

PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

Public engagement is the key

White Paper pins hopes for the nation's health on getting people involved

The consultation period on Choosing Health, the Public Health White Paper closes this month.

As well as a national consultation period, eight task groups were established in response to Derek Wanless's public health report, SECURING GOOD HEALTH FOR THE WHOLE POPULATION.

Wanless set out three scenarios for the future which assume an intrinsic link between the public's engagement in health and their health status: -

1. Slow uptake: where there is no change in the level of public engagement, health status deteriorates and the health service is relatively unresponsive.
2. Solid progress: people become more engaged in relation to their health. There is an increase in health status and people have confidence in the primary care system and use it more appropriately.
3. Fully engaged: levels of public engagement are high, life expectancy goes beyond current forecasts. The health system improves dramatically, people are confident about the health system and demand high quality healthcare.

Chair of the Consumers and Markets task group Ed Mayo said "A social marketing campaign must be established to educate the population". A key proposal of the group is that the government should devise a national advertising campaign to convey all parts of the healthy lifestyle message.

The Department of Health is currently consulting with ad agency Abbott Mead Vickers, ironically, this is the agency which helped Walkers sell 114 million extra packets of crisps.

Social marketing expert Giles Gibbons, Director of the agency Good Business said "Advertising on its own is not going to solve anything. Advertising that leads to an action or activity, for example the Nike run has got a chance because people engage in it. To do broad healthy lifestyle ads won't change anyone. Most people know what they should be doing, and those who don't will not be changed by an ad. A link to actions is essential".

The consultation closes on 28th June, full details of the White Paper and how to contribute to the consultation process can be found at:

www.dh.gov.uk/consultations

INSIDE THIS ISSUE

Listening is key to successful Involvement. Penny Lancaster presents a participatory approach on how and why we should listen to what young children are trying to say.

Jane Cooper from the Long-Term Medical Conditions Alliance (LMCA) discusses how chronic disease represents a challenge to the health care system and how partnerships at all levels are the key to successful self management

Research Findings. Keep up to date with the latest views on Patient and Public Involvement through an in-depth NHS Confederation study. See page 3 for more details.

Ailsa Harrison from Wycombe Primary Care Trust talks about breaking the cycle of cynicism and encouraging people to get involved again by telling people about how they have made a difference.

The importance of involvement from the outset in the redesign of secondary health care services in Greater Manchester is highlighted by Cath Broderick.

And much more including Case studies, PPI Tools, Network Updates, In-depth Interviews and leading opinion.

Yankee Doodle

Confidence. It is embedded in the genes of New Yorkers.

This week I found myself in a bar in Manhattan, researching the city's smoke free legislation. It reminded me of my last visit to a New York bar. Then it was a smoky place, it was 1999 and the evening of the third game of the World Series.

As I tried to recollect the rudiments of baseball I sat side-on to the bar peering at one of two TV screens. Susan walked in with the air of someone who owned the bar. There were several stools that she could have chosen to sit on. Stools where she could have remained anonymous. But to do that would, for a New Yorker, be going against nature.

She too sat side to the bar in the seat next to me. This meant we were facing each other. She looking at the screen over my shoulder, whilst I looked at the other over her shoulder.

As I reflected upon the unlikeliness of such a scenario occurring at home – single girl walking into a bar alone, then sitting face-

on to a strange man – she hit me with a question.

It concerned the batting order. I explained that I only had a flimsy grasp of the game. Susan was a genuine fan. I recognised that vacant stare during the action which is common to sports fans the world over.

In between innings she reacquainted me with the rules of baseball and coloured in the personalities and the quirks of the players. During the innings she reassumed vacant stare mode.

The more I learned the more I concentrated on the game. As I concentrated harder and harder, so the Yankees pulled back a seemingly impossible deficit to win the game. To this day, my part in the winning of the 1999 World Series has disappointingly never been acknowledged.

Over recent months we have talked to over 1000 people who are involved in PPI. For many there is this feeling of being alone in the bar, with only a rudimentary grasp of the

rules of the game. Some people are feeling isolated and disconnected.

We are determined to bring an air of confidence to the PPI community. They say that what you focus on happens. Maybe the Yankees winning the World Series was not all down to me, but everyday at PPI Monitor we are focusing on ways to make PPI more effective and as we do so to help to develop ever greater confidence and ever greater contribution.

In November we will launch the first PPI Monitor annual conference on the theme of 'confidence' with the intention of building a strong and supportive PPI community across the country. We will concentrate passionately on making the PPI world a better place.

