

# PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

## Confidence, Connection, Contribution...

### Delegates pen open letter to John Reid about the future of PPI

**Delegates at this year's PPI Monitor annual conference 'Confidence, Connection & Contribution', collectively penned an open letter to The Secretary of State, Dr John Reid.**

In a session entitled 'If I Ruled the PPI World', led by facilitator Betsy Gray-King, key themes were raised both by PPI professionals and forum members.

These included proposals for new measures to increase the involvement of the public in health by encouraging employers to give time off work; allowing more time for proper consultation to take place on service changes; and a plea for more and better training for NHS staff and forum members.

The full transcript of the letter will be published in the next edition of PPI Monitor, along with a special feature on the conference.

Other sessions at the event, which was held in Manchester on 11<sup>th</sup> November, included paralympic swimming gold medallist Sarah Bailey with tips on how champions think for those wanting to be champions for health; the CPPIH on the future of forums; inspirational speaker Gavin Cargill on finding and using your five talent themes; Cath Broderick on meaningful consultation; a dramatic and interactive piece of theatre on the issue of patient empowerment, written and produced especially for the conference by Operating Theatre; and PPI Monitor editor Malcolm McClean on how to make PPI into a word of mouth epidemic.

The feedback has been excellent. One delegate wrote "I loved the inspirational, new, creative stuff. Feels refreshing, uplifting and exciting. More stuff like this please".

We are determined to make next year's conference even better. In the meantime we will continue to bring you more of this 'stuff' every month in PPI Monitor. It has been and will continue to be the only place to be for people in PPI.

**THE NEXT EDITION OF PPI MONITOR WILL BE PUBLISHED IN JANUARY. WE LOOK FORWARD TO INSPIRING ALL OUR READERS IN THE NEW YEAR.**

#### INSIDE THIS ISSUE

**Who's in Control Anyway?** Stuart Copeland argues that PPI Forums can maximise their impact by organising themselves

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**Telling Tales.** Throughout history people have memorised and relayed their experiences through stories. Find out how to capture narratives that can be put to good use

# Magic Boomerang

As children, we whiled away many an hour staring into the window of Fred Aberdeen's newsagents. It was one of those old fashioned kind of newsagents. The kind that sold much more than just newspapers and sweets.

The shop window was a place of wonder for eight year olds. Bursting with Airfix models, itching powder, magic tricks and the like. It was a place where we indulged in dreams.

One of our favourite little fantasies concerned the plastic sixpenny boomerang which was suspended from a high shelf by a brass drawing pin, which had been unceremoniously pierced into its sellophane wrapper.

We wondered if it could be that this boomerang was like the one on TV. A magic boomerang.

We had seen the power of the magic boomerang in an Australian TV series. Whenever the boomerang was thrown, everybody except the thrower was left frozen in suspended animation, until it was caught again. This left just enough time to rearrange events or change the course of history to your advantage. It was our fantasy to one day acquire such a boomerang. We new exactly how we would use it to remove all

the goodies from Fred's shop, whilst everyone else stood fixated and unaware of what was going on.

After the Boomerang and long before Kylie Minogue, the Australians gave us Skippy, the bush kangaroo. We were fascinated that the kids did not have to go to school, and instead talked to the radio. How we longed to be able to do this.

What a land this Australia must be, we thought, with boomerangs, clever pet kangaroos and no proper school – and this was before we had even factored Kylie Minogue into the equation.

Later this month I will at least be able to live out my Skippy fantasy, when I broadcast live from London to six Australian cities. Their indigenous people want to take more control over their lives and their health, and they don't care how far afield they have to look to find fresh ideas and approaches. So that is what we will be talking about 'skippy-style' over the airwaves.

In preparing for this antipodean adventure, it occurred to me that the PPI world feels almost as though someone has thrown the boomerang. We are in the midst of a consultation about the future of the CPPIH

and patient forums and the implications of the White Paper on health have yet to be fully unravelled.

Rather than stand frozen, waiting for someone to change the course of PPI history, there is much that we can do to influence events. Of course we can make sure that key concerns and good ideas are played into the consultation. We can also begin to assess what the White Paper means for patients and the public and begin to ensure that professionals and forum members play this in to all of their activities.

We can also take a leaf out of the book of the indigenous people of Australia and look far and wide for new approaches and new ideas. A key theme of the PPI Monitor conference this year was that everybody needs to share ideas and approaches much more.

Whilst the boomerang is in motion, we must make sure that it is business as usual for PPI, and we must show that the PPI movement is getting stronger and more influential where it matters – at the grass roots.

If we don't continue to consistently show the importance and value of PPI, why should anyone want to give a Castlemaine XXXX for it? G'day.

## EDITORIAL ADVISORY BOARD

### Chris Dabbs

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

### Nick Bosanquet

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

### Zenna Atkins

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

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

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

### David Gilbert

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

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# Have your say in health

**Getting the public more involved in the NHS stepped up a gear this month as the Government began consulting members of Patient and Public Involvement Forums and other stakeholders about the new arrangements that will replace the Commission for Patient and Public Involvement in Health (CPPIH).**

The Department of Health and the CPPIH are sending consultation surveys to every member of the 572 Patient and Public Involvement Forums - some 5,000 people - to involve them in building on the huge progress already made in patient and public involvement in health. This will be backed up by a number of in-depth workshops.

The consultation focuses on future arrangements for:

- the recruitment/appointment of PPI Forum members;
- staff support for PPI Forums;
- the guidance, training and advice needs of PPI Forums and the NHS in patient and public involvement; and
- mechanisms for PPI Forums to work in partnership with the NHS, local authority Overview and Scrutiny Committees and the Healthcare Commission.

Health Minister Rosie Winterton said: "This is a real opportunity for people to have their say - we are genuinely interested in hearing

their views. Patients and the public, quite rightly, have higher expectations of the NHS than in the past. They want to be involved, informed and to influence local service provision. The establishment of PPI Forums last year set the wheels in motion. Forums have already proved to be a key resource for local people, helping people get involved and improving their experiences of the NHS. We now want to build on that."

Sharon Grant, Chair of the Commission for Patient and Public Involvement in Health said: "We are hoping that all Forum members, statutory and voluntary sector health organisations, as well as the wider public will take this chance to influence how the voice of patients and the public will be heard in health in the future."

## Listen, Consider, Respond

**'Listen, Consider, Respond' is the title of the new NHS Alliance strategy for PPI.**

A spokesman for the Alliance said "The demise of the Commission for Patient and Public Involvement in Health does not mean the policy no longer matters. On the contrary, it is just as important as ever – for the simple reason that it offers significant health gain. If primary care is about improving health as well as treating sickness, then PPI and community engagement are a tools that must be used".

As well as offering PCTs some clarity and

ideas about how best to focus PPI locally, the Alliance plans to put more pressure on the Department of Health to keep it high on their agenda and direct more resources to primary care trusts so as to make it easier for them to carry it out effectively.

Dr Brian Fisher, NHS Alliance national lead for PPI said:

"Even though there is a lot of work going on up and down the country, there is little evidence that, in practice, the views of patients and the public are stimulating much change. No one seems to be doing a great deal. It isn't happening. It seems to remain

low down on everyone's priority list.

"The Alliance believes that this is not good enough. If the NHS is to deliver the improvements we all want, then there has to be a genuine partnership between the professionals and managers in the health service and the public they serve. We have to listen to patients and local people, consider their views and respect them."

**For more information, contact Pat Goodall, 01246 410707 or [p.goodall@nhsalliance.org](mailto:p.goodall@nhsalliance.org)**

## Managing Complaints for Service Improvement

Managing Complaints for Service Improvement is a new NHSU programme to manage patient complaints in the NHS. On 25 October, NHSU officially rolled out its programme, Managing Complaints for Service Improvement, to help NHS staff improve the way they handle patient complaints.

This new programme will help complaints management staff adopt a more consistent approach in investigation and reporting to

help resolve the 90,000 written complaints that the NHS receives every year. It focuses in particular on improving local resolution. More importantly still, it will help meet the expectations of members of the public when they have a legitimate reason to complain. The programme has been developed in Partnership with Middlesex University and is the only one available in the NHS that provides an accredited qualification for complaints management. NHS staff will be

able to access the programme nationally at training venues across England. It will be delivered by trained and experienced facilitators and has already received exceptionally positive feedback from NHS staff in its South West pilot.

