

PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

Westminster Fly-in



Marie Watton describes how patient advocates are influencing services and campaigns for people with breast cancer. See page 5.

INSIDE THIS ISSUE

Westminster Fly-in – Marie Watton on how patient advocates are influencing services and campaigns for people with breast cancer

Is PI just PC? – Anna-Maria Saeb-Parsy asks if patient information is just the next stage in political correctness or a cultural revolution

The 'F' Word – How do ordinary people find out what a healthy diet is? And how up to date can their information be? Martin Ince has been finding out

The 1% Solution – Paul Skidmore looks forward to the forthcoming Demos report on public participation

Social Entrepreneurs – who are these people and how can they help to engage people in primary care? Jane South assesses the opportunity

And much, much more.....

Falls Together

In the late 1970s and early 80s there was a band who were quite successful, whilst never quite making it as household names. Still, you may have heard of them. They were called Steely Dan.

No? Think of Haitian Divorce and....well OK, just think of Haitian Divorce. I really should be able to quote you a long list of their hits. For several years, I played their Greatest Hits tape in my car. But you know how it is when you have a tape in your car, you know all the songs, but you never take the tape out to find out what they are titled.

So there is this song by Steely Dan – the one that goes “do de dedah da da da dah”. Honestly, you would know it if you heard it. Well I always liked a particular line in that song. It said “Everything that breaks apart falls together again”.

It created in my mind the idea that things in life will break apart, not quite click, or even collapse around you, yet some invisible force – nature perhaps – would spin these problems around the universe, and in time, perhaps even a long time, everything would somehow fall together again.

Maybe I’m just an old romantic, but in my life I’ve noticed how things break apart only to fall together again in a slightly different form. Giving a greater insight, providing a sprinkling of

that magic dust which when you combine a lot of it together brings wisdom.

When I was a boy, I had my photograph taken with a legend – George Best. I went one way, George went another and an unknown amateur photographer went the other, taking the photograph with him. Everything broke apart. For thirty seven years I have searched for this photo. Ploughing through old magazines and newspapers, always believing that one day it was my destiny to find it.

On the day that George Best was laid to rest, everything that broke apart fell together again, after thirty seven years. In the centrespread of the Manchester Evening News there it was. This picture. This picture of a boy and a hero and the story of the unknown photographer. Shortly after the photo was taken, The Hero, for a brief moment in time stood at the top of the world; the unknown photographer went on to become a renowned portrait photographer exhibiting in the National Portrait Gallery; and the boy began to believe that even those from the humblest of backgrounds could achieve great things.

And then everything that broke apart eventually fell together again. Leaving as these things do a little bit of that magic dust – a small contribution towards our pool of wisdom. What is it, and how can it help PPI?

It is that small things can make a big difference, and that all of us have just a brief moment when we are at the height of our powers, when we can have greatest impact – even legends die. As we enter into a New Year for PPI, let’s try to remember this. The grand strategies can be very grand, but often for people and patients it is the small human things that make such a big difference. And as we return from a break, which may have left us more exhausted than before we went, let’s shake off that lethargy. We working in PPI are on centre stage. We have a chance to change the world in a small way, which can mean a lot to people. It will not always be like this. Let’s make the most of it.

To start the year PPI Monitor is looking at a whole range of small things that make a big difference, and looking at what can be done when everything breaks apart. This is the reality for one in three of people, who will develop cancer during their lifetime. In this issue, Jane Bradburn talks about how CancerVOICES, a UK-wide network of users, patients and carers sets out to make a difference to people’s experience of care.

Perhaps everything that breaks apart does fall together again in some way. But there’s no harm in helping it on its way.

This is a New Year. We are all on centre stage. Let’s make some good things happen.

EDITORIAL ADVISORY BOARD

Chris Dabbs

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

Nick Bosanquet

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

Zenna Atkins

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

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

Malcolm Stamp CBE, DCL, FRSA, MIHM, MMS

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

David Gilbert

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

Publisher/Editor

Malcolm McClean
Six Kingsbury House, St Hilary’s
Park, Alderley Edge, Cheshire
SK9 7DA
m.mcclean@bearhunt.org.uk
Tel: 01625 584448

Editor

Chris Dabbs - Features Editor
c.dabbs@bearhunt.org.uk

Publication Coordinator

Shirley Naden-Lamb
Tel: 01625 584448

Production and Design

Spirit Design
www.spirit-design.co.uk
pattrhodes@spirit-design.co.uk
Tel: 0161 430 7771

ISSN 1742-0407

a bearhunt publication



bearhunt

News items

New pilot programmes to help people who lack capacity

Health minister Rosie Winterton has announced the seven organisations that have been chosen to pilot the new Independent Mental Capacity Advocacy (IMCA) role. From January 2006, pilot IMCA advocates will provide a service to people without capacity, who have no families or friends to support them.

An IMCA is someone appointed to support and represent a person who lacks capacity, possibly because of dementia, a brain injury, a learning disability or mental health needs, who is also faced with certain decisions about serious medical treatment and long term care moves.

For example, a person with a severe brain injury who has no friends or family and who cannot communicate through language will have an IMCA to make representations about their wishes, feelings, beliefs and values.

The IMCA will bring to the attention of the decision-makers all factors that are relevant to their decision. IMCAs will also be able to challenge the decision-maker if appropriate.

The regional pilots are trying out the practicalities of the service to identify the best way of introducing these at a national level.

The organisations piloting the IMCA service

are: Advocacy Matters, Advocacy Partners, Cambridge House Advocacy, Dorset Advocacy, POhWER, Speaking Up and Skills for People. They are spread across the country: Cambridgeshire, Cheshire, Croydon, Dorset, Hertfordshire, Merseyside, Newcastle and Southwark. The Department of Health will produce guidance for the national implementation of the IMCA service based on the experience of the pilots. Cambridge University will be undertaking a cross-site research project aimed at learning lessons from the seven sites and producing practical guidance.

Now I feel tall: What a patient-led NHS feels like

This guidance provides examples of good practice showing how the NHS is improving the patient's emotional experience. It also outlines the policy context and explains why improving the emotional experience of patients matters. This document is for chief

executives, directors and all staff who deliver the National Health Service. It aims to make the NHS more aware of the importance of improving patients' emotional experience and the relevance of this to creating a patient-led NHS.

The full document can be found at:

www.dh.gov.uk/assetRoot/04/12/44/76/04124476.pdf

Majority of women happy with birth experience, survey finds

Around 80% of women are pleased with the care they get when they have a baby, according to a Department of Health maternity services survey.

Other key findings show that women highly rate the professionalism of staff and that post natal services are widely accessed and appreciated.

The survey also asked new dads about their experiences. Their high levels of satisfaction with the service are directly linked to how much encouragement they receive from staff.

Respondents consistently said they would like more flexibility in maternity services - almost 50% of new mums think they are not given enough choice about where and

when to have ante natal classes. There was a consistent desire for more information, with the midwife being the key information source for both women and men.

The survey itself is at www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation

News items

Empowerment in Service Delivery

Involve has partnered with IPPR and MORI on a new and innovative project for the ODPM. It aims to explore what empowerment means, find practical working examples and best practice of empowerment

on service delivery in the UK and overseas, as well as developing thinking around this issue. The project's second phase will be to try some of these methods in practice, with the aim of effecting practical change at the local level.

This project is moving fast, so anyone interested and who would like to get involved should contact Involve - 020 7632 0120 or info@involving.org

People in research

'People in Research'

Wednesday 6th and
Thursday 7th September 2006
De Havilland Campus
University of Hertfordshire

INVOLVE's national conference is an event for everyone who is interested in supporting and promoting public involvement in NHS, public health and social care research and development.

The Call for Participation is now available on the Conference 2006 page of the website www.invo.org.uk.

It outlines how you can take part in the conference through:

- posters
- poster talks
- papers
- workshops

There is a box to tick, on the form, if you

would like to send a proposal and need some help in putting it together.

The closing date for submitting proposals is 20th February 2006.

Conference booking forms available 1st May 2006.

If you would like a copy of the Call for Participation in large print or in another format please contact Professional Briefings on 01920 487672

From paper to practice

Public participation is a dynamic discipline, with new techniques continually being developed and challenges emerging. Consequently Involve's learning programme aims to capture new developments and translate them into practical options for people doing participation on the ground. The events build directly on the publication

'People & Participation' bringing the methods alive and exploring the tensions that you have to manage.

