid, lunch provided and gift vouchers given to all attenders as a token of thanks. The Department of Social Security has written that these vouchers do not affect Income Support, Housing Benefit or any other benefit, as they are considered 'gestures of goodwill' with low monetary value (£5-£10).

It's no wonder many of us struggle to get certain types of users involved in what we're trying to achieve. Sure, you can get the 'usual suspects', but to reach those whose voices are not usually heard, we need to put ourselves in their shoes.

As an organisation, we need to value the opinions of our service users, not just by saying that we'll listen but also by enabling them to tell us. User involvement is much easier when professionals look at things from a user perspective. When discussing user attendance at a large event, I asked the doctors and midwives to consider dressing down. They did this, and the users said that, having been worried about what to wear, the lack of suits, ties and uniforms was a relief. They also felt valued and effective on getting feedback on how their opinions would influence service developments. This positive experience should help to ensure that they'd be involved again.

The project has now moved into a new phase. I am forming a group of about 15 women who will become the Maternity Services Users' Forum (MSUF). They will be a resource and reference group for the local PCTs and hospitals in Bradford. Individuals will become members of the Labour Ward Forums, maternity services liaison committees or other maternity-related bodies.

For the MSUF to maximise its effectiveness, we are developing a training programme accredited with the Open College Network. Each user representative is offered this free of charge, along with childcare, taxi fares, resources and gift vouchers. Recruitment has not been a struggle; in fact, a waiting list looks likely!

The greater challenge is convincing the powers-that-be in any organisation to see involvement through a user's eyes. People don't aim to be a representative; most don't even know this option exists. To elicit user involvement, the organisation must be the proactive one, seeking to remove each obstacle. This costs time, money and resources - but if PPI is worth it, then it's worth it!

Our goal should be to facilitate such a level of 'user friendly PPI' that the only reason someone is not involved is that they don't want to be, not because they can't.

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PPI – Where’s the Evidence?

There’s a lot more to PPI that surveys and leaflets. Kay Laurie outlines an approach in Barnet that starts with the evidence.

For healthcare staff of a nervous disposition, there seem to be two ‘default’ options when it comes to patient and public involvement (PPI):

- 1) do a survey
- 2) write a leaflet

For patient representatives, new to PPI and perhaps unsure about how to ‘find out’ views, the ‘let’s do a survey’ option sounds like a pretty safe bet too.

The reality is that for staff and patient representatives alike, PPI can seem like really difficult stuff. Coming from scientific, evidence-based disciplines, many healthcare staff think that anecdotal evidence is not substantial enough. Patient representatives, on the other hand, have got anecdotal stuff coming out of their ears; what they need is – wait for it – evidence!

Now, it is perfectly possible to carry out surveys until the cows come home. You can, however, be sure that when you produce your findings, someone will question them.

The good news for everyone struggling with this dilemma is the National Patients’ Survey. If you haven’t seen the one for your trust, go and track it down. Clinical governance people should know where it is if your PPI lead doesn’t, though I hope they do!

The National Patients’ Survey came out of the NHS Plan and after a quiet start is really getting a much greater profile. It now informs the NHS performance targets (the star ratings) – which certainly helps to concentrate the minds of those with very big agendas to deliver.

In 2002, the hospitals survey looked at in-patients; then in 2003 both outpatients and accident & emergency. In-patients have just been re-surveyed, together with children and young people’s services, and outpatients and A&E are about to be done again. This rolling programme enables improvement or deterioration in patients’ experiences to be tracked over time.

Primary care trusts and mental health trusts

are also in the survey programme. In the pipeline are surveys linked to the national service frameworks (coronary heart disease; older people’s services, etc.) and all this is benchmarked, so you can see how different trusts compare.

At Barnet and Chase Farm Hospitals NHS Trust as our survey contractor we use the Picker Institute, a respected charity that researches patients’ experiences. As the PPI Lead at the Trust, I am able to access the Picker results web site. That is where the diamonds are ... don’t just make do with the executive summary and headlines, get right down into the detail. Find out what patients actually said about their experience of your trust. For not only do they complete a ‘tick-box’ questionnaire, they are also invited to comment on what was good and what could be improved. If anything tells a story, it is those comments: if patient representatives want to get a good feel for what matters to patients, that is where the information is.

Ask any trust what the number one complaint is and they’ll probably say ‘communication and attitude’. Look at the qualitative feedback in comments by your patients and you will see graphically

Now, it is perfectly possible to carry out surveys until the cows come home. You can, however, be sure that when you produce your findings, someone will question them.

illustrated what that means in practice. You can use that evidence to develop ideas, programmes and training that will get to the heart of the problem.

I like the patients’ survey: it provides high-quality information, systematically and consistently gathered, benchmarked against peers. Wherever I go as I work with patients and professional colleagues, the patients’ survey is there, informing our work and helping patients to be heard.

The leaflet solution

When it comes to leaflets, it is another story. As I ranged far and wide across the Trust in my first year, it seemed that everywhere the cry would go up “we must do a leaflet!” Simultaneously, another cry would go up “But who’s going to pay for it?” It is no secret that our Trust has financial pressures, but we are not alone in that.

The patients’ survey told us that patient information, or the lack of it, was a problem. We thought we would produce a hotel-style bedside folder. But infection control were not happy – “single-use items, that’s what we are aiming for”, they declared. So it was back to the drawing board. We could have lots of leaflets, but we couldn’t put them conveniently at the bedside.

With a leap of imagination, we came up with the idea of having an in-patient magazine. Something we hoped would be readable and interesting. Compared to producing umpteen different leaflets it seemed like a cost-effective option.

Different groups (patients and professionals) did a post-it note exercise and a long list of important information was drawn up. With the help of a patient representative who previously worked as a sub-editor, we are now at the design stage and hope to produce our first in-flight patients’ magazine soon.

I’ll let you know how it goes!

Kay Laurie

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Taking responsibility for patient and public involvement

All NHS organisations are striving to make patient and public involvement (PPI) a reality and a meaningful experience for all concerned.

This implies that PPI needs both to be embedded into systems, processes and procedures and to be clearly visible in the roles and responsibilities of individual staff at all levels and reflected in their day-to-day practice and behaviour.