For more information about this programme, please contact Lyndy Pullan on: 020 8528 1850, or email: [lyndy.pullan@nhsu.org.uk](mailto:lyndy.pullan@nhsu.org.uk) or visit the NHSU website: [www.nhsu.nhs.uk](http://www.nhsu.nhs.uk)

# Pathways

**Brian Chapman reveals how a project in Manchester shows that creativity is an effective means for engaging people and communities.**

Pathways is a programme of artistic activity centred upon mental health and well-being in community settings. Artists are working with local people to find ways of overcoming emotional difficulties and daily stresses associated with ill-health.

The project is the outcome of a partnership between Manchester City Council, the South Manchester Healthy Living Network and Lime <www.limeart.org>. It encourages people to learn about themselves and explore change through the arts and creativity.

Pathways' mission is 'to explore avenues of creativity within the community and show how the arts through creative activity can play an important role in militating against mental ill-health.'

## The birth of Pathways

Pathways has been gestating in various forms for some years. With finance from the Neighbourhood Renewal Fund, the first phase (2003-4) was in Wythenshawe and the second phase (2004-5) is in central Manchester.

## The research process

Pathways is looking at new ways of addressing concerns around mental health. Earlier action research strands enable us to monitor and evaluate the progress of the project as we go along. The researchers, artists and beneficiaries have worked closely to:

- assess effects of arts intervention on the quality of life of participants
- show how the outcomes of this assessment relate to the Public Service Agreement and Health Improvement Partnership targets
- evaluate effectiveness of the referral pathways and signposting

## The creative activities

The aim was to work with local people to find ways of overcoming emotional difficulties and daily stresses to express their individuality and share their personal journeys. It was agreed that keeping these aims in mind would improve emotional literacy and capacity:

Aims and objectives	Indicators of success
To deliver participatory arts practice addressing mental health issues among older and younger people in Woodhouse and Benchill, Wythenshawe.	<ul style="list-style-type: none"> <li>■ Numbers of participants.</li> <li>■ Cross generational work.</li> <li>■ Project delivery involving people from the target areas.</li> </ul>
To improve well-being and enhance quality of life for participants.	<ul style="list-style-type: none"> <li>■ Level of self-expression and increased well-being.</li> <li>■ People feeling valued.</li> <li>■ Improved self-esteem, self-confidence and changes in lifestyle.</li> </ul>
To show ways in which artistic activity, research and referral can work together.	<ul style="list-style-type: none"> <li>■ Successful methods of self-evaluation through artistic activity.</li> <li>■ Collecting and collating meaningful data.</li> </ul>
To build partnerships with other services, organisations and agencies with the prospect of future co-ordinated arts and mental health provision city wide.	<ul style="list-style-type: none"> <li>■ Artists working in collaboration with the communities, community development agencies and public sector bodies.</li> </ul>
To uncover meanings for terms like 'well-being' and 'quality of life' among the target groups.	<ul style="list-style-type: none"> <li>■ Documentation of differing views and perspectives from the local community.</li> </ul>

## Who am I? What do I feel? Who are you?

With these, the artists were able to run the sessions with an open approach where anything was possible so long as a safe environment was maintained.

## Taking on roles and issues.

During the drama sessions, people were encouraged to 'act in' and to reverse roles with objects and symbols. This enables the participant to 'be in the other persons shoes', or in some cases speak from other facets of themselves and this way they gain insight into 'Who are you?' Having an awareness of the therapeutic value and an understanding of development theory enabled the artists to steer a constructive and safe course with an appreciation of the influence of past history on participants' reactions. On numerous occasions, people shared their histories and their understanding of past patterns.

## Creative tools

### Feelings through Photography

Photography was used in a variety of ways: as a tool to document our emotional journey,

to record sessions that used other art forms and to express feelings. Using subjects as metaphor, objects as representation, symbolism and traditional urban landscapes and portraiture images were captured to express 'how we feel inside'.

### Lifelines

Lifelines were a reference point to drama sessions and a drama in themselves. Objects were used as symbols and metaphors for significant moments and relationships within people's lives. The way in which these were spaced along an imaginary line drew attention to the importance of spaces and their relationships with each other and where they occurred in that person's life.

### Social, Cultural and Role Atoms

As a starting point members of the group experimented with their own roles. This informed understanding of each individual and each other.

The Social Atom charts the people we relate to in order of closeness. This enables us to reflect on whom we would want to draw closer to us and who is moving away.

The Role Atom gives us the opportunity to recognise the roles we play, take on, are given and create in our lives.



# Learning from experience

**Both lay people and health professionals can learn much from others' own experiences of illness. Andrew Herxheimer introduces DIPEX (Database of Individual Patient Experiences), a systematic collection, available to all.**

In 1996, Ann McPherson (a GP) and I (a clinical pharmacologist) became aware of an astonishing gap in knowledge: little was known about people's own experience of illness – doctors and other health professionals were not really interested and had their own agendas. Of course, patients talked and sometimes wrote about their experiences, but these were rarely recorded and no one learned from them. We had both just had an intensive forced learning experience: Ann with breast cancer, me with a knee replacement. We decided to collect personal experiences to help people with a new serious illness understand what it can feel like and what to expect. It has since become obvious that such collections have many other important uses.

## Building the database

Our initial attempts did not work, but Sue Ziebland, a medical sociologist, joined later and taught us that it required rigorous qualitative research, using established interview and analysis methods from social science. We now collect experiences by videoing interviews of participants at home. Each researcher takes responsibility for one condition, and asks the person to tell the story from the beginning, without interruption, encouraging them to talk about anything they want. A multidisciplinary panel, including patients and different professionals experienced with the condition, advises each researcher.

Second, we collect stories for one condition at a time, because the researcher can learn about and understand it, and it facilitates funding. The first two were high blood pressure and prostate cancer. For each condition we recruit a 'maximum variation' sample – with the help of GPs, consultants and self-help groups – because we want as far as possible to describe the full range of experiences of the illness: in men and women, old and young, different social classes and ethnic groups, from various parts of the UK, having had different treatments, with and without complications, etc. Such a sample aims to be representative of the range of

The point is that everyone who looks at an analysis of any topic within the collection should be able to find a description of an experience like their own

experience, but not to be proportionately representative, and thus cannot be used to draw conclusions about what is an 'average' or 'usual' experience. A 20-year-old with breast cancer would, for example, be dispirited to find that the collection included only stories from older women – we therefore include interviews with atypical as well as typical respondents. The point is that everyone who looks at an analysis of any topic within the collection should be able to find a description of an experience like their own – although often not from someone of the same age, gender and ethnic group as themselves. Most collections include between 35 and 50 interviews; additional ones tend to describe experiences already reflected in the sample.

Third, the interviews are transcribed and analysed according to the themes that people talk about. For each theme or topic the researcher prepares a summary, illustrated with video clips from several participants. Some themes are expected, such as anxieties felt on receiving the diagnosis, and what sources of information they used. Others surprise us: for instance, men with testicular cancer were angry when not offered a false testicle, and people with lung cancer felt intolerable stigma because of the association with cigarette smoking.

In the last stage, we put the summaries and the clips on the website, together with reliable information about the condition, questions (many from the people interviewed) and answers, and links to other

sources of information and support groups. The site also has a discussion forum for each condition, where anyone can post comments, questions and their own experience. We do not incorporate such experiences in the collections themselves as that would distort the balance of the sample. People who contribute illness experiences to open websites tend to report either very bad or very positive experiences, so conveying rather biased views.

The DIPEX site now has 14 collections ('modules'), we will add another six by the end of 2004, and work is proceeding on many others (see table). We aim to complete 100 collections in five years. One collection occupies one researcher for about 13 months.

## Unexpected discoveries

We first thought that when a collection was complete we would just go on to the next collection, but so many new or previously undocumented insights emerged that the researchers had to write them up for separate publication as scientific papers. Over 20 have now appeared: a full list will soon be on the website. Many concern aspects of illness that patients consider important, but of which many professionals are unaware or have not considered. It became clear that many people do not realise that screening can have serious disadvantages. People have different expectations from follow-up, but are rarely asked what they are, or what follow-up they want. Other findings concern patients' use of the Internet and other sources of information. Many become well informed and competent at finding what they need. People's attitudes to treatment choices and their medicines vary enormously, but they hesitate to express them and clinicians often wrongly assume that they understand their feelings. Communication between patients and professionals about embarrassing matters such as incontinence is often inadequate or insensitive.