Cardiff – Tuesday, 7 March, 2006
Manchester – Thursday, 23 March, 2006
Edinburgh – Tuesday, 28 March, 2006
London – Thursday, 30 March, 2006

Up to £295, with bursaries available. We are trying to reduce this cost so contact Involve for up to date information

If you want to find out more or book contact Involve Learning on 020 7632 0120 or learning@involving.org

Westminster Fly-in

Marie Watton describes how patient advocates are influencing services and campaigns for people with breast cancer.

Breakthrough's Campaigns & Advocacy Network (Breakthrough CAN) was formed in 2003 following Breakthrough Breast Cancer's merger with the UK Breast Cancer Coalition (UKBCC) – a charity founded in 1995 by women with a personal experience of breast cancer. Today, Breakthrough CAN is a community of over 500 individuals and 91 national and regional groups and organisations that play a crucial role in helping the charity campaign to improve breast cancer services, treatments and research across the United Kingdom.

Many Breakthrough CAN members have been personally affected by breast cancer and are able to use their unique perspective on what needs to be done to help improve services. With Jane Stephenson and Sarah Illingworth as Breakthrough CAN members and on Breakthrough's Board of Trustees, the influence of the charity's patient advocates goes to the core of its work.

By supporting and training members to become informed patient advocates in their own right, Breakthrough CAN aims to increase the influence of patients on breast cancer treatments and services in the UK as well as ensure their views feed into Breakthrough's national campaigns.

Ensuring Breakthrough CAN members have the tools they need to develop their campaigns is key, so Breakthrough provides general information and updates, information tailored to individual needs, one-to-one advice, events, training and development, and administrative support. Our quarterly member's newsletter, *The Advocate*, keeps campaigners up to date on current campaigns such as reducing radiotherapy waiting times and improving services for women with a family history of breast cancer, as well as keeping members informed of other members' campaigns, and upcoming events and forums that they can participate in.

During the year, there are a variety of opportunities for Breakthrough CAN members to come together and develop their campaigning and advocacy skills. One key event in Breakthrough CAN's campaigning calendar is the Westminster Fly-In,

Many Breakthrough CAN members have been personally affected by breast cancer and are able to use their unique perspective on what needs to be done to help improve services.

Breakthrough's annual lobby of Parliament.

Taking place in October during Breast Cancer Awareness Month, the event brings together around 80 women and men of Breakthrough CAN, both those new to advocacy and campaigning and more experienced members, who take part in a series of special workshops to develop their campaigning and lobbying skills, explore breast cancer issues and meet their local MP to discuss working together to tackle the breast cancer issues most important to them. By giving MPs plenty of notice of the event they can research the issues and have a proper discussion with their constituents.

During the event, delegates are also presented with information on two of Breakthrough's key national campaigns, which gives them the option to adopt these and build them into their own local campaign strategies if they feel they are relevant. This year, reducing waiting times for diagnosis and ensuring access to new cancer drug Herceptin for women with early breast cancer, were outlined as the key Breakthrough campaigns. The Secretary of State for Health, Patricia Hewitt, also gave

Breakthrough CAN members a huge boost at this year's event when she addressed delegates on the importance of their campaigning work.

Eileen Robertson recently joined Breakthrough CAN and attended this year's Westminster Fly-In for the first time. She met with her MP, Gillian Merron, and talked to her about access to Herceptin for women with early breast cancer. She says: "I joined Breakthrough CAN as I thought it was a great way to get my voice heard and bring about change. My MP meeting was fascinating and we achieved so much. Gillian agreed to write to our local primary care trust to bring up the issue of Herceptin and help with any press activity. Since then I've been interviewed by all of my local press, my MP has been in touch with our PCT and has kept me updated on what's happening in Parliament on Herceptin. The realisation that I can actually make a difference has really hit home since my meeting."

Alice Twitchin, Head of Breakthrough's Campaigns & Advocacy Network says: "The Westminster Fly-In provides Breakthrough CAN members with a chance to gain the confidence and skills to campaign successfully. It enables members to hear and learn from other people's experiences and campaign successes. These inspirational people are exactly who decision-makers need to hear from, as they have first hand experience of breast cancer services and can really keep policy-makers informed about the reality of breast cancer services in the UK today."

Marie Watton

Senior Media Relations Officer
Breakthrough Breast Cancer
Tel.: 020 7025 2460
Email: mariew@breakthrough.org.uk

Breakthrough CAN is free to join and welcomes anyone who's been affected by breast cancer and is interested in campaigning to improve breast cancer services, treatment and research. To find out more visit www.breakthrough.org.uk or call 020 7025 2491.

Patient Information - power to

Patient information: the next stage of political correctness or a cultural revolution in the NHS?
Anna-Maria Saeb-Parsy finds out.

'Patient Information', first mooted as a component of patient involvement in the NHS Plan¹, has been followed by a number of initiatives and calls for better patient information, from the Kennedy report² to the Consumer Association's report on the state of patient information³.

However, the new Clinical Risk Standards from the Clinical Negligence Scheme for Trusts⁴ place more emphasis on patient information and the informed patient, particularly information regarding procedures and treatments. The new Healthcare Commission's Annual Healthcare Check also places importance on the provision of information for patients by devoting a core standard to patient information⁵.

There is also international pressure to improve the quality and provision of patient information. A working group, set up by the World Health Organisation, has developed standards for health promotion in hospitals⁶. One standard looks at patient information with the objective of ensuring that patients are informed and empowered so that they are actively involved in their healthcare.

Trusts now have to take the development and provision of patient information seriously. With the advent of Choose and Book⁷, the provision of patient information may influence patients' choice of healthcare provider. Patient information cannot therefore be simply seen as the latest step in political correctness.

At Addenbrooke's Hospital, part of Cambridge University Hospitals NHS Foundation Trust, we develop procedure specific consent forms (Figure 1); these incorporate all the information about the procedure such as the risks, benefits and alternatives.

I was talking to a former patient a couple of weeks ago. She decided not to go ahead with a minor procedure after reading the related information because she did not realise how long the recovery time was. She then said "if I had been offered the operation 10 to 20 years ago, I wouldn't have had the choice, I just would have had the operation; things have changed now."

Figure 1. Example of a procedure specific consent form.

Establishing a new process for patient information:

I started as the Patient Information Development Manager, a completely new post, for Addenbrooke's in April 2005. Previously guidelines had been put in place to assist healthcare professionals in developing information for patients, but the development of patient information had never been centrally coordinated and supported.

Priorities identified for the role were to develop a policy establishing the process for developing patient information, and to establish style guidelines for information leaflets, in collaboration with our communications department.

The policy for developing

Figure 2: Addenbrooke's Patient Information Policy

the people...

patient information had to set out a robust and systematic process for developing information for patients (Figure 2).

The style guidelines had to set out a particular style for patient information leaflets that authors could follow. For example, the guidelines should set out a writing style following the principles of Plain English⁸.

The Patient Information Forum.

The Patient Information Forum (PiF) is an independent group united by a common purpose: the development, production, and dissemination of high-quality information for patients, carers, and their families.

The PiF was established in 1997 under the auspices of the King's Fund and fully supports the need for patients to become more involved with their healthcare. It acts as an independent forum for the sharing of good practice.

The Forum is funded primarily by membership dues, and now has over 100 members throughout the UK, with several international members including Australia and Israel. Membership is open to all with an interest in consumer health information themes.

The Patient Information Forum is currently run by volunteers and provides a range of services:

- accessibility issues (such as translation)
- design of health information
- education and training in health information
- establishing and running health information services
- medicines information
- public and patient involvement in producing health information
- researching health information literacy and behaviour
- setting standards for and auditing quality information
- sourcing health information
- using electronic media
- writing, producing and disseminating information

Workshops

The PiF regularly organise a range of regional and national workshops under the above themes. Topics covered include 'establishing and running health information centres' and 'information on screening'. These practical workshops allow expert speakers from the relevant area to share their knowledge with the 20 or so participants and for all to agree some practical actions to improve working in that area being discussed.

Annual Conference

Given the sad demise of the Centre for Health Information Quality, the PiF conference is now possibly the unique patient information focused event of the year. The 2006 conference, entitled 'Producing Effective Information for Patients: The Key Issues' is to be held at the Manchester Conference Centre on 28 February, 2006 - the programme is available at <https://secure.healthcare-events.co.uk/pdf/pif.pdf>

How can the Patient Information Forum help me?

The PiF helped me in a number of ways. The Department of Health Toolkit for producing patient information⁹ was developed by the former Chair of PiF, and reviewed by PiF members. The toolkit provides practical advice for authors of patient information on the writing style and also some pertinent

points about presenting leaflets for example breaking blocks of text down into bullet points. When it came to developing our style guidelines, they were largely based on the toolkit.