With the World Series in the bag I admired Susan's self assuredness. "So Susan. How often do you come into this bar"?

"This place", she looked around "never been in here in my life before".

Confident or what?

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 Samuel and Adam (4 year and 4 week old sons respectively), poetry, and (depressingly) Leeds United.

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The NHS Confederation

Patient and public involvement (PPI) – member views on the new structures

Summary of main findings

This briefing is a summary of findings from feedback at member forums held from January to April 2004 and in-depth interviews undertaken from March to April 2004. Interviewees comprised a sample of 7 Chief Executives and Chairs from Primary Care Trusts, Acute Trusts, Ambulance Trusts and Mental Health Trusts. The interviews were designed to give a more qualitative approach to the detailed analysis of the issues raised at membership meetings.

Main findings

All members were supportive of patients and the public being involved at all levels of the organisation and strongly believe PPI should be an integral part of the planning, decision making and delivery of health care.

There is a consensus view that PPI should be locally led, with locally determined flexibilities and timescales in recognition that each patient group and community is different and it takes time to build effective relationships.

Members expressed concerns about the new structures. In summary:

- The new structures superimpose a one-size-fits-all national PPI model onto every local health community and existing structures, methods and relationships that were developed and invested in over time are now vulnerable or have been lost.
- The national model confuses patient involvement (around specific patient experiences) and public consultations (on the generalities of health care).
- The new structures do not fit together; there are overlaps, tensions and fragmentation.
- The new PPI agenda is focused on measuring the process rather than the quality of patient and public involvement and the outcomes of this.

- 6 months of local PPI activity has been lost as the focus has been on supporting and managing the new structures.

PPI Forums

Members expressed specific concern about PPI Forums, in summary:

- Some members viewed the support provided to PPI Forums to be effective. However most respondents viewed the support provided as variable, as most of the organisations with local contracts to manage PPI Forums lack the capacity and understanding of the local health community and NHS as a whole.
- There is concern that contracts with organisations supporting PPI Forums are not being monitored for quality or evaluated.
- Trusts are investing a considerable amount of time and support managing the process of engaging PPI Forum members in Trust issues and educating Forum members on the NHS. Trusts are concerned that this focus takes up a disproportionate amount of time given the need to also work with the wider local community.
- The recruitment and retention of PPI Forum members is viewed as unclear, poor and at worst a serious risk. Many valuable local voices have been lost, some applied to the PPI Forum and were not recruited and of the ones that did many have since resigned.
- There is a consensus view that PPI Forum members are not representative of the local community, due to poor recruitment techniques, and in some cases vocal



single issue local campaigners have been appointed, who are not representative of the wider local community.

- Some members view it as ironic that the aim of PPI Forums was to increase accountability to and representation of the community, but the process of setting up the new structures has made this difficult.
- Some members are concerned about the quality of the support provided by some of the regional CPPIH offices.
- Members were concerned that some patient forums did not appear to be clear about their terms of reference, to the extent that more than one PPI Forum has asked the Trust to set their agenda.

Other PPI structures

- There was a consensus view that PALS is effective in supporting patients, training staff and working as part of the Trusts' team in raising awareness of PPI.

Very few comments were made about OSCs and ICAS, other than it is too early to say how well they will work with NHS Trusts or what topics they will focus on.

Rising to the Challenge:

A study of patient and public involvement in four primary care trusts

As new organisations with responsibility for the health and health care of their local populations, primary care trusts (PCTs) need to engage with patients and the wider public. This paper identifies the challenges faced by PCTs in implementing patient and public involvement and reports on a qualitative study of four PCTs in one health district. Findings from two pieces of data collection are reported on an audit of community involvement activity and 16 semi-structured interviews with individuals working in the PCTs.

The findings show that organisational capacity for undertaking patient and public involvement activities increased considerably over an 18 month period. The PCTs were found to be engaging with individuals and groups from the community and voluntary sector through a range of different structures and processes. Considerable commitment to patient and public involvement was reported but there were concerns over implementation. A number of influencing factors were identified including national policy, organisational factors, leadership, workload, access to experienced involvement workers and the pattern of local community activity. The paper discusses the implications for the development of patient and public involvement in PCTs including the importance of cultural change and the need for organisational development. The potential for PCTs to be involved in a range of participatory activities and to work with other partner organisations in localities is also discussed. The paper concludes that, despite challenges, progress can be made in implementing patient and public involvement as a mainstream activity in PCTs.