## Useful not just for patients and their families

Although DIPEX was primarily intended for patients, it is also valuable for health professionals, students, researchers and policy makers. When students learn about a condition they usually see only one or two patients, and tend to assume that all patients with it are like those they first saw. It often



takes them years to realise that is wrong. The use of DIPEX can prevent this mistake. By seeing the great variation among patients, clinicians can become more sensitive and learn to listen better and to ask.

Clinical and quantitative researchers often lack access to good data on what outcomes matter most to patients, and have tended to study those of greatest scientific or economic interest, losing the chance to examine questions that patients want answered. DIPEX pinpoints many of these and can promote discussion between patients and researchers. This also applies to policy makers, and is now part of the work of the National Institute of Clinical Excellence.

## Evaluation

DIPEX needs formal and informal evaluation, especially with patients and their families, medical and nursing students, and in postgraduate training. So far, there have been small formal evaluations using focus groups and individual interviews with breast cancer and prostate cancer patients, young people on sexual health, and people with hypertension. Most said that DIPEX would have helped them had they seen the website when they were learning about their condition, and some useful suggestions were made for improvements. An independent survey by The Tavistock Institute of about 200 visitors to the DIPEX website got largely

positive feedback. Work with students and GP trainees is now going on.

The DIPEX website won the 2004 BUPA Communication Award, and a commendation in the 2004 BMA Patient Information Award. In 2001, it got the Social Innovations Award - Medical Category, and was "Highly Commended" in the 'best publicly accessible website' category of the 2002 Healthcare IT Effectiveness Awards.

Towards an international DIPEX collaboration

Illness experiences differ between cultures and health care systems, even with the same condition. It will therefore be necessary to collect experiences in many countries, languages and communities; international collections will be essential, especially for rare conditions. When we can compare experiences in different settings, we will at last be able to tell which differences are due to culture and which to service provision. Interest is growing in Europe, Australasia and North America, and we hope to hold international workshops on the methods.

## DIPEX Research Group

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Name of collection	When ready
<b>Cancers</b>	
Bowel cancer	now
Breast cancer	now
Cervical cancer	now
Lung cancer	now
Ovarian cancer	late 2004
Prostate cancer	now
Teenage cancers	2005
Testicular cancer	now
<b>Heart Disease</b>	
Congenital heart disease in children [parents]	now
Heart attack	now
Heart failure	now
High blood pressure	now
Living with Dying	
Living with dying	now
<b>Maternity</b>	
Antenatal care	spring 2005
Breastfeeding	[ongoing]
Experiences of pregnancy	[ongoing]
Terminations for foetal abnormality	2005
<b>Mental health</b>	
Depression	now
<b>Neurological</b>	
Chronic pain	late 2004
Complex regional pain syndrome	[ongoing]
Dementia [carers]	late 2004
Epilepsy	now
<b>Screening</b>	
Antenatal screening	late 2004
Breast screening	late 2004
Cervical screening	now
<b>Others</b>	
Critical care	[ongoing]
HIV	[ongoing]
Immunisation of children	[ongoing]
Sexual health of young people	late 2004

# Involving Patients in NHS Cancer Networks

**Health services are increasingly being delivered through networks and partnerships – PPI is having to respond. John Sitzia, Phil Cotterell and Alison Richardson offer learning from the experiences of NHS cancer networks.**

## Introduction

NHS cancer services are at the forefront of patient and public involvement (PPI), stimulated by its inclusion in cancer policy initiatives (including the NHS Cancer Plan), the Manual for Cancer Services (Department of Health, 2004) and Supportive and Palliative Care Guidance (National Institute for Clinical Excellence).

The Cancer Partnership Project (CPP) which ended in March 2004, provided £15,000 per year to each cancer network in England to establish a 'partnership' group. Here we report some key findings from an independent evaluation of the initiative, in which 59 patients and NHS staff were interviewed to find out what difference the CPP had made.

## The Work of Cancer Partnership Groups

We found that most cancer networks had an active, enthusiastic group made up of both NHS service users and NHS staff, with a wide variety of staff involved, including doctors, nurses, radiotherapists, counsellors, and managers. Groups were very focused upon influencing local cancer policy and services for the benefit of patients, and ensuring that the service user perspective was integral to service developments.

The range of activities engaged in by groups was impressive, with five broad themes:

- The simple fact that the group existed was regarded as a major accomplishment; groups had credibility with NHS managers, and were perceived as serious and businesslike.
- Groups provided an easily accessible 'sounding board' for numerous NHS consultations and projects, such as new NHS capital projects.
- Groups acted as a focus for PPI, and formed the centre for widespread PPI networks.
- Patient information and communication

projects often were a key activity, such as Breaking Bad News standards or patient information leaflets.

- 'Campaigning' to change service policy and delivery, such as service provision in 'satellite' units, or to improve access and facilities for patients.

## Key Lessons Learned

The evaluation provided a wealth of information on the processes for advancement of PPI in local NHS services.

### Perseverance

Both NHS and service user respondents spoke of the enormity of the challenge of partnership working and of the complexities of change processes within the NHS.

As well as taking time, change requires constant and repeated pressure upon NHS decision-makers: one respondent talked about the "drip, drip, drip" effect, another about "chipping away" at established values and beliefs.

### Leadership, membership and support

The most successful groups were often those with dedicated and competent 'leadership', typically provided by the chairperson (usually a service user) and the group's facilitator. Facilitators – salaried NHS professionals whose prime role was to develop PPI – were reported without exception as being of crucial importance to the influence and successful functioning of the group, and required a broad set of interpersonal and professional skills. A good relationship between chairperson and facilitator was essential, as was an ability to develop a shared vision of the group's work and role.

High-level, local NHS commitment to PPI was regarded as of utmost importance, and was visible in some networks but not others.

### The developing 'rules' of partnership working

The CPP initiative provided significant new insights on partnership working. We found that the inclusion of service users in NHS decision-making 'systems', such as meetings and committees, challenges the norms of those systems in all sorts of ways.

An example is that of service users talking about personal experiences in meetings. A

founding principle of PPI is that patients 'expertise' comes from personal experiences of NHS systems. Service users considered such contributions, when delivered in moderation and with focus, to have a valid place in meetings, whereas NHS members tended to be more uncomfortable with such 'disclosure', citing concerns about ethics and confidentiality, and some suggestion that such recounting was simply not businesslike.

We concluded that Partnership Groups bridge two quite different worlds and that, through open and constructive discussions, some adjustment of cultural norms was required on both sides.

## Conclusions

Partnership groups were well organised, made a credible contribution to local NHS decision-making, and undertook a wide range of useful activities that had a positive impact upon services. The model of a 'Partnership Group' within in a clinical network is an important mechanism for meaningful PPI.

**Full copies of the Cancer Partnership Project Evaluation are available free of charge from Macmillan Cancer Relief on 020 7840 7845 or email: [clowe@macmillan.org.uk](mailto:clowe@macmillan.org.uk)**

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## Acknowledgements

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## On Trial

What is important for lay people about clinical trials? While developing a new website for potential participants, Bec Hanley and Kristina Staley found out.

Many people who use health services are asked to take part in clinical trials. But, with some notable exceptions, it is difficult to gain access to good, clear information about trials.

This article describes the development of a website about clinical trials for potential participants, their families and friends. We developed this site in partnership with service users and the public because we wanted to address the questions they might have, rather than what researchers might want to tell them. The project was supported by the National electronic Library for Health.

### Our aim

To develop a website that would answer people's general questions about clinical trials and help them to decide whether to take part.

### How we did it

We first held two focus groups with people who had never taken part in a clinical trial and asked them what they wanted to know. We then asked them which of their questions were most important. This helped us to structure the website around the topics that would most interest the public, rather than the priorities of researchers.

We also reviewed the information about trials produced by a wide range of organisations as well as the published literature on getting people's informed consent. We drew on this material to compile the draft content of the site. We asked people who had taken part in a trial or who had worked with researchers to plan and develop a trial to write about their experiences.

We then asked people from a number of different patient groups to comment on a draft version of the site, to help us produce a pilot version. We publicised this site through newsletters, conferences and emails. The pilot site had a feedback button, and we have since made further amendments based on people's views.

### What people said.

The top five questions from the focus groups were:

- How can I tell if a trial is safe?

This article describes the development of a website about clinical trials for potential participants, their families and friends.

- What are the risks and benefits of taking part in a trial?
- What happens if things go wrong?
- How can I tell if the people running the trial will do a good job?
- Will my details be kept confidential?

As well as giving feedback on the site, the patient groups made the following important points about trials in general:

- Most people really want to get information about trials specific to their condition. This reinforces the need for a user-friendly register of trials.
- It is often difficult to get information about why a trial is important to service users – every trial needs to make this clear.
- People want more information as to how they can work with researchers to take forward new areas of research.