OPM® (the Office for Public Management) has been working for a number of years with those developing policy on PPI, as well as alongside those putting PPI into practice. We were commissioned by the Welsh Assembly Government to provide advice and support for the implementation of Chapter Three of the NHS Plan for Wales (Improving Health in Wales, 2001) and to work with the NHS in Wales to develop its capacity to undertake PPI more systematically and comprehensively.

We produced two good practice guides on PPI – Signposts One and Signposts Two (see www.wales.gov.uk/signposts). Signposts One aimed to clarify the full implications of PPI at the individual and collective levels, as well as offering guidance about undertaking baseline assessment and developing strategies and action plans for PPI.

In reviewing strategies and plans, our analyses revealed that most NHS organisations in Wales had, at that stage, made some progress, but were also still grappling with a number of development challenges. Many trusts and LHBs showed a strong commitment to PPI and understood its significance. They also frequently had clear values and principles to guide their work on PPI, and most were also able to show where they were putting these principles into practice and what they were planning to do extend and develop new structures and fora for PPI. Many trusts and LHBs also recognised the importance of training staff on PPI and the need to engage the voluntary sector and other partner agencies in this future work. However, at the same time, they were struggling with the issue of how to resource the

work more fully and how to acquire and use skills and expertise to undertake PPI more effectively.

A good number of organisations failed to identify clear outcomes for the PPI work they were carrying out, such as verifying that patients were now better informed or pinpointing improvements made in services as a result of patient feedback. Sometimes organisations failed to specify outcomes because they did not have systems to monitor and measure impact. In other cases, it was unclear whether any possible outcomes were consciously planned at the outset of PPI initiatives. For example, patient or public survey work was carried out without a clear appreciation of what the results would be used for. This lack of follow-through on PPI work meant the capacity to report on achievements and tangible outcomes was very much reduced or lost altogether. It is often this report on impact and outcomes that provides the crucial evidence to those being involved (patients and public) as to what was achieved and whether their involvement with the NHS was at all worthwhile. This evidence also often provides the success stories and the good practice examples to convince staff and to provide models for others to follow.

PPI must be integrated into systems and individual responsibilities if it to have real impact, says Paul Lloyd. There are Signposts in Wales that point the way forward.

In light of what we found out from analysing the strategies and annual plans, Signposts Two was developed to support NHS organisations in taking a more strategic approach to their PPI work. Specifically, it aimed to help them to:

- focus more successfully on impact and outcomes for PPI
- work at integrating PPI into other systems and processes
- plan training and development for managers and staff to give them the confidence and competence to undertake PPI effectively
- develop networks and reach out into communities to make their PPI initiatives fully inclusive
- encourage leadership for PPI at different levels amongst managers and practitioners.

We identified examples of how different organisations had approached PPI and provided short case studies and contact details, drawn from England and Wales. We also developed and included in Signposts Two a self-assessment tool to help organisations review current practice and performance and interpret what their future development needs and priorities were.

The challenge is how we get everyone to realise the part they can play in promoting and encouraging PPI and making it a reality in all services and for all staff. This is a long-term challenge that we are just beginning to get to grips with. The first step is understanding the nature of the task ahead in all its fullness and potential complexity, before we can then begin to plan a realistic way forward. The more we can involve and engage others in this undertaking the greater the chance there is for it to succeed.

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The 'S' Word

Sexual health is one area in which feedback is least likely to arrive. But, as Caroline Davey explains, creative approaches to involving patients and the public can produce valuable results.

One of the few areas of health care about which people are unlikely to provide feedback or make a complaint is sexual health. Indeed, conversations with MPs confirm that they rarely – if ever – get letters from disgruntled constituents complaining about how long they had to wait for an abortion or the poor state of the local GUM (genito-urinary medicine) clinic. The wish to remain anonymous is a major issue in sexual health services, whose sensitive nature means that individual service users may not speak up about their experiences or preferences.

The lack of individual patient voices in the area of sexual health proves to be a real barrier to service improvement, particularly where resources are scarce and there is competition for funding and prioritisation. Although organisations such as the fpa (the Family Planning Association) and the Terrence Higgins Trust act as champions and advocates at a national level, there are few local champions for sexual health services. User experience of these services is most likely to derive from one-off or occasional visits to particular services, rather than from sustained treatment or contact. The exception to this is HIV treatment and care, and it is no surprise that user groups have developed in this more than any other area of sexual health.

It is therefore crucially important that there is an active approach to engaging the public and others in commenting on sexual health services, and that this takes place in ways that enable people to provide feedback without sacrificing their wish for anonymity. It may be necessary to utilise means of gathering user feedback which will guarantee confidentiality – for example, anonymous questionnaires which can be completed and returned either within the health care setting or by post. In addition, many users of sexual health services will be making a one-off visit. Feedback mechanisms should take this

The lack of individual patient voices in the area of sexual health proves to be a real barrier to service improvement, particularly where resources are scarce and there is competition for funding and prioritisation.

into account and ask for information and comments relevant to this experience. For example, the fpa national helpline, which provides confidential information and advice about sexual health, operates an anonymous user feedback mechanism. This provides useful information about our helpline service and enables us to respond to user suggestions for improvement.

Beyond direct public involvement, there are other ways of assessing services against established standards and criteria. For example, members of local PPI forums could play a useful role in undertaking 'mystery shopper' activities in sexual health services. There is a useful guidance video describing a case study of such activity undertaken by young people called Undercover: uncovered, available from the Centre for HIV and Sexual Health <<http://www.sexualhealthsheffield.co.uk/>>, which may help in planning activity of this kind. It is, however, important to remember that this sort of activity must be very carefully planned in advance, and it may be necessary to get the agreement of your local trust. The new GMS (general medical services) contract has a detailed section that recognises the importance of user feedback, and the forthcoming MedFASH (Medical Foundation for AIDS and Sexual Health)

standards for sexual health, due in spring 2005, will include a user standard, both of which may provide useful input to planning user involvement.

Where it is difficult to get user feedback on a particular service, there can be other useful sources of information. These include the staff who work 'on the ground' in services, who are likely to be fully aware of shortcomings at the service and of the kinds of experiences that users have – indeed, they may have received feedback or comments from users at first-hand. In addition, local PALS staff and representatives of relevant voluntary organisations or independent providers may have a helpful perspective on these services gained from working directly with users.