Author: Jane South - Primary Health Care Research and Development 2004

New publication from the Department of Health - <http://www.publications.doh.gov.uk/complaints/toolkit/index.htm>

This good practice guide is for complaints managers working throughout the NHS in England. Many do not have teams to support them in their work, or may be very new to the job. So the DOH have designed the guide to give you instant information, links to much more detailed information and where to go for advice.

Each of the sections gives concise information and links to the websites of organisations where you will find the detailed material that you may need to help you with the more difficult issues.

As you use the website you will see that it is deliberately focussed on local resolution. "We did this because the second stage is currently being revised. Also, a lot of information is already available on the second stage of the complaints process online and in publications. But if you focus on making local resolution work well, then the second stage becomes less important because you will have resolved the majority of complaints."

Handling complaints in the NHS is based on the existing complaints regulations and guidance that are already in use. But there are plans to review the procedures, and when this happens the DOH will amend the website and explain how the changes will affect you.

The information and good practice used in the guide is grounded in people's direct experience of working with the current procedures. "We did this by inviting practitioners, convenors, lay chairs, and complaints managers from around the country to take part in a series of workshops. We asked people to bring examples of good practice to the workshops or send them in, and we made cold calls to trusts. The search for examples of good practice will continue and we will add them to the website."

So, as legislation changes, and as more good practice in this field emerges, the website will be updated to give you the very latest materials and access to relevant facts.

Latest News from The Health Foundation

What do patients want - a worldwide study

Under a new partnership with The Commonwealth Fund of New York, The Health Foundation is investigating what people in the UK, USA, Canada, Australia and New Zealand think about the healthcare they receive. Through our support, for the first time, the International Health Policy Survey is taking an in-depth look at the views of patients and the public in England, Scotland, Wales and Northern Ireland, comparing them to each other and to the views of patients in the other four countries.

The survey will ask questions like: How do people feel about the healthcare they receive? What kind of relationship do they want to have with their doctor and other healthcare staff? To what extent do different people want to be involved as an active partner in their care – and how often do they feel this is on offer?

The Health Foundation believes that dramatic improvements in the health of the public will only be possible if there are significant improvements in access to information about health and healthcare. The survey, reaching 7,000 people worldwide, will provide a comprehensive picture of the state of 'health literacy': the extent to which people are able to access healthcare information and apply it to their own circumstances. The survey will also show the extent to which social inequalities affect patients' abilities to make informed decisions about their health and healthcare.

The results will be published early in 2005.

Evaluation of Local Strategic Partnerships

Community engagement - A briefing note for local strategic partnerships by local strategic partnerships which provides briefing materials for local strategic partnerships (LSPs) in taking forward community engagement. It provides examples of practice, as well as a self-completion toolkit that LSPs can use in their specific local circumstances.

Emerging themes

The set's research underlined the importance of increased clarity about the aims and objectives of different elements of community involvement in partnerships; the development of realistic goals for local level action; establishment of baseline information to use in community involvement processes and allowing a degree of flexibility for community involvement at local level.

Clarity around roles and responsibilities of different communities/structures/stakeholders in partnership working were highlighted as being important.

Regular, targeted and summarised communication within and between partnerships and substructures, about a partnership's aims, objectives, structures, linkages and progress, were thought to be particularly important for engaging and involving stakeholders. Outreach from the LSP to themed or local groups was thought important for engagement, and particularly accessing and involving excluded communities.

The importance of monitoring strategic and local partnership activity was thought key

- looking at each part of the system and what different local partnerships were doing, and feedback to borough-wide partnership groups on emerging themes and issues.

Support, training and development for LSP members and stakeholders was thought to be crucial - perhaps arms length but tailored to particular needs.

A framework for community engagement

A framework was developed by the set to help partnerships assess their progress towards effective community engagement. The framework is intended to show that engaging stakeholders in the work of an LSP cannot and should not be divorced from the day-to-day or strategic activity of that partnership.

It considers three key elements:

- the partnership's different communities
- the styles and methods of engaging these communities
- four integral guiding principles for engagement of these communities at any level.

The guiding principles, detailed below, form the basis of self assessment checklists which partnerships can work through to assess their own performance:

Ownership: successful partnerships are able to work from common objectives towards a collective, shared vision. This is particularly important when engaging communities;

meaningful involvement can only come from participants feeling that they are contributing towards goals that they have helped to formulate.

Partnership structure/inclusivity: The structure of the partnership is the overt demonstration of its commitment to engagement. How decision makers are chosen to sit on the partnership, and methods for feeding in others' views, show to those involved and those outside that different groups' views are taken into account in decision making, planning and delivery.