The King's Fund has also developed Producing Patient Information¹⁰. This book explains how to research, develop and produce effective patient information. This was instrumental when developing our policy for developing, reviewing and monitoring patient information.

Despite these practical guides, the PiF helped me most because it put me in touch with people who have been working with patient information for years. They offered advice and shared many of their publications and policies; this sharing has been the most invaluable aspect of the PiF for me.

Anna-Maria Saeb-Parsy

Patient Information Development Manager
Addenbrooke's Hospital
Cambridge University Hospitals NHS
Foundation Trust
tel.: 01223 216032
email: anna-maria.saeb-parsy@addenbrookes.nhs.uk

Further details of PiF can be found at www.pifonline.org.uk

If you have any queries about PiF, please contact their Chair, Mark Duman, at chair@pifonline.org.uk

- 1 Department of Health. The NHS Plan: A Plan for Investment – A Plan for Reform. The Stationary Office. 2000: Chapter 10.
- 2 The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol. The Stationary Office. 2001
- 3 Consumers' Association. Patient Information: What's the prognosis? Consumers' Association. 2003
- 4 NHS Litigation Authority. Clinical Negligence Scheme for Trusts General Clinical Risk Management Standards. NHS Litigation Authority 2005
- 5 Healthcare Commission. Criteria for assessing core standards: Information for acute services. Healthcare Commission. 2005: 22.
- 6 World Health Organization Europe. Standards for health promotion in hospitals. World Health Organization. 2004: 12.
- 7 Department of Health. Better information, better choices, better health: Putting information at the centre of health. The Stationary Office. 2004
- 8 www.plainenglish.co.uk
- 9 Department of Health. Toolkit for Producing Patient Information. The Stationary Office. 2003.
- 10 Mark Duman. Producing Patient Information: How to research, develop and produce effective information resources. Kings Fund. March 2003

CancerVOICES

Jane Bradburn explains how Macmillan Cancer Relief helps give cancer patients and carers a voice.

More than a quarter of a million people are newly diagnosed with cancer each year; one in three of us will develop cancer in our lifetime. This means that there is a huge body of people affected by cancer who may want to get more actively involved in cancer services during or after treatment. Some may simply want to fundraise, or tell their story in the media, but many want to use their experience to help improve services.

CancerVOICES is a UK-wide network of service users, patients and carers who want to work together with others to make a difference to people's experience of care. It is supported by Macmillan Cancer Relief and aims to:

- enable patients and carers to access the support they need to participate equally and effectively in decision making and consultation forums about cancer services
- provide people living with cancer, including carers, with the training and support they need to make their voice heard
- work with existing NHS and voluntary groups to facilitate and maximise change
- develop the first sustainable UK-wide, diverse network of cancer service users.

The CancerVOICES team works closely with cancer self-help and support group members, health service users, carers and health professionals, all of whom are playing a key role in taking this work forward and influencing decision-making about cancer services.

CancerVOICES is already making a difference at local, regional and national levels, where users are taking part in improving services.

Partnerships

Partnership working has been very much the watchword of CancerVOICES. NHS cancer partnership groups were set up across England as part of a joint Department of Health and Macmillan Cancer Relief initiative, which started in 2002 following on from the 2001 NHS Cancer Plan. These groups of cancer patients, carers and health

professionals work together within the 34 cancer networks to improve cancer services. Similar work is ongoing in the other devolved nations to ensure user involvement in their Cancer Plans.

CancerVOICES training is offered to the groups as well as support for the NHS partnership facilitators who work with them. Macmillan also provides grants.

The training has proved very popular with service users and health professionals. It offers ways of feeling more confident, working in partnership, understanding the NHS and working on committees.

Partnership groups have been successful in changing services, for example by improving patient information, the design of clinics and procedures and as evidenced by independent research. The research did, however, highlight a number of issues including recruitment and diversity. These are challenges for all public and patient involvement (PPI). A UK-wide BME network has been set up which enables black and ethnic minority groups to raise awareness of cancer and enable members to find support and have their voices heard.

Linking with PPI forums is also an important issue for many cancer partnership groups. Representatives from the groups meet regularly as part of gathering of health professionals and managers from all the cancer networks. At a recent meeting, a workshop was held on working with PPI forums. Experiences were both positive and negative.

Some groups had found that their local PPI forum was less than enthusiastic about contact or that they were seen as competition for potential users. However, other groups had had really positive experiences, especially where PPI forums recognised a group's value in accessing users' views, such as where cancer services are being reconfigured. The advantages of membership of PPI forums are seen as leading to opportunities for real influence on local cancer services. Pat Eagle, a member of the Peninsula Cancer Partnership Group explains:

"There was an advertisement from the Government asking for people to join the forums. I applied, had an interview and was accepted, but was selected for the Primary Care Trust Forum. This has given me a better understanding of the way the National Health Service works. It also enables me to see things from both sides of the fence. My local Teaching Primary Care Trust asked for volunteers to sit at the Board meetings in the public and confidential parts of the meeting. On several occasions, I have attended as deputy for the Chair of our Forum. We even have our own name plates."

"Through this I volunteered for the PEC (the Professional Executive Committee), which is formed of mainly GPs. This gives another angle on how the decisions are made. Sitting on the PEC gives me the chance to lobby for cancer services."

We at Macmillan support the development of user involvement in cancer services and encourage links with PPI forums in order to maximise the impact people affected by cancer can have not only on cancer services, but also on the wider NHS. As Sarah Howarth, PPI Manager for the Trafford Healthcare NHS Trust wrote recently :

"Partnership groups have a wealth of knowledge and experience on cancer-related issues which can be harnessed by PPI forum, rather than wasting time and effort tackling the issues independently. By working together, partnership groups and PPI forums can combine their knowledge, skills, enthusiasm and statutory powers to make sure that patients and the public have a really effective voice influencing NHS cancer services."

Jane Bradburn

User Involvement Adviser
Macmillan Cancer Relief
tel.: 020 7091 2013
email: jbradburn@macmillan.org.uk

To get involved go to:
www.cancervoices.org.uk

Food for thought

Even the least fit members of society know that there is a close connection between diet and health. But how do people find out what a healthy diet is? And in a world of non-stop innovation, how up to date is their knowledge? Martin Ince has been finding some answers.

Like other research councils, the Biotechnology and Biological Sciences Research Council (BBSRC) has a duty to engage the public in the work it does. It wants to see how its priorities align with public ideas about the use of research money provided by the taxpayer. This applies especially to food and health, which are major public concerns as well as being priorities for BBSRC. It funds research on them in universities and at one of its sponsored institutes, the Institute of Food Research.

BBSRC employed MORI, working with me, to find out more by direct contact with the public. Both qualitative research – asking comparatively small groups their opinion in depth – and quantitative methods – seeking the opinion of broad national groups – were used in the study.

The signs were favourable from the beginning. The qualitative research used one group in the London area – in Sutton – and one in the Midlands, in Stafford.

When MORI recruited participants for the workshops they were told that these would be about 'People's general views about diet and health'. First to be brought together were the Sutton group. Asked about the main issues to do with society that they think about in their day-to-day lives, they mentioned both health and food (though as they had been recruited to discuss their views in this area, this may have been why, at least in some cases). In the quantitative work which MORI undertook in July and August 2005, with a sample of 2,095 people across the United Kingdom, "health" and "good health" emerged ahead of issues such as money, education and crime as public concerns. Members of the general public think they are well-informed about research on diet and health, and that they know what a healthy diet is. The people we consulted think they know what they should eat, although they agree that "other people" in society might be less well-informed than they are.

Asked about "research," the general public takes an inclusive line. For them, it can mean anything from deciding which hotel to go to on holiday, to finding the cure to a serious disease.

We found, however, that public knowledge about food and health is not keeping pace with scientific change. For example, people have an awareness of the human genome project. But the idea that it might generate findings on individual susceptibility to disease, or an individual's need to consume or avoid specific foods, is not yet current. For example, people are aware of recent research suggesting that broccoli might protect against cancer, but not that it might benefit some people more than others.

Nor are older scientific advances necessarily familiar. One participant asked rhetorically how vegetables could possibly be improved without genetic manipulation, obviously in ignorance of traditional plant breeding. At the time, we were discussing broccoli, which does not exist in the wild and was created by plant breeding. In general, members of our qualitative groups are used to novel foods appearing in shops, but are not aware of how they get there.

But the plot thickened when the public encountered details of diet and health research projects. Six projects funded by BBSRC were presented to the public in a highly summary form.