More generally, it is important to work to promote a positive atmosphere and culture around sexual health services – for it is inevitable that services that are shabby, deprioritised and hidden away will perpetuate their own reputation as a secretive and shameful area of health care. It is crucial that all who work in and advocate for health recognise and embrace sexual health as an integral part of public health. As the recent consultation paper Choosing Health? noted, "Sexual health is one of the few health areas that affects the majority of the population and is relevant through the greater part of our lives". We must not forget about it.

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fpa (the Family Planning Association) is the UK's leading sexual health charity. For more information go to the web site at <http://www.fpa.org.uk>

Barnsley Tool Kit Nails Down PPI

Barnsley Primary Care Trust has developed a toolkit aimed at helping and encouraging staff to take responsibility for involving patients and the public in their work. Here's how they went about it.

Though the Health and Social Care Act now places a duty on trusts to involve and consult the public, it was recognised that staff needed a starting point and guidance on various ways of going about it.

The idea to produce a toolkit for staff was born and a consultation process began, led by the PCT's Business Planning Coordinator, Val Cole. She says: "We wanted something that all staff could refer to easily when deciding how best to engage members of the public and service users. We wanted to give them advice on ways of recruiting participants, reaching them, supporting them, training them and keeping their interest up over time."

Last year staff from all PCT departments were invited to attend one of two specially organised workshops from which a number of PPI champions emerged, offering their experience, commitment and knowledge, on operational and strategic levels, about the effective involvement of service users in the delivery and shaping of local health services.

From the workshops, a PPI Reference Group was formed, chaired by one of the PCT's non-executive directors, Linda Burgess. She says: "The group quickly identified that staff needed more concrete guidance on how to undertake PPI activities. The profile of patient and public involvement also needed raising within the PCT itself."

The proposed contents of the toolkit were discussed with the various organisations that make up the Barnsley Community Involvement Support group - including Social Services, the Barnsley District General Hospital Trust, Voluntary Action Barnsley, the Barnsley Participation Process, South Yorkshire Strategic Health Authority and the Clients' Alliance.

The toolkit itself was distributed to every department in the PCT. It contains sections

explaining what PPI is and why it is important, how to plan people's involvement, overcoming the barriers to participation and the various methods and approaches.

The toolkit advises on gathering information from people, how to organise exhibitions, meetings and events, how to deal with and involve the media, how to produce leaflets and other promotional materials and how to run meetings.

It has sections on how to target specific groups, how to get feedback and evaluate it and recommends further reading and sources of information. The toolkit includes a flowchart, which is also displayed on staff notice boards, providing a quick reference guide on what to do to involve the public and patients.

Once produced, the toolkit was presented and discussed at various PCT departmental meetings and now locality and public health specialists are introducing it into GP surgeries to encourage discussion about PPI.

Val Cole says: "The whole exercise has provided an excellent opportunity to talk directly with departments themselves about PPI and has encouraged engagement in the PPI agenda in other parts of the PCT. It has challenged some assumptions and also been thought-provoking."

"The process of talking at departmental meetings has also developed relationships and trust between those directly engaged in PPI and those whose main remit is to encourage and facilitate PPI in the PCT. It has also brought champions to the fore, including managers and staff that have a particular interest in PPI, who have contributed innovative suggestions and ideas."



Now that the toolkit – produced in an indexed folder – has been distributed and promoted, work is ongoing to develop standards in PPI and address training issues for both staff and participants in the PPI programme.

Shirley Simpson of the Clients' Alliance, says: "The toolkit is very good. It talks about real involvement and not tokenism – which is what's important to the audiences we're trying to reach and get involved. The toolkit is so good, I'm not giving my copy back to the PCT!"

Several PCTs have now asked for copies of the toolkit. Nisha Sankey of the South Worcestershire PCT wrote: "We had recognised the need to provide staff with a "desk top" tool to help them put training into practice. The Barnsley toolkit provided us with an excellent starting point and meant we didn't have to re-invent the wheel and start from scratch. The toolkit and the flowchart are excellent and are helping us put PPI into practice."

For further information about the Barnsley PCT PPI toolkit, contact Val Cole on 01226 777058 or e-mail val.cole@barnsleypct.nhs.uk

A CUP OF COFFEE WITH...

Chris Dabbs, Fellow of the School for Social Entrepreneurs, and Chair of Passionately Curious Ltd

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

Chris Dabbs is well known to readers of PPI Monitor as the man who writes to Mrs Buggins.

I've known him for many years in many guises. As time has gone on I've picked up little snippets about the life and times of Mr Dabbs. I thought it was time to piece them together over a cup of coffee.

Chris had an idyllic childhood. He says "You couldn't get much further away from the inner city. We lived in a small village in the Cotswolds". His recollections of the village sweet shop where he grew up sound like something out of a Dickens novel "We had a shop filled with big old sweet jars containing the likes of coconut mushrooms. In the winter villagers would come down to the shop on horseback or even skis".

He progressed from sweets to cakes when he moved to Eccles to become the Secretary of Salford Community Health Council, and it was here that his interest in involving people in health took root.

He says "In 1995 we were engaged in three mega-consultations about the future of big specialist services across Greater Manchester".

At the same time local people were becoming more vocal "We had been contacted about the concept of a nurse led primary care practice. The Health Authority was saying that local people would not go for it, but there was no evidence to back up this assumption. We decided to ask local people what they thought. We focused on a particular estate and asked them what they thought their biggest health problems were".

Interestingly, the view on the streets had little to do with the future of specialist services. "Their biggest problems were considered to be stress and breathing. They said that these could be improved by bringing public transport back through the estate and reducing traffic on the dual carriageway".

It was at this moment that Chris became really committed to developing proper patient and public involvement "I can remember the day. I was putting together responses on hi-tech services, whilst locals

He went on to establish the first School for Social Entrepreneurs outside of London, back in Salford, and it is a model that has been replicated now throughout the UK.

He now spends much of his time writing, talking and thinking about PPI and is Chair of Passionately Curious, a social enterprise which is also a PPI Forum Support Organisation. His gift for seeing into the future has led to him being tagged as a 'Futurologist'.