### Next steps

The website was launched at the National Institute for Clinical Excellence (NICE) conference on 30 November, 2004. It is at [www.nelh.nhs.uk/clinicaltrials](http://www.nelh.nhs.uk/clinicaltrials)

We are still welcoming feedback on the site, which we hope will soon be made available through NHS Direct Online.

### Lessons learned

This was a very useful way to develop a website. By asking people what they wanted to know before we started writing, we were able to reflect the priorities of potential readers, rather than our own views. It was crucial that the project sponsors were committed to listening to the views of service users, rather than being overly influenced by what researchers wanted to include.

We also found that people were content with clear, written information. Most people thought that video clips or audio recordings would only be difficult to download without adding any value.

From our experience, if we were to do a similar project in the future we would:

- Allow more time. The project took longer than we had anticipated – because for example, we needed to allow for publication timetables of newsletters.
- Do more work with the web designer to ensure that the site is accessible to as many people as possible. There are guidelines produced by organisations such as Mencap and the Royal National Institute of the Blind (RNIB) about making websites more accessible. We benefited from feedback from people with visual impairments about how to improve some of the visual aspects of our site.
- Include more stories from people who have taken part in a trial or who have worked in partnership with researchers to plan, monitor or evaluate a trial. These provide an engaging and easily accessible way to find out what taking part in a trial actually means.
- Do more to ensure that people who do not have access to the Internet can still get access to this information. For example, by finding additional resources to publish and promote a hard copy version.

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# The Scottish Route

## Patients and the public at the heart of health services.

**Devolution is steadily having its impact on patient and public involvement across the UK. David Steel and Ann Clark describe the new approach to patient focus and public involvement in health services in Scotland.**

### Introduction.

The NHS Reform Scotland Act 2004 is laying the foundations for some fundamental changes to patient focus and public involvement in health services (PFPI). Since 1975, local health councils (LHCs) in Scotland, similar to the former community health councils in England, have had a statutory duty to represent the voice of patients and the public in the NHS. From the 31 March, 2005, LHCs will be dissolved. The 15 local NHS boards, which are responsible for all NHS services in their area, now have a statutory duty to involve the public and to deliver patient-focused services. From 1 April 2005, the new Scottish Health Council (SHC) will monitor the performance of NHS boards. The SHC will be a national organisation with a local office in each of the 15 NHS board areas.

NHS boards are already required to have a strategic framework for achieving public involvement and a patient-focused NHS. The Scottish Executive's commitment to patient focus and public involvement was confirmed in the White Paper Partnership for Care; a three-year programme to implement patient focus and public involvement was published in 2001. NHS boards are expected to:

- treat people with respect, as individuals and involve them in their own care
- design services for and with the people who use them
- involve people and communities in improving the quality of care, influencing priorities and planning services.

The NHS Reform Scotland Act 2004 is laying the foundations for some fundamental changes to patient focus and public involvement in health services (PFPI)

As an interim arrangement pending the establishment of the Scottish Health Council, NHS boards have been supported to take forward the PFPI agenda by the Involving People Team at the Scottish Executive Health Department. The SHC will build on their work and take on new responsibilities.

### Assessing the Performance of NHS Boards.

The SHC will assess the quality and extent of the patient focus and public involvement activities of NHS boards and the impact in terms of service outcomes and improvements. Evidence provided by NHS boards about their performance will be verified by the SHC as part of an ongoing dialogue throughout the year. The SHC assessments will form a key part of the annual NHS accountability review process and will be made public, following discussion with NHS boards. An annual report will provide patients, the public and NHS Scotland with relevant, accurate and comparable information on the quality and extent of patient focus and public involvement, celebrating successes as well as highlighting areas for improvement.

In addition to this broad assessment process, the SHC will also advise the Minister for Health and Community Care on whether NHS boards have adequately followed Scottish Executive Health Department guidance on service redesign consultations.

This is a 'hot topic' in Scotland at present as NHS boards seek to balance quality, safety and financial considerations within the context of the European Working Time Directive, the new GP contract and general workforce pressures.

Where there has been a serious failure of performance in relation to PFPI, the SHC will be able to ask the Minister to use his powers to intervene or require a consultation to be done again.

### Supporting the Development of Best Practice.

The SHC will continue to support the networks of NHS board designated directors and PFPI staff with which the Involving People Team have worked over the past

three years. A number of partnerships with other organisations working in the PFPI field have already produced a range of tools to support NHS boards, including the Building Foundations toolkit and a Sustainability Framework for PFPI developed with the Scottish Council Foundation. The SHC will have particular responsibilities for ensuring that people whose voice is not normally heard have equal opportunity to get involved in health services. Delivering day-to-day PFPI activities will be for NHS boards, but the SHC will carry out research and pilot new ways of working with communities where PFPI is less well developed.

### Patients and the Public Driving the Quality Agenda.

The Scottish Executive wants the needs of patients, carers and communities considered alongside clinical effectiveness and value-for-money, as the main drivers of service improvement in the NHS. Hence, the SHC will be part of NHS Quality Improvement Scotland. NHS QIS was formed in 2003 from five organisations that all had a role in improving the quality and effectiveness of health services. NHS QIS sets standards, reviews performance and promotes best practice through guidelines and advice to NHS boards. It works closely with Audit Scotland, other inspectorates and organisations such as the National Institute for Clinical Excellence (NICE).

PFPI is already part of the generic and service specific standards developed by NHS QIS. Lay people are involved in the working groups that develop the standards and in the review teams assessing performance. It is hoped that the link with the 15 local offices of the Scottish Health Council will enable NHS QIS to considerably strengthen its own PFPI activity and ensure many more patients, carers and members of the public participate in quality assuring health services.

### Patient Feedback – a route to Patient Focus and Service Improvement.

In the new system, wherever possible, patients, carers and the public will speak for themselves rather than being represented by local health council members and staff.

# Telling stories

Where support is required to enable people to get involved, the SHC will provide advice on what is needed and NHS boards will have a duty to put that support in place. The SHC will 'close the loop' by ensuring that NHS Boards provide evidence of what improvements have resulted from feedback and that people have been informed of how their views have been taken into account.

NHS boards will also commission local, independent information and advice services to assist people who wish to make a comment or complaint. Citizens Advice Scotland is developing a national specification and standards for these services and the SHC will assess their effectiveness on the ground.

## SHC – in Touch with Local Communities.

The SHC will need to achieve excellent standards of patient focus and public involvement in its own activities. One of the building blocks will be voluntary members of Local Advisory Councils (LACs) who will be the 'eyes and ears' of the SHC in local communities across Scotland. As well as being local ambassadors for patient focus and public involvement, members will use their knowledge and experience as users of health services to advise the SHC and to assist local offices to assess the PFPI performance of NHS boards. LACs will also nominate three of the nine Scottish Council members. Interest in membership of the Scottish Health Council has been high with over 500 requests for application forms. Hopefully, this will be replicated at local level.

## Conclusion

PFPI is being taken down a rather different route in Scotland to the other UK nations, in an attempt to build PFPI into the mainstream structures of service delivery and improvement in NHS Scotland. It will be interesting in a year's time to compare feedback about the new system from NHS staff in Scotland with their counterparts elsewhere in the UK.

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**Throughout history, people have memorised and relayed their experiences and concerns through stories. Chris Dabbs outlines methods available to capture narratives that can be put to good use.**

With all NHS bodies now having a duty to involve and consult patients and the public in planning and developing services, and decisions to be made that affect them, there is a desire to use new ways to discover lay priorities.

One growing area of interest is gathering narratives from individuals to identify and explore key issues. Patient diaries have been used for some years, but there is a much wider range of options from which to choose.

## Blogging and vlogging.

A web log is literally a "log" on the web: a shared on-line journal in which the author (or "blogger") posts diary entries, posted in reverse chronological order, about their personal experiences, hobbies and thoughts. An emerging development is vlogging – video weblogs. As the cost of technology falls, this will become increasingly accessible to more people and organisations.

There are, however, cautions: while web-based narratives offer critical opportunities to create and share knowledge, the Internet is not an inherently empowering medium, as it can affirm social norms of consumerism, gender, individualism, etc., and tends to favour more privileged groups.