For example, participants in our group sessions often said at the outset that "everyone knows" what a healthy diet is for a pregnant woman. But after hearing about a project on maternal diet, looking at possible connections between immune system weakness in adults and what their mother ate while pregnant, they agreed that this was an area in which research might mean improved health.

The six projects we chose described most of the areas in BBSRC's remit for diet and health research. The maternal diet project, and another on genes and diet, are pioneering science which makes use of our emerging knowledge of the genome. The genes and diet project is looking at the scope for specific foods to "turn on" genes that might benefit specific at-risk groups such as potential cancer sufferers.

Other projects were looking at how people

Even the least fit members of society know that there is a close connection between diet and health.

get their tastes for foods, how healthy the typical British diet is, and at the use of swipe cards to register accurately what people eat. Finally, one project looked at a chemical reaction that causes browning, which could have applications in food manufacturing.

It turns out the public is sceptical about the role of industry when it contemplates research ideas, and particularly about industry's profit motive and how it might commission research to benefit its own commercial aims, rather than focussing on public benefit. The public also wants research to be ethical and is keen for it to help the developing world. Perhaps most importantly, the public accepts that diet and health research might take time to produce benefits. Intriguingly, both young and old take this line. The exception is people of middle years who tend to be parents of young children. The evidence from our qualitative research suggests that this responsibility reduces their enthusiasm for spending that is not going to benefit their children in the short-term.

Research councils should take into account all their stakeholders' views when taking strategic decisions. This work was rich in insights about how the public views this use of taxpayers' money, and shows that such consultation is worthwhile. The findings were presented to a policy audience in London on 12 October and at the MORI Science Seminar on 18 October, and are being used to inform the BBSRC's own thinking. We feel that the exercise has been a useful one on dialogue with the public, particularly about funding in a complex area such as scientific research.

Martin Ince

Science writer and journalist
tel.: 020 8672 6977
email: martin@martinince.com

For more information about the BBSRC's work on science and society, go to www.bbsrc.ac.uk/society/Welcome.html

Training for success

In a follow-up to an article in the May 2005 issue of PPI Monitor, Sandy Herron-Marx and colleagues describe their project on service user and carer training and facilitation for involvement.

Background

Training is a key principle of user involvement as it enables service users and carers to become more knowledgeable and empowered to engage effectively in user involvement activity. Training should not be carried out in isolation. Support and facilitation is also needed to connect people to the 'real world' of the NHS as part of the whole training process. This can help to foster relationships, build confidence and strengthen opportunities for involvement where previously none may have existed. These principles are reflected within the commissioning and development of the project and the training and facilitation resource described here.

Aim of the project

The project aimed to develop, try out and evaluate a 'training and facilitation' resource to help service users and carers work with local NHS organisations. It was developed to:

- help people gain and build knowledge, skill and confidence in how to become involved in the NHS
- help link people directly with the NHS and set up a mechanism to provide continual support before, during and after the training
- provide an opportunity for local people to get involved in developing the resource
- provide opportunities for people to get involved in training and supporting others

How we did it

The project started in February 2003 and finished in March 2004. There were four stages to the project:

Stage 1 - finding the right people to create the resource. A team of 19 people – NHS staff and service users and carers supported and guided the development and the running of the project. People were invited to take part in the project 'review and reference group' from local patient groups and forums.

Stage 2 - development of the resource. This was an ongoing activity. The project

review and reference group guided the initial (and the ongoing) content and format of the resource. Once a draft of the resource was developed, it was shared with a wider audience through a number of local consultation days. 62 people from local and national patient/carer groups and forums, local NHS staff and known researchers and specialist practitioners in the field and members of key organisations (such as the local Community Health Council, Ethnic Minority Advisory Group, National Childbirth Trust and People in Partnership) attended. Feedback from the workshops was instrumental in developing the resource further.

Stage 3 - a trial run of the training using the resource for local people in two pilot areas – the Heart of England NHS Foundation Trust and South Worcestershire Primary Care Trust. 15 people took part in the training. The aim of the trial training was to 'kick start' involvement but to also further consider the training from the perspective of the recipient. Of these, seven were service users who had had some experience in working with the NHS and the remaining eight were new to involvement activity. The team felt that when developing the resource it was crucial to gain a combination of both perspectives. Participation was invited through newspaper articles, radio interviews and posters.

Stage 4 - an evaluation of the training. Direct information by the trainees, observation of the training sessions and trainer feedback was used to write the final version of the training and facilitation resource.

Main features

The training and facilitation resource is made up of five 'units', each of which covers a different area for involvement. There are three 'core' units aimed at developing general knowledge and skills necessary for working well with the NHS ('User involvement in the NHS', 'What does involvement mean for me?' and 'Feeling empowered in user involvement'). The two 'theme' theme units are focused either on developing involvement possibilities in

service review, planning and improvement or on any aspect of research and development activity. Each unit has a number of 'parts'. For instance:

Unit 2 – what does user involvement mean for me?

- Part A** – personal experiences of health services
- Part B** – learning from others
- Part C** – practical issues in user involvement
- Part D** – problems and benefits in user involvement

The 'parts' enable the resource to be used in a flexible way. Throughout, units or part-units can be combined in a variety of ways. This is to help the training to be 'tailor-made' through a 'pick and mix' approach to planning training and facilitation for involvement.

Throughout the resource, the trainer is aided by the use of a 'trainer handbook' outlining what to consider and prepare before, during and after training, top-tips for training, background debates and discussions for each area covered. Participants are guided through each unit or part by a 'participant handbook'. This is an abbreviated version of the trainer handbook whilst still containing all the necessary elements to help facilitate learning and self-development. Throughout, the resource uses examples of service user and carer involvement to help people learn from the experience of others. Exercises are set up throughout the resource to help people engage and build relationships with their local NHS organisations. This is through guided 'link time' built into the training time. To avoid the development of 'stand-alone' training, linking people into organisations while providing and building mechanisms to support them before, during and after training is crucial to the ongoing success for involvement activity.

Who was it for?

The training is for any service user, carer or local community member who feels they would benefit from attending the training

– from beginners to people who want to expand upon an existing role. The project team recognise it is not for everyone and people require different types of support (both formal and informal).

Trainer story – Simon Heng

As a tetraplegic, I am an experienced consumer of health services. I am the chair of the Worcestershire Association of Service Users (WASU) and have been involved in user involvement activities for eight years. I was originally approached to act as a Service User Representative on the Review and Reference Group of the User Training Project. As the work on developing training materials progressed, it became clear that the impact of the training would be enhanced if some of the trainers were service users themselves. This helped to create a safe, positive and shared environment for participants, and helped demonstrate that the materials were directly relevant to service users. My involvement also highlighted that competence in this area was within service users grasp. I had some experience in piloting and developing training packages, so I volunteered to be part of the training team.

The training itself went quite smoothly. Once the training team had established an understanding with the writer, and a practical format for the training materials was established, the training sessions themselves achieved their aims, in terms of both participants' understanding of the issues and the practical skills involved, and in terms of their enhanced commitment to representing user issues. I found it stimulating and exciting to practise my skills as a trainer again, after a break of many years: previously, I had drawn on my experience as a practitioner, but my involvement in this project meant that I was drawing from my own life experiences. Not only was I well supported by the other team members, but I also felt included as an equal partner. In my opinion, this helped motivate other service users to become trainers. To my knowledge, at least half of the participants have become increasingly involved in service user representation since the end of the training course.

Since my involvement in this project, I have continued to be involved in training both service users, to enhance their skills and self-confidence in working with service providers,

Training is a key principle of user involvement as it enables service users and carers to become more knowledgeable and empowered to engage effectively in user involvement activity.

and with service providers themselves, addressing Patient and Public Involvement issues. I have also been invited to take part in nurse and social work education at University College Worcester and North East Worcestershire College.