Perhaps his gift is related to his belief that you have to be active rather than passive, a value which he lives in what most of us would consider an extraordinary way. He says "When I moved house in 1996, I wondered if I could survive without television for two weeks". He has not had a television since this time. "It's about use of time; trying to engage with things other than in a passive way that TV encourages".

It's a decision he does not regret. "TV as we know it is going to disappear in 10-15 years time – TV will be on demand. We will have a choice about whether it is passive. It could be a more interactive and controllable medium. It could even

create communities and engage people, becoming a tool of communication rather than a tool of reception. People won't accept just being shown things anymore. TV is following the path of health in some senses".

Chris Dabbs is a paradox. You have to be careful calling someone a paradox in Eccles – it could be misconstrued and end in tears – but he is. He belongs in the past, yet he lives in the future; he has a passive nature, yet is more active than most of us can even consider being; and infuriatingly confesses to being a chocaholic without carrying an ounce of extra weight.

Perhaps we should all dispense with the goggle box.

Chris Dabbs is a paradox. You have to be careful calling someone a paradox in Eccles – it could be misconstrued and end in tears – but he is. He belongs in the past, yet he lives in the future; he has a passive nature, yet is more active than most of us can even consider being; and infuriatingly confesses to being a chocaholic without carrying an ounce of extra weight.

were saying that these small things will change our lives. The two things didn't fit. One was a managerial agenda, one was a real life agenda".

As a result, Salford CHC completely redesigned itself as an organisation. According to Dabbs "One of the key things was doing what we now call PPI, that is, people doing things - not having it done for them - engaging with those that don't get heard". Some people in the CHC movement regarded them as heretics.

Fired up by this shift in emphasis towards the people, Chris took a one year secondment to the School for Social Entrepreneurs. His thesis was 'The future for Public involvement in health & healthcare' looking at Europe, Australasia and outside the health system.

Concordance - involving patients i

Geraldine Mynors talks about a Department of Health funded project to involve patients in decisions about their medication.

Patient and public involvement in health service policy, planning and provision is now mainstream in the NHS - almost fashionable, as Jessie Cunnett wrote in April's PPI Monitor. But what about promoting involvement and partnership at a personal level - giving patients a say about the medicines they receive? The process of supporting patients to become partners in decisions about their treatment is known as concordance (Box 1), and the Medicines Partnership aims to help people get the best out of their medicines by promoting this concept throughout the NHS and trying out ways of putting it into practice.

Why do we need a new word for taking medicines? Drug treatment is the most common medical intervention in the NHS but the traditional model of doctor prescribing is paternalistic and frequently unsuccessful. The level of prescribing is increasing all the time - an average older person now receives over 33 prescription items a year. But at the same time, compliance (the extent to which patients take medicines as prescribed) may be as low as 50% with long-term medication. This makes a mockery of evidence-based medicine and wastes NHS resources (it is estimated that the value of medicines returned to pharmacies every year is £230 million, and the cost of treating ill health which could have been prevented is much more). Somewhere, there is a mismatch between what is being prescribed and what patients choose to take.

Concordance recognises why patients may not take their medicines in the way doctors would like. Their beliefs and understanding of the diagnosis and proposed treatment are very often not the same as those of a health professional. They have their own views and experiences about being ill and, ultimately, it is their decision whether or not to take a medicine. Health professionals need to reach an agreement with them about it, even though it might not be easy to achieve.

If patients are to make the choices that produce the best health outcomes, they need information to help them understand their options and support to enable them to be

Concordance recognises why patients may not take their medicines in the way doctors would like.

partners in their care. In turn, the attitude of health professionals must change so they perceive prescribing as something they do with, not for, patients. The Medicines Partnership is working towards these objectives in several ways (Box 2).

One example of the innovative approaches to concordance that we support is decision tools to help patients make difficult decisions about long-term treatment. Together with the National Hospital for Neurology and Neurosurgery, the MS Trust and the MS Society, we are developing a web-based decision tool to support patients with multiple sclerosis who are thinking about whether to start on disease modifying drugs. The tool will enable them to understand the options for drug and other treatments, hear other patients talking about their experiences of making the decision, and make a choice about management based on their personal values. It provides the support they need to participate actively in deciding whether to start treatment and which form of the drug they would prefer. We expect to launch the decision tool in September this year, and see it as a model for other similar tools in other conditions.

We are also working with Poole Primary Care Trust to test a decision aid for patients with osteoporosis - which if successful will be made available more widely. Reflecting the older population affected by this condition, this tool is a booklet and audiotape rather than web-based, and is introduced to patients at a pharmacist-led group workshop. Patients explore how they feel about different treatments, self-care options and

issues arising from their condition; identify questions that they would like to ask; and consider how they want to be involved in decisions about managing their osteoporosis, before returning for an individual session with a GP. The response in the first patient workshops has been excellent. "There was a strong focus on self-care with lots of discussion about changes to diet and lifestyle that can also reduce the risk of fracturing," Project Manager Caroline Kelham said. "One attendee was delighted to find out just how much calcium there is in a bar of chocolate!"

A frequent complaint from patients and doctors alike is how little time they have in a typical consultation, so it's important that patients are able to identify their expectations and articulate their needs clearly. One project in Devon is helping them do just that. This is a randomised control trial in which patients complete 'agenda' forms while waiting for their appointment. In a pilot study, the forms enabled patients to identify their ideas, concerns and expectations and facilitated communication with the GP. "A patient can often come into a consultation with a very clear idea of what is wrong with them, but they see it as your role as the doctor to find out," one doctor commented. "The agenda form really helps them share their ideas and helps me to work with them on a plan of action which suits their needs. In many cases, that isn't a prescription."

One of the most useful tools in involving patients in decisions about long-term conditions is regular medication review with a doctor, nurse or pharmacist. In order to help patients know what to expect in a medication review and prepare their questions and issues, the Medicines Partnership has developed Focus on your Medicines - a patient's guide to medication review (www.medicines-partnership.org/medication-review/toolkit/patient-guides). The uptake for this guide has been tremendous, with over 350,000 copies ordered so far by PCTs and patient organisations. To support health professionals implement medication review in a way which involves patients in decisions about their care, we have produced Room for Review - a guide to medication review (www.medicines-partnership.org/medication-review/welcome/room-for-review) and we are evaluating a medication review pack for

In decisions about their treatment

nursing and residential homes.