**There is a good introductory guide to blogging and vlogging at [www.guardian.co.uk/weblog/special/0,10627,744914,00.html](http://www.guardian.co.uk/weblog/special/0,10627,744914,00.html).**

## Discovery interviews.

Discovery interviews allow professionals to hear in person patients' and carers' stories and feelings in their own words and better understand how they can help make a difference. Tape-recorded and then transcribed, the transcripts of the semi-structured interviews can (once identifiable details have been removed) be shared with clinical teams to generate ideas for service improvements.

Discovery interviews enable patients and carers to provide a comprehensive picture of both recollections and experiences. They are a powerful tool through which to learn from patient and carer stories and to understand

With all NHS bodies now having a duty to involve and consult patients and the public in planning and developing services, and decisions to be made that affect them, there is a desire to use new ways to discover lay priorities.

issues from their perspectives. While discovery interviews allow space for patients and carers to explore their own agenda, certain levels of skills and knowledge are required of interviewers to be effective.

**A guide to using discovery interviews to improve care is at [www.modern.nhs.uk/serviceimprovement/1338/4668/CHD%20Discovery%20Interviews.pdf](http://www.modern.nhs.uk/serviceimprovement/1338/4668/CHD%20Discovery%20Interviews.pdf)**

## Patient diaries.

Using a set of guiding questions, a patient or carer keeps a personal written record of their care and treatment over time. The best results come following face-to-face explanations of how a diary should be completed. As well as a paper-based diary, technology now enables electronic versions, including the use of personal digital assistants or even interactive voice response.

Diaries not only allow the individual to identify and explore experiences, ideas and solutions, but also have the advantage of being a record made at the time rather than using hindsight. They are, however, time-consuming for both writer and reader; this considerable investment creates an expectation of consequent action, which requires good forward planning.

# Telling stories - cont

More details at [www.modern.nhs.uk/improvementguides/patients/5\\_4.html](http://www.modern.nhs.uk/improvementguides/patients/5_4.html)

## Patient experiences.

DIPEX (Database of Individual Patient Experiences) is a significant and growing resource offering a wide variety of personal experiences of serious illness, health problems and health-related matters. You can watch, listen to or read interviews, find reliable information on treatment choices and where to find support. The site covers cancers, heart disease, living with dying, mental health, neurological conditions and screening programmes. There are plans for new areas on pregnancy, teenage health, long-term conditions and many others.

The DIPEX web site is at [www.dipex.org/](http://www.dipex.org/)

## Patient shadowing / tracking.

In shadowing, a patient is accompanied as they use services over an agreed period of time. There is then an opportunity for non-judgemental reflection of the experiences. The lessons learned are then used to improve services.

Although requiring considerable preparation and time, shadowing does offer the opportunity for deeper personal understanding of experiences, stronger rapport between patients and professionals, and experiencing the culture and environment in which others operate.

More details at [www.modern.nhs.uk/improvementguides/patients/5\\_3.html](http://www.modern.nhs.uk/improvementguides/patients/5_3.html)

## Personal stories.

Searching for personal narratives is now relatively easy though the Internet. Personal story sites are very useful – simply put in “personal stories + [name of illness]” in a good search engine.

These sites and pages offer an unedited range of experiences and perspectives, which can raise issues and concerns that might not otherwise be highlighted in other forms of communication and discussion. The authors are, however, self-selecting and tend to reflect more active and articulate personalities. The focuses also tend to favour conditions that little affect communication skills: there is less material relating to conditions that are associated with neurological or some sensory impairments.

One growing area of interest is gathering narratives from individuals to identify and explore key issues. Patient diaries have been used for some years, but there is a much wider range of options from which to choose.

## Story dialogue.

The story dialogue method builds on traditional, oral communication and learning techniques. A mixture of story and structured dialogue is used based on four types of question: “what?” (description), “why?” (explanation), “so what?” (synthesis), and “now what?” (action). With a skilled facilitator, open questions are asked of the storyteller by others to generate dialogue, but with a particular set of objectives in mind: to move from personal experience to more generalised knowledge (insights) and action.

This approach was developed in the health promotion field to recognise and respect the expertise that people have in their own lives. The process is structured so that valuable personal experiences are used to draw out insights into important themes and issues, around which action can be planned.

The story dialogue method can yield a wealth of expertise, and is most powerful when different individuals tell several stories around the same theme. The common features can then be identified to inform a practical action plan. The process does, however, take time (especially if sensitive issues are raised) and some people find

moving from the particulars of personal stories to assessing and analysing the generalised learning from them.

For further details see, [www.evaluationtrust.org/tools/story.html](http://www.evaluationtrust.org/tools/story.html)

## Story telling.

Story telling allows a patient or carer to tell their story to a professional from another service. The interview is tape-recorded, from which a ‘mind map’ is extracted, including the use of direct quotes. The person is then asked to confirm what was heard. Once the account is agreed, an action plan is drawn up and fed back to the individual.

This approach lets the patient or carer set the agenda, and raise the issues of concern to them, from their perspective. It does, however, require involvement from people in other services, and needs ways to deal with issues highlighted that do not relate to the particular service in question.

For more details on storytelling, see [www.creatingthe21stcentury.org/](http://www.creatingthe21stcentury.org/) and [www.stevedenning.com](http://www.stevedenning.com)

## Visual methods.

While stories are generally perceived as being oral or written, other means are available. It is possible to use record narratives using visual methods, such as photography, art and video, which might be good for people with literacy problems or some sensory impairments.

Some groups such as children and young people may also prefer them. For example, puppetry has been found an effective way to facilitate dialogue with children, and the Social Policy Research Unit of the University of York have looked into involving children and young people with a chronic illness or physical disability in health services development - [www.healthinpartnership.org/studies/lightfoot.html](http://www.healthinpartnership.org/studies/lightfoot.html)

# Partnership at its best

**To many people, Royal Colleges are little-known organisations; yet these are influential bodies – most of which are working with patients more and more. Joy Dale and Tina Ambury explain the work of the leader in this field.**

The Royal College of General Practitioners (RCGP) is considered to be one of the most forward-thinking professional organisations in health care. This is certainly true with respect to patient involvement and promotion of patient-centred care. In 1983, the RCGP was the first of the Royal Colleges to establish a Patient Liaison Group, which evolved into today's Patient Partnership Group (PPG).

The uniqueness of the Group originally lay not only in its function but also in its composition. Membership was, and remains, five general practitioners (GPs) – up to three of whom are members of the Council of the RCGP – and seven lay members, giving a lay majority. The Group has a lay Chair and both medical and lay Vice-Chairs. This configuration works well and is the model that has since been adopted by many other Royal Colleges.

Issues and concerns are discussed in open and direct debate between professional and lay members. Decisions taken and comments expressed publicly are those agreed between the whole Group. Although the RCGP provide administrative support for the Group, it does not attempt to influence the decisions that are reached.

The stated aim of the PPG is to promote patient partnership in primary care and to highlight patients' concerns and needs.

Lay members are appointed for their skills and experience in patient representation. They do not to promote the interests of any particular group of people or attempt to impose their personal values or beliefs on the Group.

For the purposes of the Group, 'lay member' is defined as "someone who is not and has not been medically qualified". However, lay members who have knowledge of health service delivery, either in a voluntary or employed capacity, as well as having significant user or carer experience, settle more easily into the work of the PPG.

The GP members practice in a diverse range of situations – rural and urban. They might hold administrative, research or other appointments, and may practice as partners in one practice or hold a series of sessional appointments.

The PPG is representative in many ways but less so in others. It is not, for example, fully representative of geographical spread, ethnicity and patients with special needs. These deficiencies are largely overcome by the widely diverse range of service users with whom members of the Group are in continual contact. They are consequently able to reflect all views and issues of concern. Parity in geographical representation does remain a problem. One of the PPG's targets for 2005 is to encourage and facilitate RCGP Faculties (the local arms of the College) to appoint lay members to their Boards.

## How does the PPG operate?

The Group meets quarterly. Meetings are timed to take place shortly before the RCGP Council Meeting. The arrangement gives an opportunity for the PPG to comment collectively on agenda items. The Chair of the PPG is invited to Council Meetings as an observer who can freely participate in the debate.

During PPG meetings, all members are asked to feed back issues of concern brought to their attention by users of primary health care. Discussion between medical and lay members can often sufficiently clarify the situation for an explanation to be conveyed to the patient by the lay member. Often the issue is part of a wider national debate such as out-of-hours provision. Knowledge of patients' experiences is always useful to the PPG when it is involved in an advisory capacity in shaping national policy.

The influence of the PPG extends in many directions. Members serve on various College committees and working groups. Members are asked to present a short report of the meetings they have attended at quarterly Group meetings. This ensures that all members are kept informed of College developments and national trends in primary care.