Items to share

As with much user involvement, this project required a great deal of energy, enthusiasm and commitment. In developing training for service user and carer involvement, it is important to:

- prepare and continually support members of the project review and reference group
- provide an opportunity at the end of the project or training to put a 'line underneath' it and to celebrate achievement and recognise contribution.
- invite views from a wider audience to ensure perspectives and concepts are fully developed and understood
- use case examples where possible to ensure the sharing of ideas and experience
- avoid developing 'stand-alone' training,

people need to be provided with an opportunity to link directly into the NHS organisation before, during and after training

- use guided opportunities for self-reflection and development where ever possible
- tailor-make training to suit the audience, use a 'pick and mix' approach to ensure flexibility and responsiveness to local need
- encourage people to share their fears and anxieties and to learn how to understand each other and the world of the NHS

Authors

Sandy Herron-Marx, School of Health Sciences, University of Birmingham

Marguerite Standing, Disability Advisory Group, Heart of England NHS Foundation Trust

Gillian Waterhouse, Heart of England NHS Foundation Trust

Mandy Williams, Heart of England NHS Foundation Trust

Dr. Sandy Herron-Marx

School of Health Sciences
University of Birmingham

tel.: 0121 414 3571

email: s.herronmarx@bham.ac.uk

The training and facilitation resource can be downloaded free of charge from <http://healthscinet.bham.ac.uk/TrainingFacilitationResource/>

Acknowledgements

Many people contributed to the development of this resource. The authors would like to thank the review and reference group: Eric Brooker, Linda Dunn, Jill Edwards, Riaz Janjua, Meryl Johnson-Mair, Bethan Miles, Sheila Neary and Nisha Sankey. Thank you to Steve Leverett, Simon Heng and Rosemary Wilson who acted as co-trainers and to Kathleen Stacey for her huge contribution to the work. Thank you to the people who took part in both the consultation workshops and the training events. Thank you to all the staff (from South Worcestershire Primary Care Trust and the Heart of England NHS Foundation Trust), who were link the sites/people for the training. Thank you to the project funders: the National Patient Safety Agency and the Heart of England NHS Foundation Trust.

Participation: The 1% Solution

In the March 2005 issue of PPI Monitor, Paul Skidmore and colleagues considered whether involving citizens in governance might really make a significant change. Paul now reports on their findings – and offers a solution.

Introduction

Politicians are interested in finding new ways to involve people in making decisions about the way public services in their area are run. Community participation in governance has moved from the margins towards the mainstream.

New structures have been created to promote community participation in the governance of services like health (such as patient and public involvement forums and NHS foundation trust boards), economic regeneration (such as New Deal for Communities boards) and housing (such as tenant management organisations).

Three reasons are put forward for doing this:

- it leads to better and more responsive services
- it tackles people's disengagement from politics and the democratic process
- it builds social capital

Demos has spent the last 18 months testing out the last of these claims. Put simply, does the community benefit from participation?

Untangling social capital

Social capital interests policy-makers because of a growing body of evidence which says that it leads to better outcomes for communities. Certain kinds of social networks enable citizens and communities to access certain resources they can use to work together to tackle problems for themselves. Examples might include using your contacts to help a friend find a job and cooperating with your neighbours to address nuisance behaviour on an estate.

Policies to promote community participation in governance are concerned with a particular kind of social capital. The theory is that by involving people in the governance of services, participants build relationships with public institutions or officials that give their community access to valuable external resources like money, support or political

leverage. For instance, a community group might hear about a new pot of funding because they were close to someone in the public agency making it available. These relationships are sometimes described as 'linking' social capital.

There is, however, no reason to suppose that this kind of social capital will be widely or fairly shared. It is more likely to be embodied in key relationships between particular individuals or organisations; for example, between the chair of a residents' association and the housing professionals in the local authority. Who benefits from this social capital depends in large part on the broader social ties that the residents' association has with people in the neighbourhood.

In other words, having a representative from your community involved in governance does not necessarily mean you get any benefit, especially if you are not part of their social network – their circle of friends, acquaintances and contacts. On one of the estates we studied, having community participants involved in governance had been valuable to a group of parents concerned about their children's education but not for a group of young unemployed men. So social capital is a bit like legal tender – just because it is valuable to some people at one time and place does not mean it will be valuable in others.

It follows that rather than just assume that putting people on committees will create social capital, we need to work out how to enable the widest possible range of people in the community to access it. That means paying attention to the connection between formal structures and more informal associations like community projects, mother and toddler groups, book clubs, faith organisations or sports clubs. For example, the group of young unemployed men did enjoy a close relationship with the manager of a local community owned gym, who was a community activist but felt excluded from formal governance.

In short, to understand whether the community benefits from participation in governance, we need to know who participates and how this participation relates to other, more informal types of community involvement and active citizenship.

Insiders and outsiders

In our research, we found that the people who participate in governance tend to be the people who are already involved: the already well-connected just get better connected. Relatively few people were involved in governance and the few people involved in one setting tended to be the same few people in another setting: the school governor also sat on the patients' panel as well as being a board member of the regeneration partnership. This is the familiar "usual suspects" problem.

But we also found that the way governance arrangements work makes this problem worse. The "usual suspects" problem is not just the product of the bad practices of particular institutions. In particular, a number of forces create "barriers to entry" for those who are not involved in governance and increase the likelihood that those already involved will become more so. We describe six 'network dynamics', which arise from the way people in and around community participation relate to one another:

- **Preferential attachment:** the more governance structures you are involved in, the more attractive a potential participant you become to others because of the information or influence you bring with you.
- **The rich get richer:** having some linking social capital makes it easier for you to create more. You acquire knowledge and skills about how the system works, make contacts and earn a reputation for being a 'good' participant.
- **Closure:** the value of linking social capital often comes from preventing others from accessing it e.g. it suits public

sector partners to work with particular community representatives.

- **Self-exclusion:** potential participants may choose to exclude themselves from governance because they decide it is not for them.
- **Community dependency:** by routinely taking on a disproportionate burden of governance activities, community participants create a vicious circle which increases that burden.
- **Institutional dependency:** institutions get in the habit of recruiting existing participants who are a known quantity.

So, community participation tends to be dominated by a small group of insiders who are disproportionately involved in a large number of governance activities. The social capital created by opening up governance to community involvement tends to be concentrated in the hands of this small group. A much larger group of outsiders choose not to participate in formal governance, even if they are involved in more informal activities. As a result, formal governance structures are not necessarily embedded in the informal everyday spaces of community life in a way that would make them easy for the average citizen to access.

If we want to ensure that there are stronger links between community participation in governance and social capital, then pushing harder on the existing approach is likely to be counterproductive. Simply encouraging more people to participate seems a somewhat forlorn hope given the range of forces helping to perpetuate the current division between insiders and outsiders, whilst creating even more structures is likely just to increase the burden on a few already over-stretched community activists.

The alternative is to try to find the points where stronger and more effective connections can be made between formal participation by a small group of insiders and the more informal, everyday social networks in which a much bigger group of citizens spend a significant part of their lives. Rather than expect everyone to participate in formal governance equally, we should try to make more people's everyday civic engagement count, by designing the formal structures of governance in a way that taps into the informal spaces of community life which they

routinely inhabit. As one of our interviewees put it, "People already congregate in school, church, at the bus stop . . . We need to work harder to find them – don't assume if they don't turn up to meetings they're not interested."

What does this mean: The 1% Solution

First, it is not getting everyone to participate in governance that matters. It is getting governance to reflect the contribution of a much wider range of types of participation. Rather than try to change people's participation so it fits existing structures, we should change the structures so they fit people's participation. Instead of trying to corral the young people who attend a youth club or the mums in a playgroup into getting involved in governance, we should ask how governance can get involved with them.

Second, participants in governance will find it much easier to mobilise others and plug into their networks if the formal structures they inhabit are places where real power lies.

Third, the goal of policy should not be to invent ever more structures of participation but to invest in changing cultures of participation in the long term.

Fourth, if these principles were adopted, we could begin to realise a system that only mobilised 1% of citizens to participate actively in governance, but which was more legitimate, effective and a more promising basis on which to build for the future than the one we have now.

In our final report, due out in early 2006, we set out what we think the ingredients of this "1% Solution" might be. In the meantime, we would welcome reflections from those involved in patient and public involvement about how closely our research mirrors their own experience. Please write to us at hello@demos.co.uk

Paul Skidmore

Senior Researcher

Demos

tel.: 0845 458 5949

email: paul.skidmore@demos.co.uk



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?

Will one of your case
studies help someone
else?

Share your challenges
and successes with other
readers.

Talk to Malcolm on
01625 584448
or email on
m.mcclean@bearhunt.org.uk

Global Voices

Patients around the world have united to call for meaningful involvement. Jo Harkness introduces a new international policy and guidelines.

Patients' organizations provide vital support and information to patients, families and carers on an individual level. This role is evolving to include an increasing focus on advocacy, bringing a valuable perspective and knowledge to health policy debates. However, amongst the many other stakeholder groups – such as the health care professions, academia and industry – patients' views are not always given the consideration they deserve in policy-making and practice. Patient involvement is often merely tokenism: its influence on policy-making restricted by practical and financial structures, differing knowledge bases, cultural barriers and personal attitudes.