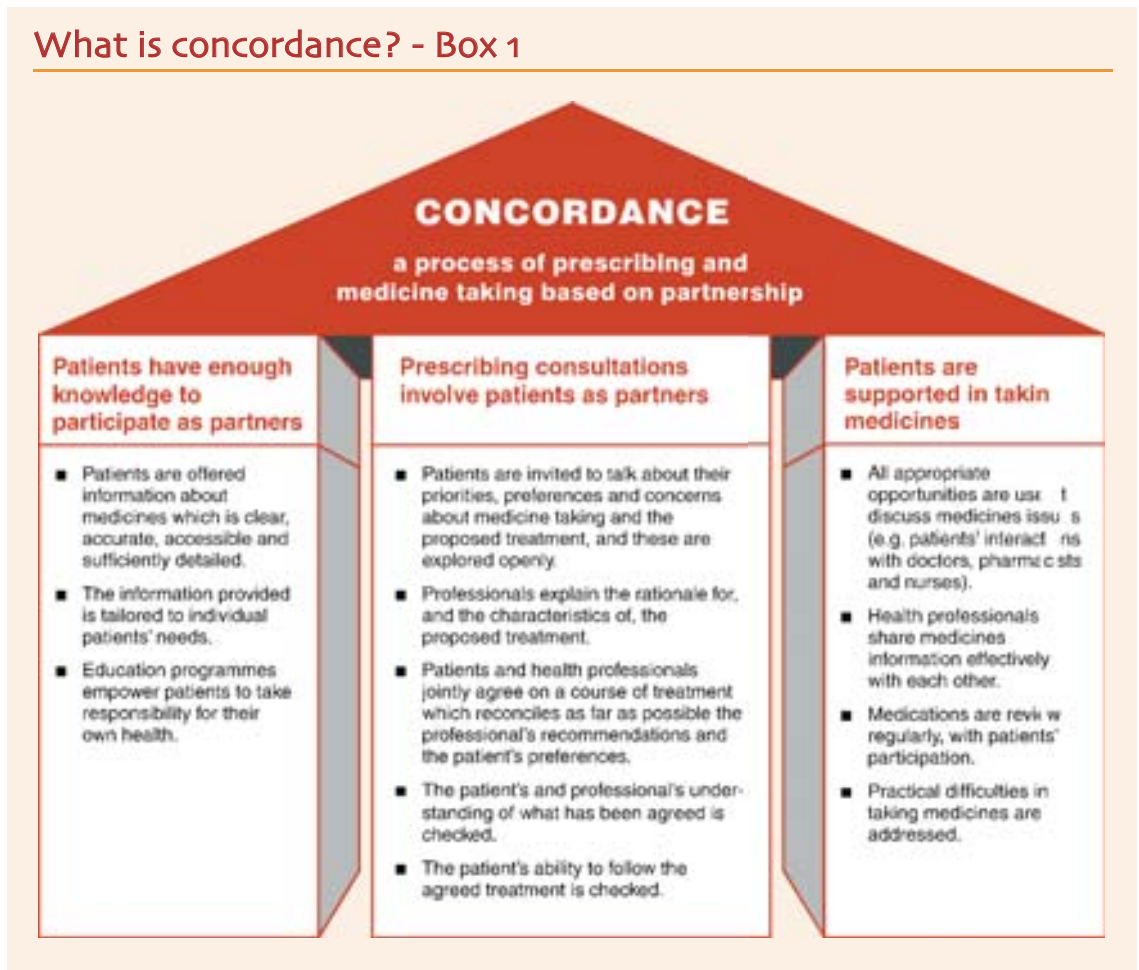
These are just some of the many initiatives the Medicines Partnership is involved in. We are naturally very encouraged by the progress to date but there is a long way to go to change the culture both of prescribers and patients in sharing decisions about medicines. If you would like to know more and perhaps get involved in promoting concordance, visit our website at www.medicines-partnership.org.

The Task Force on Medicines Partnership is a Department of Health funded programme which aims to enable patients to get the most out of medications by involving them as partners in prescribing decisions and supporting them in medicine-taking. The Task Force is a national collaboration involving doctors, pharmacists, nurses, patients, the NHS, the pharmaceutical industry and academics. It is supported by the Medicines Partnership Centre based at the Royal Pharmaceutical Society, under the directorship of Joanne Shaw.

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What is concordance? - Box 1



Strategies of the Medicines Partnership - Box 2

Changing professional behaviour

Building the skills of pharmacists, doctors and nurses to involve patients as partners in treatment decisions and to support them in taking medicines.

Shaping policy

Working with the Department of Health and other NHS organisations to ensure that patient partnership is embedded in key policy initiatives.

Enabling patients to be partners

Ensuring that patients expect to be involved as partners in prescribing decisions and have the information and support to do so.

Services to support concordance

Showing how concordance can be put into practice by identifying and supporting practical concordance projects within the NHS, industry and patient organisations.

Knowledge management

Supporting the programme by drawing together research evidence, translating this into practical knowledge and seeking to encourage further research – especially on how to measure and audit concordance.

Finding your way

Some groups have been virtually ignored within PPI, including people with dementia. Kate Allan outlines how to develop effective approaches to communication and consultation.

We all know that communicating and consulting with service users is, or should be, a core part of delivering services, but sometimes it can be difficult for providers to address these needs. This is especially so when service users have a complex, fluctuating condition which often profoundly affects their ways of communicating – the range of conditions collectively referred to as dementia. Over the last 12 years or so, we have seen radical and hopeful changes in the way the dementia is understood. Nevertheless, the day-to-day challenge of involving and consulting people who have dementia remains very great. A study undertaken at the Dementia Services Development Centre at the University of Stirling¹ explored ways in which practitioners could address these priorities as an integrated part of what they do every day. The main practical outcome is a new kind of learning and development tool which supports communication and consultation in a way that is both service user-centred and practitioner-centred. It is called Finding Your Way: Explorations in Communication.²

One of the lessons from the research was that although practitioners know that communication is important and have a natural interest in the subject, they often find it difficult to know where to start in giving it more specific attention. One of the starting points in using Finding Your Way, therefore, is to select one aspect of communication on which to focus attention for a specific period of time, say a day or a shift. This is called 'focusing'. It could be looking more closely to the way a person moves their body, or observing how they smile or laugh, or noticing what sorts of words they use to express themselves.