PPG members are amazingly tolerant of the amount of reading material they receive from the College. As well as committee papers and other primary care information, members receive copies of statutory consultation papers covering health care and well-being. Although they have no obligation to reply to consultation papers, the response rate from PPG members is remarkably high.

Similarly the PPG is often asked to comment on videotapes on health matters. Tapes of Simulated Surgery consultations are particularly interesting. These tapes are used in GP training so authentic patient opinion

adds to their value as a teaching tool.

The RCGP web site provides access to patient-related information. In response to public enquiries, the PPG has produced explanatory leaflets such as 'Common Abbreviations used by Doctors', 'The Meaning of Awards and Qualifications that Doctors Have' and 'Removal of Patients from GPs' Lists' (recently updated in line with the new GP Contract).

PPG members are often asked to represent the Group at promotional and social events hosted by the College and other health care organisations. The personal satisfaction that members gain from the activities of the PPG is hard to measure accurately. Consequently, personal comment from the authors is the most appropriate conclusion.

"Participating in this group has been one of the highlights of my term of Office. The level of debate at the meetings is invariably high, always stimulating and informative. Working with lay colleagues in this way helps ground the College in 'real life' and enables us to be clear that we are representing our patients' views when developing policy. Apart from which it is a lively, enjoyable process." (Dr. Tina Ambury).

"I was apprehensive that my experience as a patient representative in a northern city were not sufficient to allow me to participate in the prestigious work of the RCGP. Little did I realise that I was embarking on some of the most rewarding experiences of my life. I have had opportunities to represent patients' interests in situations that I had never even dreamed of." (Joy Dale, Chair of the PPG.)

## Learning points:

1. Patient representatives are able to constructively discuss health care matters and provision of health care services directly with professionals.
2. Patient representatives provide an effective channel to distribute health related information and to receive matters of concern from local populations.
3. Patient representatives are able to successfully lead and undertake complex initiatives.
4. Everyone, including patient representatives, thrive on acknowledgement of tasks well done.

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Visit the RCGP web site [www.rcgp.org.uk](http://www.rcgp.org.uk) to learn more of the activities of the College and its Patient Partnership Group.

# Connect and Communicate

**Communication problems form the single greatest barrier to involvement – but they are not insurmountable. Susie Parr describes principles and practicalities of involving people with a communication disability.**

Stroke is the single greatest cause of disability in the UK adult population. Of the 100 000 people who have a stroke each year in the UK, over one third acquire some form of aphasia. For someone with aphasia, all channels of communication (speech, listening and understanding, reading and writing) are affected. The impact of this on every aspect of life is not hard to imagine. While some recovery can be made in the early weeks following stroke, many people with aphasia are left with long-term difficulties that profoundly compromise their participation in work, social life, leisure interests and personal relationships. For those with severe aphasia, who struggle to understand others and express themselves in any form, isolation, powerlessness and social exclusion are common experiences. Services and support may be inaccessible. Work, leisure and social opportunities are limited. People with severe aphasia are vulnerable to the strategies, actions and interactions of others, who may lack the skills and knowledge to offer appropriate support.

These are the main findings of a recent research project, funded by The Joseph Rowntree Foundation, which explored the experience of people living with severe aphasia (Parr, 2004). In the project, service providers, voluntary organisations and self-help groups were surveyed, and paid and unpaid carers took part in in-depth interviews. The main focus of the project was, however, an ethnographic study of 20 people with severe aphasia, who agreed to be observed in a number of day-to-day settings including residential and nursing homes, day centres, therapy and volunteer support groups. During 60 observational sessions, everything was documented in detail: interactions, the environment and physical spaces, activities, rituals, routines and so on. Field notes were analysed and the emerging themes fed back to participants for their comments.

## Inclusive research

Many challenges arose in the project. For example, trying to locate participants with severe aphasia was extremely difficult, as therapists had lost touch with them, they

Stroke is the single greatest cause of disability in the UK adult population. Of the 100 000 people who have a stroke each year in the UK, over one third acquire some form of aphasia.

were often unable to participate in stroke groups and their aphasia was often not recognised or understood in the various care settings they entered. The greatest challenge, however, concerned our aspiration to make the project as accessible as possible to the people it was about. People with aphasia are routinely excluded from stroke research, perhaps because it is expected they will struggle to respond to questions, surveys and questionnaires. Those with profound communication impairments disappear from research. Our aim was not just to make this group the focus of the research project but to ensure that people with severe aphasia were engaged as participants and also as advisors to the project.

To enable the engagement of the participants, and to ensure that they understood the project and the part they were to play, these measures were taken:

- consent form made accessible for people who may not be able to read or write (key words, illustrations and icons, tick boxes)
  - time spent with each participant going through the information and consent materials and checking that it was understood
  - all administration concerning appointments and visits was aphasia-friendly and followed up with phone calls.
  - feedback of key themes conducted in small groups with communication support, using specially created materials and illustrations, plus visual analogue rating scales.
  - as well as the formal report, an accessible report was produced, using stories and images to convey the key points. This is in the process of production, and will be distributed to participants and other interested parties.
- The Joseph Rowntree Foundation (JRF) suggests that the projects it funds establish a steering or advisory group. Our group comprised academics and researchers and five people with aphasia, three of whom had major difficulties following complex discussions and expressing their thoughts and opinions. To facilitate their involvement in discussions and decisions about the research process, we took these steps:
- on-line communication support (checking out understanding and enabling expression using drawing, writing, repetition, re-visiting key points and decisions)
  - longer meetings, with frequent breaks and refreshments
  - establishing ground rules (for example allowing time for communication support; slowing the pace of discussion)
  - holding pre-meetings and de-briefing meetings of people with aphasia
  - aphasia-friendly minutes, briefing notes and agendas
  - separate meetings for people with aphasia to discuss data and progress
  - tape-recording transcripts of observational data for people with aphasia
  - holding a series of meetings close together to maintain impetus and retention of issues.
- time spent negotiating with carers, discussing the competence of the person with aphasia (which relatives and carers sometimes doubted)
  - accessible project information (simple text, boiled down to key words, large font, specially commissioned illustrations)

## Learning points

We learned an enormous amount from the process of conducting this project as well as from the study itself. For example, we realised that it was not enough simply to set ground rules for members of the advisory panel: everyone on the panel would have benefited from training. People with aphasia would have welcomed training about research methods, how the JRF advisory groups work and about the scope and limits of their role as project advisors. Panel members without aphasia found it very difficult to modify, streamline and slow down their communication. They would have benefited from learning about aphasia and from practical training in communication support. We had not anticipated or allowed time for this. Time was a big issue for us. Adding in the extra meetings, and stretching the duration of the meetings themselves as well as allowing for preparation and debriefing, was something that we had not taken into account. We were extremely fortunate that the Foundation was prepared to be flexible and creative in their support for us as we problem-solved and devised new ways of doing things along the way.

Dissemination faced us with some questions, which we have not yet resolved. Is it possible to make theories and complex, detailed findings accessible without 'dumbing them down'? Are accessible forms of dissemination valued as much as publications in, for example, peer-reviewed journals? Although there is much talk about involving users in research, how acceptable are the necessary processes of involvement to potential funders, particularly as they often demand as much time and attention as the subject of the research? It seems likely that the research culture has some way to go before its interest in user involvement can move away from tokenism.

## Other applications: Connect, the communication disability network

Lessons learned from the severe aphasia project have fed into user involvement endeavours at Connect, which is a voluntary sector organisation seeking to influence services for people with stroke and aphasia. The organisation is pioneering accessible information and resources for people with stroke and aphasia, such as the newly

published Stroke and Aphasia Handbook. This provides seamless information on a range of health, social care and welfare, and draws heavily on the accounts of people who have experienced stroke and aphasia who were consulted in a series of interviews and focus group discussions. These consultations were organised in such a way as to make them accessible, with plenty of reviewing, re-capping, clear documents and on-line communication support. Connect also offers training on a number of topics including user involvement and how to make research accessible and inclusive.

Connect has established a forum of people with aphasia (called Live-Wire) whose purpose is to monitor user involvement in all aspects of the organisation's activities: developing and delivering training, therapy and support services, governance and so on. Part of creating authentic involvement for this group necessitates providing accessible information, minutes and agendas plus a comprehensive training and induction programme for Live-Wire members. This, combined with on-line communication support, means that people with aphasia are able to contribute fully to the discussions, decisions and policy development which otherwise they might find inaccessible.