Working styles and commitment to change: Your partnership will not be perfect. However, to engage communities successfully, as well as fulfilling its many other responsibilities, it should model effective ways of working for different circumstances and groups and be ready to monitor, evaluate, change and move forward.

Relationships and culture: A partnership cannot be expected to work like any one of its constituent organisations, or to work without additional development time and resources and support to do things differently, particularly with regard to community engagement. Individuals and groups need practical and development support to engage effectively with each other and those 'outside' the process.

Authors: An action learning set of 10 LSPs

Price: Free online (PDF 681 Kb)

Website: http://www.odpm.gov.uk/stellent/groups/odpm_localgov/documents/page/odpm_locgov_o28897.pdf

Patient and Public Involvement in Health: The evidence for policy implementation.

Adding considerably to the evidence for the involvement of patients, carers and the public in health decision-making. Findings from the 12 research projects in the Health in Partnership programme.

Executive Summary

The involvement of patients, carers and the public in health decision-making is at the heart of the modernisation of the NHS. This policy drive is founded on good evidence. Health in Partnership, a Department of Health research programme, adds considerably to this evidence. This report is a synthesis of the findings from the 12 research projects in the programme.

The following are the key findings from the programme:

- Patient involvement increases patient satisfaction.
- Patients feel involved in their care when they are treated as equal partners, listened to and properly informed.
- Health professionals are generally positive about patient involvement, seeing it as a

rewarding process for themselves as well as for patients.

- Communication skills contribute to increased patient satisfaction, participation and health care behaviours.
- The organisation of clinics and consultations plays a significant role in enabling and inhibiting patient involvement.
- High quality information enables both self-management and patient involvement, but identifying the right information at the right time is difficult.
- Public involvement influences the policies, plans and services of NHS organisations and increases the confidence, understanding and skills of the people who participate.
- Leadership, board commitment and inclusion in strategic planning are all important for the success of public involvement, which should be a shared corporate responsibility.

- The diversity of values that inspire involvement work can be a source of strength, but little attention is paid to these values and the ways in which they influence the practice of involvement.
- Public awareness of the opportunities for involvement in the NHS is low, but this does not reflect a lack of willingness to become involved.
- The importance of involving all local communities, including so-called 'hard to reach' groups such as ethnic groups, children and young people, is widely recognised.
- For any member of staff, gaining confidence and skills in involvement work requires experience of the benefits of involvement and training and education in the methods of involvement.

Authors: Farrell, Christine; Department of Health

Price: Free online (PDF, 240K)

Website: <http://www.dh.gov.uk/assetRoot/04/08/23/34/04082334.pdf>

Case Studies

Case study

Positive Publicity

Engaging the public “not just when a major change is proposed, but in the ongoing planning of services” - that’s what the guidance on Section 11 of the Health and Social Care Act says we have to do. That little phrase has raised the profile of the whole subject. But it’s an imperfect science, and we’re always trying to find out how to overcome those shortcomings.

In the last few years, I’ve worked in an area where there’s a certain amount of resistance to public involvement. For example, at a recent meeting of patients and carers, there was a rebellion at the agenda item ‘Date of next meeting’. Ground down by years of being asked for their views with no apparent result, they voted with their feet and refused to attend any more meetings.

Now that’s not to say the public’s views haven’t made a difference, but rather that if they did, no one told them. So that’s what I wanted to do – tell people that we really were committed to making a difference with their views. I hoped that this would break the cycle of cynicism and encourage people to get involved again. In particular I wanted people to join the Wycombe Health Network. This is a group of people willing to give their views by phone, email, post or text, without having to sit in the traditional meeting in a draughty village hall. I contact them regularly to ask for their opinions on the latest developments, for example the location of our planned Diagnostic Centre.

My aim was to reach as many people as possible with my message – ‘your views do make a difference’ – backed up with evidence and examples of real practical

changes that had happened. Armed with NatPaCT project funding, I took a one page advertisement in the District Council’s newsletter, Community Voice, which is delivered to every household in the PCT area. We have a substantial population of Urdu speakers, so I distributed Urdu versions through our local community groups. Of course many Urdu speakers are not Urdu readers, but nevertheless I decided it would send a good message – “your views are important too”. I also worked with our local Association for the Blind, to develop large print and audio tape versions and distributed them to their database.

The last part of the project – a health fair, with sign-language and Urdu interpreters, has still to take place.

But what have I learnt so far? As with any experiment, sometimes effects are surprising, sometimes unintended, and sometimes prove what is only common sense.

The information in Community Voice certainly produced a response – many people phoned to tell their stories of health care. They enjoyed the opportunity to tell someone about what had happened – a valuable exercise in itself - but few were willing to continue any involvement.