The next step is 'reflecting': thinking about what has been noticed at the focusing stage. To structure this activity, there is a small booklet which provides a set of questions assisting the practitioner in making sense of what they saw or heard at the focusing stage. For example, could the person's actions or words have been influenced by their emotion or mood, or their physical health or well-

being? Or might they have been affected by the physical environment, or the presence of other people? Subjects such as background and culture, gender and sexuality, and spirituality and religion are also covered here, but in any one situation only one or two may be immediately relevant.

The reflecting activity has another crucial dimension. Whenever we interact with another person, we bring our own background, feelings and values into the situation, so the above questions are also directed towards the practitioner. For example, the 'background and culture' page asks, "Do you think that what you picked up on here was influenced by anything from your background or where you come from?" This dimension forms part of the practitioner-centred nature of the tool. (Other aspects of this include suggestions for ways of making connections between our own experiences and those of people with dementia, encouragement to seek support and supervision, and giving information and reassurance about the complexities and demands of working closely with persons who have dementia).

The third step is called 'exploring' and enables the practitioner to use what they have learned at the first two steps to improve their communication practice. Here there are a variety of practical suggestions for things to do (such as slowing down when speaking to an individual with dementia, allowing there to be silences), points to bear in mind when working with people generally (for example, that dementia is a variable condition and one 'failure' should not mean abandoning a particular approach).

At each stage of the work with the booklets, the practitioner is provided with links to a source book that provides information, ideas and perspectives in a variety of formats. This includes text, suggestions for activities, discussion points, quotations from persons with dementia, relatives, practitioners, etc. As well as being a back-up resource for work with the booklets, the source book is designed to have an attractive 'dip-in' quality that could provide a starting point for the 'focusing, reflecting, exploring' sequence.

There are three sets of booklets:

- the first sets work with persons with dementia in a wider social context by encouraging practitioners to use the

'focusing, reflecting, exploring' format in relation to communication in everyday life

- the second, 'care practice', helps practitioners to understand more about the kind of communication going on in their usual day to day work
- the third, 'consultation and involvement', uses the same structure to help practitioners to identify, create and utilise opportunities for the person with dementia to express preferences, make decisions and choices, and to have more influence over how support and care is provided.

As well as referring to the source book for more information and ideas, these booklets also link to a set of leaflets providing suggestions for a wide range of activities.

A further aspect of the practitioner-centredness of the tool is the recognition that each worker will have different starting points for thinking about communication, and will follow individual pathways through the material according to their needs and interests, and those of the people with whom they are working. There is, however, strong encouragement throughout for practitioners to take advantage of opportunities to talk to colleagues about their experiences and ideas.

Communicating with people is something we all need to do to remain healthy and creative, and genuine communication with persons with dementia has the potential to transform the experience of working in this field, and to reveal the many fascinations and rewards of working with people who are living with the condition.

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References

1. Allan K (2001) Communication and Consultation: Exploring ways for staff to involve people with dementia in developing services, Bristol: The Policy Press
2. Allan K (2002) Finding Your Way: Explorations in Communication, Stirling: Dementia Services Development Centre

Both publications are available from the Dementia Services Development Centre at the University of Stirling on 01786 467740 – <http://www.dementia.stir.ac.uk>

Participants not subjects - promoting public involvement in research

Research and development are very influential in health and social care, but have been dominated by professionals and academics. Helen Hayes introduces the national focus for public involvement in R&D.

INVOLVE is an advisory group on public involvement in research and development (R&D) in the Department of Health. We met for the first time in 1996, as Consumers in NHS Research. For the next five years, we offered advice to the Director of R&D for the NHS on involving members of the public in NHS research. In 2001, we began to cover R&D commissioned in other areas of the Department of Health through its Policy Research Programme. This includes R&D in the areas of public health and social care. To reflect this wider remit, we changed our name to INVOLVE in 2003.

The group meets four times a year. It has about 20 members: a broad mix of people including users of health and social care services, carers, representatives of voluntary organisations, health and social service managers, and researchers. We believe that involving members of the public leads to research that is:

- more relevant to people's needs and concerns
- more reliable
- more likely to be used

If research reflects the needs and views of the public, it is more likely to produce results that can be used to improve health and social care services.

What do we mean by 'the public'?

When talking about 'the public' INVOLVE means people who are:

- patients and potential patients
- informal (unpaid) carers
- people who use health and social services as well as:

- members of the public who may be targeted by health promotion programmes
- organisations that represent the interests of people who use health and social care services

- groups asking for research because they believe they have been exposed to potentially harmful substances or products such as asbestos and pesticides

What do we mean by 'involvement'?

By public involvement in research INVOLVE means active involvement, where the people involved are not the 'subjects' of research but are active participants, such as members of a research steering committee.

Active involvement is where research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

What are our aims?

INVOLVE aims to ensure that public involvement improves the way that:

- decisions are made about what should be a priority for research
- research is commissioned (chosen and funded)
- research is carried out
- research findings are communicated

What are our objectives?

- to develop key alliances and partnerships which can promote greater public involvement in research
- to support members of the public to play an active role in research
- to monitor and assess the effects of public involvement in NHS, public health and social care research.

The INVOLVE Support Unit

INVOLVE has a Support Unit to carry out its work. Based in Eastleigh in Hampshire, the Support Unit:

- builds links with and provides information advice and support to members of the public, researchers and those working within the NHS research programmes and the Policy Research Programme
- gives practical support to the INVOLVE group
- produces publications on the involvement of the public in research
- gives talks and workshops and organises conferences on public involvement in research
- runs a web site <http://www.invo.org.uk/>

- maintains a public database of research projects which involve or have involved people who use services

INVOLVE publications

We have produced a wide range of publications all of which are available for downloading from our web site <http://www.invo.org.uk/> These include:

- Involving the Public in NHS, Public Health and Social Care Research: briefing notes for researchers
- Getting Involved in Research. A guide for consumers
- A Guide to Paying Members of the Public Actively Involved in Research

Training for public involvement

Users of health and social care services bring unique and invaluable experience, knowledge and perspectives to research. Sometimes, however, people need to gain new and specific skills and knowledge to be actively involved in research, and so research training for service users is a key principle of successful involvement. INVOLVE commissioned the TRUE project to explore the provision of such training. Carried out by a collaborative service user / university / NHS team, the summary and full reports¹ of the project are available from our web site <http://www.invo.org.uk/>

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Reference:

1. Lockey R, Sitzia J, Gillingham T, Millyard J, Miller C, Ahmed S, Beales A, Bennett C, Parfoot S, Sigris G, and Sigris J (2004) Training for service user involvement in health and social care research: a study of training provision and participants' experiences (The True Project), Worthing and Southlands Hospitals NHS Trust.