While undoubtedly challenging, trying to involve people with aphasia in research and in the running of Connect brings numerous



benefits. It has made us take stock of taken-for-granted procedures and try to do things differently: stretch time-frames; organise meetings in new ways; think carefully about support, training and environments; and subject esoteric information, theories and interpretations to scrutiny and clarification. We are starting to understand what equalising the social relations of research and service delivery actually means in practice. We have learned that making research processes and outputs (and the endeavours of an organisation such as Connect) accessible for people with aphasia can open them up for everyone. In a new project, supported by The King's Fund, we aim to draw on our experience to create a resource that will help statutory and voluntary organisations enhance the 'communication access' of their services and functions.

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Connect has established a forum of people with aphasia

The Stroke and Aphasia Handbook costs £20 plus postage and packing and is available from [www.ukconnect.org](http://www.ukconnect.org)

Parr, S. (2004) Living with severe aphasia: the experience of communication impairment after stroke. Brighton, Pavilion Publishing.

# The Generation Game

## Building Evidence, Demonstrating Effectiveness.

**It has never been easy to demonstrate the impact of your organisation but doing it when the project aims are diverse and work is measured in generations is especially difficult. Community centres are complex organisations with a range of projects and hosted activities. Mark Parker explains how the network of multi-purpose centres called bassac has been trying to tackle the issue.**

Working across many fields such as health, social care, information and advice, crime reduction, lifelong learning and housing, bassac members are difficult to pin down. Located in areas experiencing social exclusion, they are governed by community members. Most have professional staff but rely on short-term funding to sustain critical services for a range of service users. As they try to meet the community need in the round, most have several projects focused on different service users with diverse outcomes.

In this context, the overall impact is difficult to measure. Monitoring of service use such as the numbers attending or the leaflets distributed provides a basic framework for assessing projects against targets and routinely developing tactics to respond to changes. Evaluation is less frequently used in the community sector yet has the potential to fundamentally affect the desired outcomes and to make strategic changes to the direction of the project or the priorities of the organisation. Both monitoring and evaluation are often limited to project level and assessing the outcomes of the whole organisation remains daunting for many.

In 2000, the Active Communities Unit at the Home Office funded bassac to work with its members to develop some practical tools to address this area. The approach was to work closely with a range of members firstly to define the areas of added value they wanted to assess and secondly to develop and pilot tools designed to this brief. We held workshops in London and York with groups of members who looked at their own monitoring and evaluation practice and considered how they might want to argue the case for their added value as multi-purpose community-based organisations.

We subsequently developed three outline tools for adaptation in the local setting:

- mapping the user journey through the organisation
- making the financial argument
- surveying social capital

### Mapping user journeys.

Multi-purpose organisations often work with the same individuals in several ways. One person may use the café, book a dance class, drop their child at the crèche and volunteer to deliver leaflets. With separate groups of staff and purposes for each activity, it is very difficult to identify how much this is happening and to whom. The tool helped organisations use a method from Participatory Appraisal to draw a map of individual user journeys through the organisation. By interviewing the person with a physical "map" of the services before them, volunteers and staff were able to build up a picture of their involvement sometimes over decades. This resource has then been used to inform management decisions about integration of services and helped everyone see how far different projects interact.

### Making the financial argument.

Community-based organisations are very intent on making every penny count. Such organisations receive much help pro bono, as gifts or voluntary effort; such resources are seldom accounted for, yet add significant value. They are also meeting raw human need every day, often in situations that are much more informal and accessible than the relevant statutory agency. Indeed, their work often saves the state significant costs by diversion and prevention. Putting several services within a single organisation saves those services each having to cost their independent overheads. We developed some guidance about how to use financial data wisely to persuade other stakeholders of the added value the organisation brings to the table.

### Surveying social capital.

In many areas, networks of trust and collaboration are at low ebb. Multi-purpose organisations have traditionally seen themselves engaged in community development yet found it hard to clearly articulate progress in so many aspects of human need. With the development of tools for measuring levels of social capital, local organisations have a means of expressing their mission in quantifiable terms. Despite the length of time taken to affect social capital in any population and problems of ascribing the result to the work of a single organisation, this approach was seen to

offer some valuable hints to a way local organisations (perhaps as groups) might assess the ultimate impact of their work over years. We drew together a questionnaire based on nationally-tested questions and suggested that member organisations asked the same questions to two distinct groups – their own users and the wider community. Comparing and contrasting the results would offer insights into the way work might be focused, developed or abandoned.

In all 16 organisations agreed to work with us on the pilot phase from October 2003 to March 2004. Subsequently, an audit of their experience revealed some significant findings. Whilst all the tools were put to use, only a minority of organisations had been able to make effective use of them in the time frame. Many community centres had faced such change in their circumstances (such as a severe reduction in funds or a change of leadership) that they were unable to deliver on the pilot. In others, the effort to make cultural change stick across the organisation had been thwarted by lack of priority and management skill. Six months was clearly too short a timeframe to move these organisations from an essentially reactive mode to one in which reflection on data delivered enduring benefit for users.

The tools proved useful where they were used effectively. The lessons from this pilot will be fed into the developing pattern of support to frontline organisations under the banner of ChangeUp, where such developments are focused in the performance improvement field. The tools are still in formation and we hope to make them more robust and practical as a result of the feedback from the pilots. Measuring your impact on the whole community remains a tricky issue. Getting clear about the objective and the hurdles to be overcome has taken us a step forward.

**Mark Parker**

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# Community Care Development: a new concept?

**Local communities can respond to their own support and 'community care' needs. A development project in Hull has shown a way, as Deborah Quilgars explains.**

'Community care' and 'community development' have received little joint discussion. Whilst social inclusion policy agendas have brought a renewed focus on communities and a heightened role for community development, care and support issues have been largely neglected in area-based work. In contrast, despite social work's community work origins, community care continues to adopt an individualised approach to delivering support and care.

Identifying this gap, a three-year initiative, the Hull Community Care Development Project, was set up by a partnership of local statutory and voluntary sector agencies to find out whether the community sector could be supported in addressing unmet low-level support and care needs. A Community Care Development Coordinator was appointed to work in two deprived areas of Hull.

The project used community development principles to address support and care issues at a local level, attempting to assist local people in identifying their own priorities and needs. The Coordinator invested time in building up relationships and partnerships through networking and community lunches, supported existing groups and helped to establish new community groups and activities, as well as liaising at city-wide level to influence strategic policy development.

The project had a considerable impact at local level, with key benefits including:

- **Opening of new community facilities:** extending the range of community facilities available to local residents, including specialist youth facilities.
- **Increase in community activities:** activity-based groups were set up including crafts, local history and indoor bowls; a youth network was established, with outreach and centre-based activities; a health garage was set up and run from a local community centre.
- **Benefits of the community activities:** social and health benefits included low-

level mutual support and structured support to marginalised young people.

"... what it does is bring people together. Some people who come to these groups now didn't mix, didn't socialise. They are becoming socially included ... I think there is an element of it in all groups, but with these groups, because they were set up under that auspice, I think people have come together wanting to care more."  
(community member).

- **Developing and strengthening networks:** community groups and active community members were supported in working alongside formal and voluntary bodies; new consultative mechanisms were established including a local Network of residents and local agencies working in the area.
- **New models of working:** the project supported several new partnership arrangements between agencies and community players; agencies were willing to try new ways of working, in community settings, where previously they had little involvement with the community.
- **Developing capacity:** over the three-year period, the project worked closely with several community leaders who were sometimes struggling to get initiatives off the ground, providing support with confidence raising, applying for funding, and developing constitutions.

- **Increased resources:** the development project cost just under £100 000 but helped generate nearly £500 000 for the two areas.

A number of key challenges were, however, also experienced. A shortage of volunteers meant that some activities were unable to be set up or sustained. New community spaces were sometimes contested, and community politics meant that networks were not always able to represent all parts of the community. Community groups generally found it difficult to reach more vulnerable groups in the population. Agencies and the community often had different approaches, which needed careful negotiation.

Overall, the project was most successful in addressing broad community development issue, with communities prioritising issues such as community facilities and provision for young people. This success in part arose from community definitions of community care: interpreting the concept very broadly as developing a 'caring' community. Whilst some low-level health and social care benefits were achieved, it proved more difficult to develop specific care and support initiatives.

The 'invisibility' of people with care and support needs at a community level was a particular barrier. It was concluded that future community care development projects would require an advocacy role that could highlight both the needs and contributions that people with care and support needs can make to the community.