The International Alliance of Patients' Organizations (IAPO) has developed a Policy Statement and Guidelines on Patient Involvement with the aim of helping patient involvement activities to be appropriate – addressing the practical, financial and educational needs of participants and meaningful – contributing to the shaping of health care policies.

The rationale for patient involvement

It is increasingly recognised that the long-term users and beneficiaries of health care – the patients themselves – and the organizations that can effectively represent them – the patients' organizations – should be involved in health policy. The most fundamental reason is that decisions, at whatever level they are made, will ultimately affect patients' lives and, therefore, patients and patient representatives have a moral and ethical right to play a meaningful role in developing health care policies.

In addition to the social justification, there is also a growing body of evidence that developing policies with the patient at the centre – patient-centred health care – is an appropriate way to address the needs of people with long-term conditions. Patient-centred health care, achieved through patient involvement in health policy, will help ensure that the health system is designed to address the needs of patients, making it possible for them to meaningfully engage in their

personal care and effectively manage their condition. The benefits include the promotion of greater patient responsibility and optimal usage that ultimately lead to improved health outcomes, quality of life and patient satisfaction.

A united call from patients' organizations

The global Policy Statement on Patient Involvement – the first of its kind – demonstrates the united position of IAPO's member organizations on patient involvement in health policy. It calls for all involved in health care – patients' organizations, health care professionals, providers, companies, policy-makers and others – to work towards meaningful patient involvement where patient views are listened to and, importantly, acted upon. It was developed through a consultation process with patients' organizations from Canada to the Czech Republic, from Slovenia to Spain, from Uganda to Uruguay and from the United Kingdom to the United States.

Promoting and assisting change

A common reason given for not involving patients in decision-making processes is not knowing how. IAPO has developed procedural Guidelines for Patient Involvement, providing practical assistance appropriate for all involved in health care. These can be considered for any processes and projects that can affect patients' lives. In addition, patients' organizations can use the Guidelines to make it easier for to ask for and receive appropriate involvement.

The Guidelines comprise a simple checklist covering aspects necessary to achieve meaningful and comprehensive patient involvement. Key aspects, which are expanded upon in IAPO's Guidelines, are to incorporate:

- robust and transparent mechanisms to ensure that patient views are acted upon, not just recorded
- inclusion in initiation, design, implementation, communication and evaluation of initiatives
- practical, psychological, financial and educational support for participants
- varied methods to reach underrepresented groups and to gather a diversity of views

There are many starting points for patient-centred health care and patient involvement depending on national wealth, culture and attitudes. What is important is that throughout the world people understand about patient-centred health care and that patients and patients' organizations are given a seat at the table and work in partnership with health care professionals, providers, policy-makers, industry representatives and each other, helping to shape the health care of the future.

Jo Harkness

Policy and External Affairs Director
International Alliance of Patients' Organizations
tel.: 020 7721 7597
email: policy@patientsorganizations.org
web site: www.patientsorganizations.org

Selected references

1. Bauman A E, Fardy H J, Harris P G (2003), Getting it right: why bother with patient-centred care?. *Medical Journal of Australia*, 179 (5), 253-256.
2. Department of Health (2004), *Patient and Public Involvement in Health: The Evidence for Policy Implementation*. London: Department of Health Publications.
3. Little P, Everitt H, Williamson I, et al. (2001), Observational study of effect of patient centredness and positive approach in outcomes of general practice consultations, *British Medical Journal*, 323: 908-911.

IAPO's Policy Statement and Guidelines on Patient Involvement are available on IAPO's website at www.patientsorganizations.org/involvement.

We are currently looking for patient involvement case studies from around the world to act as a further resource. What has worked, or not? What research or anecdotal evidence do you have? What are the barriers or problems? What are the advantages? If you have an interesting or inspirational experience and would like to share it with us, please contact Jo Harkness on policy@patientsorganizations.org.

For further information go to
www.patientsorganizations.org

IAPO Guidelines on Patient Involvement

IAPO recommends these guidelines are followed by international, regional, national and local organizations to involve patients and patients' organizations in all activities related to healthcare policy, systems and delivery, whether formal or informal.

You can use these guidelines as a project checklist:

- ✓ = Guideline has been met
- x = Guideline has not been met
- = Guideline not applicable

1. Identify issue and set out the objectives

- Identify the process, activity or issue which could impact on patients
- Determine the initial scope of the proposed activity; be realistic bearing in mind the planning and implementation phases
- Identify your objectives and consider the stakeholder groups to be involved
- Consider the benefits and challenges of patient involvement, for you and for the patients
- Aim to engage stakeholders in all phases of the activity from as early as possible (e.g. design, implementation, communication, evaluation)

2. Identify appropriate patient representatives

- Ask patients and patients' organizations to determine who the stakeholders are on their side and who could best represent them in your activity
- Use varied methods to identify and engage patient representatives (e.g. through patients' organizations, general and specialist media, publicity campaigns using websites and print materials)
- Try to be inclusive of underrepresented groups (e.g. the elderly, minority ethnic and religious groups, those with impaired mobility) and consider balance (e.g. age, gender, disease area) and the representativeness of the patients or patient representatives involved

3. Encourage participation and motivate

- Encourage participation by demonstrating the importance of the issue, providing supporting information and evidence
- Be transparent to build trust
- Be specific and avoid vague phrasing - outline expectations, roles and responsibilities
- Provide feedback to build loyalty and to encourage continued engagement

4. Determine appropriate methods of involvement

- Invite patient representatives to input into planning and to suggest objectives and methods; discuss and agree these
- Seek out and evaluate existing methods to avoid duplication of effort
- Use more than one method of involvement (e.g. inclusion on committees and steering groups, focus groups¹, consultation exercises, advisory networks, patient forums, online tools)

5. Give support to enable involvement

- Ask patients and patient representatives to define patients' needs in the project and accommodate individuals' requirements as much as possible
- Consider the requirements of patients with impaired mobility and health (e.g. accessible venue, time to rest)
- Bear in mind individuals' limits and needs (e.g. mobility, time, money, language constraints)
- Understand and plan for non-attendance of patients due to ill health or relapse
- Be approachable and listen to individuals' comments or concerns about their involvement
- Provide realistic time scales
- Provide reimbursement for all expenses incurred and offer a per diem for the time provided by patient representatives (be aware that some may be unable or unwilling to accept this)

6. Provide information, education and training

- Ask patient representatives what information and training they need to be engaged in the project
- Provide appropriate training as necessary to ensure a balance of knowledge among stakeholders
- Ensure all materials and information are presented in an accessible format and suitable for culture, age, gender and mental and physical ability, conforming to health literacy principles where relevant
- Consider website accessibility, remembering that not everyone has access to the internet

7. Monitor the involvement – ensure that it makes a difference

- Ensure that involvement is ongoing
- Ensure that patient representatives are equal participants

- Record results and, more importantly, act upon them to implement changes

8. Evaluate the project

- Review involvement mechanisms regularly, incorporating patient feedback to implement improvements
- Involve patients in helping you to develop new objectives and modify existing ones

9. Recognize involvement

- Thank all participants that have contributed to the project
- Publicly acknowledge participation (e.g. if input has contributed to final documents, acknowledge this)

Think holistically – beyond the individual project

10. Reassess internal frameworks

- Examine methods of policy development, implementation and evaluation, identifying potential barriers to effective patient involvement and ways to address them
- Make appropriate changes to improve internal frameworks

11. Educate staff

- Make sure everyone in the organization understands the value and importance of patient involvement
- Share best practice internally and externally
- Look out for conferences and opportunities to train staff about patient involvement

Related Publications and Selected References

IAPO Policy Statement: Patient Involvement www.patientsorganizations.org/involvement

IAPO Policy Statement and Guidelines: Health Literacy www.patientsorganizations.org/healthliteracy

Thompson AGH, (2003/2004). Moving beyond the rhetoric of citizen involvement: Strategies for enablement. *Eurohealth*, 9(4): 5-8 (further references are available at www.patientsorganizations.org/involvement)

IAPO is a unique alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world.

© 2005 IAPO. All rights reserved. These guidelines were adopted in April 2005 by IAPO following member consultation.

¹ A focus group is a small group of stakeholders brought together to discuss an issue.

Compliance in Medicine Taking

Many medicines are not taken effectively. Ros Levenson and Geraldine Mynors have been seeking the views and beliefs of patients to find out how decisions are made – and how they might be improved.