The new persuaders

As trust in institutions declines, PPI practitioners should engage the 'protagonists' within people's community and social networks – or risk being caught unawares, according to Viki Cooke and Graeme Trayner.

The situation can often seem bleak for those trying to connect institutions with the people they are there to serve. It's been a widely repeated mantra that there has been a decline in trust towards organisations in all spheres, whether in politics and the public sector, business or religion. Indeed, people exhibit a default scepticism towards institutional motives and explanations, as seen most notably in health with the panic over the MMR vaccine.

Our premise at Opinion Leader Research is that the situation is not as bleak as it may seem. Our research has shown that rather than not trusting anyone at all, people just trust differently. Instead of trusting leaders and institutions, people are turning to those they know in their peer groups and social networks for advice and counsel.

We believe this presents the public involvement movement with major opportunities. By connecting with 'trusted people' in peer groups, organisations can discover more shared ground and create stronger solutions.

Grassroots change

Our research on trust has revealed that within every social network and community there are trusted people others turn to for advice. We call these people 'protagonists'. The power of a protagonist lies in their natural ability to persuade others in their peer group or network of their views. In contrast to the perceived 'spin' of much institutional communication, protagonists are trusted by their peers due to their authenticity and lack of 'agenda'.

Being a protagonist is very much a psychological 'state of mind', rather than a specific demographic or socio-economic type. It is not about gender or age, occupation or level of education. They are everywhere – you find them in the office, down the pub, in the playground, and on the building site. We estimate that 1 in 15 people in the UK are protagonists.

The quality of thinking is increased when the 'amateur' strategists work together with the 'actual' decision-makers.

In relative contrast to their specific peers, protagonists are more articulate, charismatic, and engaged. They tend to be involved in a range of different pursuits and activities, and act as 'connectors' between different social networks. They communicate stances, positions and recommendations through those networks with passion and vigour.

Change is increasingly coming from 'below' due to the power of protagonists. In politics, the fuel crisis of 2000, the Countryside Alliance, and pensioners' protests over council tax are all movements that were originally started by a handful of protagonists. In all three cases, conventional leaders and the mainstream media were caught unawares. The emergence of the empowered patient – armed with information off the web, and more than willing to argue with doctors – reflects a society where influence and power is now diffuse.

The new persuaders

Opinion Leader Research has developed thinking on how to recruit and engage with protagonists. We use a three-stage approach to locate protagonists in an area. Firstly, we ask people a series of questions on behaviour and attitudes. In particular, we explore levels of social interaction and involvement in informal and formal networks. Secondly, we use peer-referral methods to determine who the most influential people are in an area, and back-check individuals who are referred to by numerous others. Lastly, we audition all potential protagonists in a workshop setting, to ensure they meet our criteria.

We have conducted a range of consultations with protagonists, involving both traditional approaches such as group discussions as well as more innovative techniques such as ethnography and creative brainstorming. Our experience of engaging with protagonists for major British companies and organisations illustrates how those in public involvement can also benefit from connecting with this important group.

Consulting with protagonists allows organisations to connect with those shaping opinion 'out there'. Though the shift towards public involvement has been a boon to those working in health, too often consultation can fail into the "public meeting syndrome". Participants may be vocal and opinionated, but are they the people who are really influential in their communities? Are you listening to the right people? Are you responding effectively to what they say?

Building change

Listening to protagonists can help organisations work out how to change opinions. Too much consultation represents a nice "talking shop" for those involved, which have little impact beyond the strict confines of the consultation. As the people who shape and mould the opinions of others in their peer groups, protagonists can help



organisations break out of those limitations.

The power of protagonists is that they can turn an idea or thought into a commonly accepted stance. As engaged and articulate individuals, they have the ability to enthuse and persuade. As a result, through connecting to protagonists, organisations can understand how to appear more relevant, in touch and in tune. If you can win the protagonists over, then you can win the mainstream over.

Predicting change

Protagonists can also act as an 'early-warning system' for organisations. Our experience is that protagonists are 'ahead of the curve' in terms of mainstream and media opinion. Our ongoing research has shown protagonists taking positions on issues and topics before they were adopted by others, such as frustration over Tony Blair's leadership, anxieties over personal debt and growing boredom with reality and makeover TV. Ongoing engagement with protagonists in an area can allow organisations to identify challenges early on, before they become issues. With health concerns such as childhood obesity flaring up regularly, how powerful can proper issue-detection be for organisations?

Creating change

Above all, authorities and organisations should tap into protagonists' natural creativity. As engaged, articulate and charismatic individuals, they thrive on

acting as 'amateur' strategists on behalf of an organisation. They enjoy coming up with answers to questions an organisation may face, and ideas on how to address issues in the future. Working with companies and organisations, we have asked protagonists to develop new strategies, new services and new communication plans.

The quality of thinking is increased when the 'amateur' strategists work together with the 'actual' decision-makers. Opinion Leader Research recently convened workshops for the Office of Public Service Reform and the Department of Health, where patients worked with healthcare workers and policymakers to identify priorities on

aspects of health policy. The workshops allowed people to find shared ground with policymakers, and moved away from the usual griping about the NHS. Critically, the protagonists within the workshops emerged early on, taking the lead, shaping the thinking of others, and entering into vigorous debate with policymakers and healthcare professionals.

Connecting with the influencers

Organisations have long known that opinions and views were being shaped 'out there', but there was an inevitable sense of mystery about how opinion change actually worked. Our thinking on protagonists now gives organisations the opportunity to connect with those starting trends, shaping opinions, and bringing about change. Protagonists are out there talking about your issues – shouldn't you be joining the conversation?

Viki Cooke is Joint Chief Executive and Graeme Trayner is a Director at Opinion Leader Research.