**Deborah Quilgars**

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## Further information:

The full report, *Communities Caring and Developing: Lessons from Hull*, ISBN 1 85935 189 1, is available from Policy Press (tel: 0117 331 4054; email [tpp-info@bristol.ac.uk](mailto:tpp-info@bristol.ac.uk)).

A summary, *Community Care Development: a new concept*, is available at <http://www.jrf.org.uk/knowledge/findings/socialcare/534.asp>

# Who is in control anyway?

To maximise the impact of local voices in health, PPI forums need to take the initiative in organising themselves, argues **Stuart Copeland**.

'Participation' in the 1940s was more vibrant and representative than it is today, even though there was less emphasis put on the concept then. Today, 'participation' has been replaced with disengagement.

PPI forums aspire to maximise 'participation' of patients and the public, to ensure that local communities' voices and interests are heard by the health policy community, and to empower communities to shape and improve their health and overall well-being. This role has been somewhat undermined by the 'professional monopolists' and the 'corporate rationalisers'. Both have been critical of PPI in shaping health and well-being since the establishment of the community health councils in 1973. They have redirected their criticisms towards the ability of PPI forums to represent the voices of local communities. These criticisms include: -

- Lack of professional responsibility and insider knowledge, where health care personnel are best placed to make decisions on directing limited resources toward the greatest need.
- The division between health service providers and commissioning in the NHS 'internal market' results in semi-autonomous and commercially orientated hospital trusts making commercial decisions without need for consultation.
- There are limited resources allocated to health, and the debate is not wide enough to include challenging the power of the pharmaceutical companies to lower prices.
- Not enough professional knowledge, information or experience to allow effective community participation in the local decision-making processes.
- PPI forums will be driven by sensationalist media, resulting in a distortion of communication between the professionals and the community.
- After 20 years of the promotion of the internal market and consumerism, making public services responsive to market forces has resulted in PPI forums and community representatives treating health providers like supermarkets that deliver products,

rather than a public service driven by human values.

- PPI forums and health representation is significantly controlled and informed by the middle classes, rather than unemployed people, the working classes, young people and unorganised social groups. The judgements should therefore be left to the professionals.

Some of these criticisms are completely erroneous and serve only to undermine the good work of PPI forums. Some do, however, have validity; PPI forums can and have identified these, and started to address them through the Commission for Patient and Public Involvement in Health (CPPIH). For example, the CPPIH have developed a number of seminars and 'meet the expert sessions' for some PPI forums. This has, however, been undermined by the 'meddle and muddle' caused by the announcement in July 2004 by John Reid, the Secretary of State for Health, that the CPPIH is to be abolished<sup>1</sup>. This creates considerable uncertainty for PPI forums, and how to ensure central cohesion and a holistic approach to public and patient engagement in shaping the health of local communities.

The Government did, however, establish PPI forums to arrange their own governance structures, operational and strategic policy, and work programmes. It is, therefore, the responsibility of PPI forums to fill the new vacuum. They should establish a Federation of Public and Patient Forums (FPPF) for each region or other obvious geographical area. This would ensure the local voices of the PPI forums are effectively, efficiently and economically represented whilst ensuring legitimacy from the wider health policy community. By developing the role of PPI forums, the FPPFs could be considered the second phase of democratising the NHS. They would provide a cohesive community voice, while safeguarding the interests of local communities in shaping health and tackling the wider determinants of health. PPI forums would need to nominate an 'issue network' member to sit on both their local forum and the FPPF. For clarity of roles, the FPPF must have a structure of portfolio holders.

An FPPF would form from a 'federation' of PPI forum interests, overseeing pooled resources, commissioning research and support, communication initiatives, joint working protocols and strengthening the local voices of PPI forums through expanding the 'issue network' with other local public and voluntary organisations. The local autonomy of PPI forums would be unaffected, although a FPPF would support PPI forums to empower the local public and patients to engage as a collective. It would thus move towards the 'holy grail' of patient empowerment through consensual and "joint decisions between the clinician and patient"<sup>2</sup>.

Each Federation would provide other local health scrutinisers, representatives, media and groups an effective mechanism to communicate with PPI forums within the 'Issue Network'. This would also provide cross-PPI forum communication on areas like work priorities, provide meaningful and representative social research results, developing innovative strategies and an effective public/community networking and communications policy.

The PPI forum framework needs to evolve and expand to strengthen their organisational capacity to represent public and patient voices. The FPPFs would ensure that local community voices can compete and command the same respect and status within the health policy community as do Health Scrutiny Committees (about which the Health Service Journal found evidence of operating out of political interests), the British Medical Association (an interest group for the medical profession), and 'corporate rationalisers' (appointed as guardians of the 'internal market' and consumer-driven NHS). In time, a strategy could perhaps be developed for patients to directly elect members to the FPPF.

**Stuart Copeland**

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This article is a synopsis of a longer document, **PPI forums need to take the initiative in organising themselves to maximise the impact of the local voice in the health policy community.**

<sup>1</sup> Department of Health (2004), Reconfiguring the Department of Health's Arm's Length Bodies.

<sup>2</sup> Guadagnoli, E. and Ward, P. (1998), "Patient participation in decision-making", *Social Science and Medicine*, 47(3): 329-339.

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# EVENTS CALENDAR

## Last Word from Chris Dabbs



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

### Dear Mrs. Buggins,

**What an experience! Our visit to the Chinese community centre was stimulating. Life can be lived positively in many different ways – often unnoticed by others, even when round the corner. I hope that we will develop our new networks.**

British people are not renowned for their linguistic skills or their enthusiasm to learn anything other than English. But the world is changing. If asked, I would advise a parent that perhaps the best language for their child to learn now is Chinese (in one of its many versions).

China has a long and impressive history. Chinese populations across the world have had substantial impacts where they have settled. Most significant now, though, is the incredible development of China itself. Its economy is growing at a stupendous rate, and much of its society is unrecognisable from that of even 20 or 30 years ago. It seems to be moving faster than anywhere else, except in population – India will soon overtake it as the largest nation.

What is perhaps most interesting is China's approach to other countries, especially its neighbours. For historical reasons, other Asian countries have feared China's resurgence as a potential superpower. Yet, in many respects, this appears to be changing.

The present approach of the United States to other countries could be characterised as "You are either with us or against us". By contrast, China under President Hu Jintao (and perhaps before) seems to be asking others, "How might we help you?" or "How might we help each other?" Guess which approach is proving the more attractive, despite understandable wariness.

This is working with the European Union: in 2004, the EU and China will each become

the other's leading trading partner; there are far more Chinese students in Europe than in the USA; there is joint work on both political and military stages. There are not only shared concerns, but the Sino-European axis offers an alternative to the dominance of the United States.

There are several lessons here. First, apparently divergent approaches usually have the potential to gain from collaboration. Second, an approach based on mutual interests will almost always be more effective than one based on "friend or foe". Third, having a common competitor can provide a shared objective and bring people together – it's human nature.

Those of us trying to develop patient and public involvement in health can learn from China. We should regard and treat both managers and health professionals as potential allies, rather than grouping them into friends and opponents. Lay perspectives will gain most if we identify the areas of mutual gain with both groups. This will work best – even with the unavoidable frictions – if there is a common target or enemy that is of shared concern.

If PPI is to be truly embraced in the mainstream, the first step is to really listen not only to lay people, but equally to the concerns and interests of managers and health professionals.

In the meantime, I'm off to get a copy of Chinese for Dummies!

Keep well

**Chris**

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

### Rethinking the Structures for PPI

Friday 3rd December  
The Resource Centre  
356 Holloway Road, London N7 6PA  
10am - 4pm  
Lunch provided.

Cost £90 for statutory and commercial organisations, £45 for voluntary organisations CHCs and PPIFs, £22.50 for individuals. Some free places for people on means tested benefits

**Socialist Health Association**  
0870 013 0065

### Patient and Public Involvement in the NHS

10-14 January, 2005  
University of Warwick  
Price: £590/£775

**Contact: Sally Glassborow, Centre for Primary Health Care Studies**  
telephone: (024) 7657 5553  
fax: (024) 7657 4893  
email: [S.A.Glassborow@warwick.ac.uk](mailto:S.A.Glassborow@warwick.ac.uk)

### Using Your National Patient Survey Results-

One Day Event for Hospital Trusts King's Fund, Central London on Monday December 13th 2004. Listen, consider, respond. Three words that sum up how primary care trusts and GP practices should go about implementing policies for patient and public involvement in health (PPI).

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