The volume of prescribed medicines in the United Kingdom is enormous and increasing rapidly: the average person in England received 13.1 prescription items in 2003, a 40% increase over the previous decade¹. Medical advances mean that diseases previously regarded as terminal, such as HIV and some cancers, are becoming long-term conditions needing long-term treatment. But medicines cause a range of problems: adverse reactions are implicated in a significant proportion – up to 17% – of hospital admissions². Many patients report that their lives are dominated by medicine taking and the associated unwanted side effects.

But perhaps the most significant unresolved issue in relation to medicines is that for the very many prescriptions written in good faith, a large proportion do not result in medicines being taken effectively. Non-compliance with prescribed medicine has been recognised as a problem for many years. It results in unnecessary ill-health, premature death, and significant avoidable cost to the NHS. Non-compliance comes in many forms: depending on the disease area, as many as one in five patients fails to take the first step of collecting a prescription from the pharmacy. Many patients on short-term medications depart from recommended doses within a day or two of starting treatment. Research evidence shows that adherence overall is approximately 50% but varies across different medication regimens, different illnesses and different treatment settings.

The fact is that patients are not the passive recipients of prescribing decisions. They have their own views about medicines, how they should be used and how medicine taking fits in with their daily lives. These views are based on a personal set of beliefs and understanding influenced by factors including the experience of family and friends, culture, education and social requirements. Research shows that patients' beliefs about medicines are the key influence on whether, when and how they take their medicines³. Practical and logistical difficulties may play a part – getting to the pharmacy, opening the container,

The volume of prescribed medicines in the United Kingdom is enormous and increasing rapidly: the average person in England received 13.1 prescription items in 2003, a 40% increase over the previous decade

remembering the details of a complicated regimen. But in most cases non-adherence results from conscious choices, which involve weighing up perceived risks and benefits of treatment.

Interview-based patient research has recently been published which provides further insight into the issues which patients face when making choices about medicines. The work was commissioned by Medicines Partnership, a Department of Health programme aimed at helping patients to get the most out of medicines by involving them in prescribing decisions and supporting them in medicine taking, and undertaken as part of the development of 'A question of choice: compliance in Medicine Taking'⁴, a review of the literature on non-compliance across 13 different disease areas. The aims of the interviews were:

- To enable patients with conditions covered by the literature review to highlight, in their own words, issues that are important to them in deciding whether and how to take prescribed medicines.

- To seek views from patients' organisations on key issues that may affect patients' compliance with prescribed medication.

Many of the issues raised by patients and their organisations – for example, the need for information and concern about unwanted effects of medication – were common across quite different conditions, but different patients unsurprisingly expressed very differing views about their medicines.

The following were key themes which came out of the interviews:

There are concerns about the quality of information about medicines, particularly the confusing nature of patient information leaflets. In addition, some times are better than others to receive and take in information about medicines.

"The information leaflets – if you can read them and many of them are very small print – many people are terrified to take the medicines. I found them over-informative. So I read them all once and then didn't bother to read them again." (Man age 43, had Hodgkin's disease)

"More information on the medications [after a bypass] would be really useful, and there is a need for more education but the question is when. If you do too much beforehand it can frighten people. At the time of giving out the tablets the nurses are so busy. Also, at the time, I was in such a poor state that I wouldn't have taken it in. For about two weeks I felt I was still affected by the anaesthetic. Fortunately I have a good GP and he went through it, what each one did." (Man age 71, recovering from triple bypass)

Many patients make a careful consideration when balancing up the undesirable effects of medicines with the benefits, and this can present them with dilemmas.

"A lot of the disease-modifying drugs are toxic, so you have to decide what is worse – the disease or the drugs. I give it a lot of thought. I have two young grandchildren and my daughter is pregnant so I take the medication as I really need the mobility. I might have to trade that off against the itchiness and liver problems. I didn't take the disease modifying medication until the rheumatoid arthritis got worse." (Woman age 50 with arthritis)

"At that time [when the depression started] I was quite happy to take medication ... In my third spell, following a suicide attempt, they gave me lithium and I read up about it. I came off it because of what I read about the effect on the liver and kidneys ... At one stage I was referred to a reflexologist; she was someone to talk to and was influential at that stage. She believed medication was a poison to the system so I came off the medication. I got into difficulties after a few months and was put on Pimozide, for which there is a high number of deaths through heart attacks, and I was not on it for long. I told the psychiatrist I had come off it and he said 'no point coming back if you don't want treatment.'" (Man age 61 with depression)

People see it as important to be able to raise questions and issues whilst on medication, but for some it is difficult.

"What the patient wants out of their own life is the primary consideration. You must feel able to discuss and debate with the doctor what you are taking and the effect it has on you." (Man age 56, had heart attack two years ago)

"The pressure on staff at diabetic clinics and in hospitals is such that they don't get a lot of time to talk to people – maybe just 15 minutes. And you can't take it all in in that time." (Man age 69 with type one diabetes)

Some people expressed a desire to comply with medication that was linked to their gratitude for the care received.

"I think the doctors do know best and it's for your own good. You take your medication as it is for your own good. If you had lots of side effects you could go back and ask for a change. But otherwise, why bother to go to the doctor?" (Woman age 45, had breast cancer)

"They have spent a lot of money on me, so you have to get on and enjoy life." (Woman age 45, had breast cancer)

"If I go to a professional I am seeking professional advice and if I ignore it I am doing so at my peril. I won't accept anything without a good reason – one must always question – but having got the information, people shouldn't flout the advice. So long as you know what

the medication is for, and what it is intended to do, if you don't take it, that's your stupidity." (Man age 78, had aortic aneurysm repaired in 1995)

Unintentional issues, such as forgetfulness and inability to open medicine containers, remained major factors with certain conditions and particularly amongst older people.

"It can be difficult getting at the pills. You have to remember to ask for a non-childproof bottle. Then they give you blister strips and they can be awkward. The edges of the foil are tough and sharp. I can sometimes forget whether I have taken my painkillers. Some pills come in strips of ten. For things like Paracetamol or Coproxamol that you can only take eight a day it would be best if the strips came in eights. Then you'd know if your strip was empty you could not take any more that day." (Person with arthritis)

"One of my main niggles is that I find it very useful when the tablet has the day of the week alongside it. They don't all have this. I know I start the pack on a Monday and can count back, but I do wonder about older people or people who are a bit confused." (Woman age 49 with diabetes and heart problems)

In the past, efforts to improve medicine taking have focussed on various combinations of providing clearer education and instruction about medicines. It is, however, increasingly recognised that key to making better use of medicines is involving patients as partners in decisions about their medicines – sometimes described as medicines concordance.

Critically, concordance describes a two-way process of agreement between a practitioner

and a patient, not a patient behaviour. It is about mutual communication and shared decision making. Information which helps patients to understand the risks and benefits of the options and reach an informed decision about treatment is certainly an important component in the process, but equally important is eliciting the patients' views about their willingness and practical ability to follow a course of treatment. Patients also need to know where they can access ongoing support once a treatment has started – particularly when they run up against unanticipated side effects or come across information (often in the patient information leaflet) which gives them cause for concern.

There are many practical ways to try to put concordance into practice. A major concern for prescribers is the potential increase in the length of consultations required truly to reach agreement with a patient about the right treatment option. However, given the high stakes in terms of health and financial cost of helping patients to get more out of medicines, an investment of time at the point of key prescribing decisions can pay dividends down the line.

Ros Levenson

Independent Researcher

Geraldine Mynors

Head of Projects

Medicines Partnership

tel.: 020 7572 2476

email: geraldine.mynors@rpsgb.org

Further help is available on the Medicines Partnership website at www.medicines-partnership.org, along with full copies of the research reports.

References:

- 1 Prescriptions dispensed in the community. Statistics for 1993-2003, Department of Health.
- 2 National Service Framework for Older People, Department of Health.
- 3 Horne, R. and Weinman, J., Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *Journal of Psychosomatic Research* 47(6): 555-567.
- 4 Carter, S., Taylor, D. and Levenson, R., A question of choice: compliance in Medicine Taking, Medicines Partnership 2003.

The fact is that patients are not the passive recipients of prescribing decisions.

Patients Accelerating Change

The third phase of a unique programme which uses feedback from patients to improve health care services has recently been launched. Danielle Swain reports on progress on working partnership with patients.

Following two successful pilot years, hospitals from across the country are once again taking part in Patients Accelerating Change (PAC), an initiative which is jointly run by healthcare research charity, Picker Institute Europe, and the NHS Clinical Governance Support Team (CGST).

The PAC programme has three core objectives:

- to help healthcare professionals to listen and learn from patients' feedback on their experiences
- to deliver real improvements in the quality of healthcare services for patients
- to ensure patients are involved in developing solutions.