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Change is increasingly coming from 'below' due to the power of protagonists.

The New Persuaders report is available at <http://www.opinionleader.co.uk/download/newpersuadersreport1.pdf>

Shaping our lives

Many organisations engaged in PPI are set up for people; less common are organisations of people. Fran Branfield introduces the work of Shaping Our Lives: the national user network.

Shaping Our Lives is a national user-controlled organisation: our management group and board of directors are all service users and/or disabled people. We aim to increase the say and involvement health and social care service users have over their lives and in the services they use.

Shaping Our Lives supports the development of local user involvement that improves the lives and support service users have:

- to gain a stronger voice for user-controlled organisations
- to enable groups to link to other user-controlled groups
- to work across all service user groups in an equal and accessible manner
- to work for race equality
- to facilitate service user involvement at national level to make change
- to develop links worldwide with international user-controlled organisations.

Variety

Shaping Our Lives covers a variety of work. We have carried out projects that put service users' ideas and views alongside other people's to improve policy and practice about: user involvement; quality of services and support; and mental health services.

We have held national conferences to bring together not only service users, but also service providers, researchers, educationalists and practitioners with service users. We have also organised national workshops run by service users, for example, to improve training and education in social work and social care, to see how service users want to be involved in health services, and to explore how they can have more say in research.

Barriers

The Minister for Community Care, Stephen Ladyman, recently asked us to find out about the problems service users have getting

involved and receiving benefits. The resulting report: *Contributing On Equal Terms: getting involved and the benefits system*, is currently being discussed by the Department of Health and the Department of Work and Pensions. We will soon be publishing this and it will be available on our web site - <http://www.shapingourlives.org.uk/>.

We are also working with the Disability Rights Commission, asking disabled people about the things in society which stop them being included.

User-controlled organisations and knowledge

As part of a project funded by the Joseph Rowntree Foundation, we aim to explore with other service users their views, ideas, experience and proposals for developing and supporting local user-controlled organisations. We are asking disabled people and service users to tell us a bit about what they think are key issues for user-controlled organisations trying to operate most effectively and keep in contact with other service users at local level.

To follow this, we would also like to ask service users and disabled people some questions about the development of service user knowledge. By this we mean the knowledge that we as service users and disabled people have and can develop. Our knowledge, which is based on our direct personal experience, is different to that of professionals, which is based on their professional training.

An organisation called INVOLVE has asked us, along with FOLK.US, to do some work about user-controlled research – what it is and how is it done. We are currently running a series of focus groups with service user researchers and service users who have a particular interest in this area so that we can ensure that the report reflects as wide and diverse group of service users as possible.

Access

Access has become a crucial and defining issue for us in Shaping Our Lives. When we got Department of Health funding, we made a determined commitment to develop a comprehensive access policy in all that we do. We believe that this is something that

all organisations must do if they are to work effectively, inclusively and equally with service users.

Often access is interpreted in very narrow terms, particularly physically enabling wheelchair access and access for people with physical and sensory impairments. This is important and still too often not ensured.

We have come to learn and realise that:

- one group, such as people with physical impairments, may not know about the access needs of another, such as mental health service users / survivors, or that these may be potentially conflicting
- access is not only an issue about the environment and physical space, but crucially also about communication, culture and how things are done, so that everyone can understand and contribute as much as possible
- this will mean the need for changes in how we work and how we do things: enabling adequate and appropriate opportunities for preparation; providing information; and making decisions
- this will probably mean taking more time
- making things more accessible for any individual improves things for everyone
- at the heart of an effective access policy is a commitment to equality and respect, to seeking to value each person, their rights and needs, to ensure they can make their maximum contribution and most effectively get across what they want and for that to be addressed as far as possible.

Such an approach to access must be an essential part of the working of any organisation that truly wants to involve service users on equal terms: to develop a user-centred approach to their work. It takes time. It takes commitment. It takes money. It doesn't generally earn brownie points from the powers-that-be. For all that, it's crucial for us as service users.

Fran Branfield
Manager

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Last Word from Chris Dabbs



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

Dear Mrs. Buggins,

I hope that you had a good holiday; time and space can foster new thoughts. The problem is that many, if not most, people cannot see the relevance of new things.

When the telephone appeared, received thinking was that each town might need one; after all, that was good enough for the telegraph. Later, people wondered about the purpose of television. Early on, the founder of IBM could not see why the world would need more than a few computers, and even in the 1970s some IT pioneers did not foresee personal computers in most homes.

How we might laugh at these views now; 20-20 hindsight never makes mistakes. Yet, we adopted VHS as the standard for video, even though Betamax was superior. We buy huge volumes of bottled water at inflated prices, although tap water is at least as good and vastly cheaper. Perhaps we maintain a tradition of believing we are cleverer than we are.

What can be learned from all this? First, innovations must be put into the right context. The fax machine was invented in the mid-nineteenth century, but faxes did not take off until the 1980s. Second, what we believe is what makes the difference – much more so than facts: stories and images sell. Third, despite how ‘individual’ we like to feel, most of what we believe and do follows social patterns. It is an odd, confident person who goes against the tide.

Few people are genuine visionaries, focusing on what is to come years, decades or even centuries hence. They are often perceived as unusual or marginal. It is good that there are

not many of them; otherwise few practical things would get done!

A key to acceptance is not to persuade everyone – some people will resist for as long as possible – but to win over enough by making it feel relevant (and worth the cost). The oft-quoted mark is adoption by 40% of the audience.

In this respect, social and organisational change are no different. Building on ebbs and flows from the 1950s onwards, patient and public involvement as we now know it started with a few visionaries and ‘early adopters’ in the early 1990s, spotting emerging trends and then seeking to influence them according to a set of values. Within some trusts, some people caught on in the late 1990s and introduced the concept of PPI. In others, the point of acceptance has yet to occur.

Those who believe in PPI have to relate it to the real-life priorities of others who can enable or inhibit it. They have to use the right stories and images to reach hearts at least as much as minds. Only when enough people feel it is the right thing to do and see it as being in their own interests will PPI become part of everyday life.

We should aim to make PPI as indispensable as the telephone, even if most people in health still see it as marginal to them. Here’s to reaching the 40%!

keep well

Chris

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

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