PAC encourages organisations to use results from patient surveys and other sources of patient feedback to identify areas for improvement. Patients and staff then work in partnership to agree solutions and implement quality improvements. Since PAC was first launched in summer 2003, it has stimulated many innovative approaches to actively engaging patients and carers. Working in this way has highlighted that it is often the simple low cost solutions inspired by patients that make the biggest impact.

Under the Government's new Standards for Better Health, all health care organisations are required to make progress towards continuously improving the patient experience, based on the feedback of patients, carers and relatives. PAC provides a focused, effective way for trusts to achieve this by creating an environment where patients and staff work together to ensure services are truly responsive to patients' needs. PAC is also designed to put patients at the heart of clinical governance in practice.

Building on the theme of 'Better Information, A Better Experience', the 2005-2006 PAC programme was launched in October and will run for ten months. The programme provides four national training days, local networking events, resource materials and ongoing individual trust-level support.

Following two successful pilot years, hospitals from across the country are once again taking part in Patients Accelerating Change (PAC)

To support the delivery of PAC projects, CGST and the Picker Institute have produced a resource pack aimed at giving organisations and their staff a flavour of the success that PAC can achieve and highlighting the learning to date. This includes information on some of the projects undertaken during the pilot stages of the programme, which produced impressive results.

- At Rotherham General Hospitals NHS Trust, a new protocol was introduced allowing patients to receive immediate feedback from urology scans where the results were benign. In the first month alone, 30 patients were saved the anxiety of waiting for a follow-up appointment, and it is estimated that the potential saving of consultant time could be up to 325 outpatient appointments a year.
- University College Hospitals London NHS Trust developed new signage in the haematology department and revised outpatient letters with improved directions. As a result, the number of patients going to the wrong place for blood tests was reduced from 25% to none.
- A discharge resource folder was produced by Mid Essex Hospital Services NHS Trust, including essential contact details and

tailored information about medication. Feedback has been very positive, with staff reporting a reduction in the number of queries they receive from patients and their families.

As well as continuing to work with acute trusts there are plans to develop the PAC approach in mental health and primary care over the coming year.

Danielle Swain

Quality Improvement Manager
 Picker Institute Europe
 tel.: 01865 208108
 email: danielle.swain@pickereurope.ac.uk

For more information, please visit www.pickereurope.org or www.cgsupport.nhs.uk

Case Study

Whipps Cross University Hospital NHS Trust

Staff and patients at Whipps Cross decided to focus on reducing post-operative pain.

"Colleagues found it a delight to work with patients and the PAC programme encouraged real partnership between them. They were amazed how generously patient representatives have given their time. The national profile of this project meant staff really felt they were able to contribute in a positive way and see the benefits of having patients involved. Patient survey results are now being used in several business cases and all business plans. This demonstrates that our Trust has recognised the real value of the surveys and this has mainly been achieved through the PAC project." (Patient and Public Involvement Manager).

"It was great to be part of a professional team and to see things from both sides and it gave us a better understanding of how the hospital and the NHS works. It was interesting to come up against barriers, such as poor communication and lack of resources and funds, and to break them down. The project gave us the confidence to go round the wards talking to patients and staff who took on board what we had to say and acted upon it. We felt that people were listening to us, we were no longer being treated as hospital numbers, we were treated as equals." (Patient Representative).

SUBSCRIBE NOW TO PPI MONITOR

PPI MONITOR

you can subscribe now by filling in this form and posting to the address below or by fax to 01625 585674

If you would like to subscribe to **PPI Monitor**, published 10 times a year, please see the details below
Subscribe for 2 years now and receive a 25% discount off the second year's subscription

Risk free subscription - note that you may cancel your subscription at any time and receive a full refund for all unmailed issues

Details

Name _____

Email _____

Job Title _____

Organisation _____

Address _____

Postcode _____

Tel _____ Fax _____

Nominate a colleague or associate within your organisation who you think may wish to receive a free sample copy of PPI MONITOR.

Name

Email

Job title

Method of payment (see below for subscription costs)

I enclose a cheque made payable to bearhunt ltd for £

or

please invoice my organisation at

Public and private sectors

1 year @ £295 or 2 years @ £565

Registered charities

1 year @ £195 or 2 years @ £340

BACs details are as follows:

Name of account: Bearhunt Ltd
Account no.: 98841262
Sort Code: 01-05-41
Bank Name: National Westminster Bank plc

Bank Address: PO Box 65
2 Chestergate
Macclesfield
SK11 6BS

Last Word from Chris Dabbs



Dear Mrs. Buggins,

Thank you for keeping me in touch with your sister's progress. It is distressing to have to deal with a loved one who has a terminal illness.

When I visited your sister in the hospital, I wondered what had happened to all our achievements through patient and public involvement. I thought I had passed into a parallel universe.

Entering the ward, my greeting was a sink surrounded by curling posters. Alongside it was a flip chart, with the legend, "STOP! WASH YOUR HANDS WITH SOAP AND WATER. THIS MEANS YOU." Such a warm and welcoming embrace.

With no one on the nurses' station, I eventually found a member of staff after five minutes of wandering. I was asked to take a seat – right underneath leaflets about what to do after a death. This cheered me up no end.

Once I got to see your sister, I understood what you had said about her experience. Although she was already weak and anxious, there was constant banging, noise and loud conversations. There was no view outside, and the beds were just three feet apart. Opposite was a poor lady who was coughing up so much that it was no surprise that your sister caught an infection.

There were repeated checks, prods and tests, with little evidence that half of them contributed to your sister's well-being. None of the staff had much time to actually do any caring or even listening.

Despite raising concerns with the matron and even the Deputy Director of Nursing, nothing changed. So, it is a relief to know that we managed to arrange a transfer to the local hospice.

What a contrast! A warm welcome from a receptionist, who showed me where to go.

The environment felt positive and homely. The quiet and peacefulness of the place was wonderful, and there was only the clinical equipment necessary. Staff spent time with people, and the behaviour of relatives and visitors was noticeably calmer.

Your sister was much more positive about her situation. In hospital, she had been very pessimistic. There was clearly a link between her condition and the physical and social environment.

Perhaps most of the patient and public involvement work is just rhetoric? When this is someone's experience, perhaps we need to be more ruthless about ensuring the right service provider, regardless of whether they are statutory, private or social enterprise.

It seems as though the acute hospital is virtually incapable of actually providing a healing environment. No wonder so much money is spent on people in their final few weeks of life. Maybe much of it is wasted, when it might be better invested in developing hospice providers to take on care from acute hospitals.

I hope that your complaint to the hospital is successful, and that one day people who are dying all get the dignity they deserve, and are treated as people rather than as conditions. Perhaps senior clinicians and senior managers – and maybe more PPI staff – should experience their own services more directly.

Keep well

Chris

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

Publishing, Editorial and Advertising Offices
Bearhunt
Six Kingsbury House, St Hilary's Park,
Alderley Edge, Cheshire SK9 7DA
Tel: 01625 584448 • Fax: 01625 585674

EVENTS CALENDAR

New evening course in participation studies

DEPT OF PEACE STUDIES -
UNIVERSITY OF BRADFORD

As a taster for the new Foundation Degree in Active Citizenship and Participation, the Department is running a free-standing module in Participatory Theories, Values and Practices.

There will be 11 sessions and the module will run on Tuesdays from 6-8pm beginning on the 31st January 2006.

For more information and details on how to enrol contact: Dr Lucy Brill: l.m.brill@bradford.ac.uk Tel: 01274 235419.

The Promise of Participation

9 February 2006
18:30 for a 19:00 start
212 High Holborn, London.

Involve is holding a reception on Thursday 9 February, to launch its first political pamphlet, 'The Promise of Participation'.

Anyone who wishes to attend should contact Involve at
Reception@involving.org

Patient Information Conference

Tuesday 28th February 2006
Manchester Conference Centre

This conference has been designed to outline, in practical terms, the steps that should be taken to ensure that accurate and timely information is delivered to patients, through the most appropriate channels.

CPD ACCREDITED

To view a copy of the conference brochure or to book online, click on <https://secure.healthcare-events.co.uk/conferences/confdisplay.asp?id=469>

Picker Institute Europe
Tel: +44 (0)1865 208100
Fax: +44 (0)1865 208101
Web: <http://www.pickereurope.org>
Email: Danielle.Swain@pickereurope.org

For all subscription enquiries contact the above address or email m.mcclean@bearhunt.org.uk

a bearhunt publication - www.bearhunt.org.uk