Following the distribution of the Urdu version, there was a sudden increase in the number of cases from Urdu speakers to the Patient Advice and Liaison Service. This was an unintended, but welcome effect, as monitoring had suggested we were not reaching that community equally. But no new members for the Network.

The most successful part in encouraging people to join the Network was the distribution through the Association for the Blind. Now many public documents include the phrase, “If you would like this document



in large print please call.....” I think the difference here was that I didn’t wait for a call, but proactively made the audio tapes and large print versions and ensured they were sent to the appropriate people.

I discussed the results of the project with the PCT’s public involvement group – a group of local people who meet monthly to give me some input on my work and help me carry out projects in the best way possible for patients and the public. The group also includes one of the non-executive directors, so that there is a direct link to the Board. I was disappointed with the outcomes of the project, but they were more realistic. “You can’t remove all those years of inaction with just one piece of publicity! You have to keep on giving that message out.”

So I’m making a deliberate effort to add a third strand to my work – still listening to views, still trying to make changes based on those views, but never forgetting to tell people about how they have made a difference, always letting people know that their contribution is valued. Thinking about it, it’s not only polite, it’s common sense.

Ailsa Harrison

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Case Studies

Case study

A secret of great involvement is...timing

Major developments always entail substantial challenges for patient and public involvement. In East Berkshire and South Buckinghamshire, our starting point was a recent Statement of Case developed by Heatherwood and Wexham Park Hospitals NHS Trust (HWPH) for a major capital development across its two sites.

As the acute trust serves an area covered by four primary care trusts (Bracknell Forest, Chiltern & South Buckinghamshire, Slough, and Windsor, Ascot & Maidenhead), the importance of working together was critical. The PPI managers for each of the Berkshire PCTs and the acute trust had already been meeting and sharing ideas/developments for some months. We are all committed to supporting each other and working in the best interests of the overall health economy.

Our approach.

In late 2003, we planned for public engagement, including one event specifically for the PPI forums in East Berkshire. We advertised the six public events in the local media, outpatient clinics and GP practices. Flyers were distributed through voluntary organisations and community groups. We hosted the series of events in different venues in January and February 2004, in order to discuss the best ways to provide services, and the best locations for them. Each ran for 2 hours, with introductions from chief executives, professional executive committee chairs and others, and facilitation by PPI and PALS managers from the different trusts. Over 100 people attended, who provided a wealth of qualitative information.

To support this activity, BMG Research carried out a programme of market research at the same time across East Berkshire, producing considerable quantitative data. This involved 1,047 face-to-face interviews with samples of households in each PCT area in East Berkshire. Of those surveyed, there was a near-even split between men and women, with some 12% describing themselves as being non-white (most in Slough). Almost

half of respondents were between 25 and 44 years, a third between 45 and 64, with the rest almost evenly divided between the 18-24 and 65+ age groups. While 945 had English as their first language, 98 others mainly spoke English (but as a second language, most commonly to Punjabi, Urdu, Hindi and Italian). Two people spoke no English at all, and 4% of respondents needed some or all of the interview translated.

Results.

The key issues from the open events covered three main areas of concern for the public:

Acute hospital services:

- There is real value in having a single acute site with 'everything under one roof'.
- People are willing to travel further to access the right consultant / right treatment.
- Patient choice is a major theme: to be able to choose, with good information and support from health care professionals, the best site and the best consultant for planned treatments.

Primary care services

- GPs are most able to deal with minor accidents/injuries, and are the 'gatekeeper' to all other health services.
- An expansion of services at practice level, including rehabilitation, minor surgery, general health education and diagnostics, is keenly desired.
- People are largely very happy to be treated by specialist nurses.

Communications and technology

- The current configuration of services in East Berkshire is confusing. There is a need for better information about what is available where, and for the patient journey to be simplified wherever possible.
- People valued services such as walk-in centres, but were often unclear about who could access such centres.
- There was a real push for better use of technology – e-mailing test results, telemedicine, outpatient clinics with video links to specialist consultants and on-line patient notes.

What did we learn?

- Planning such events takes much more time than one might initially allow – although often the time scale for consultation is out of our control, where we do have the luxury of having that, we need to plan three months or more in advance.
- Due to the timings of the Statement of Case, we had to start advertising our events just before and immediately after Christmas. This is not a good idea – do not do it!
- Having a 'timekeeper' for the workshops is really helpful to facilitators – keeping to time is essential.
- Ideally, each group in a workshop needs a facilitator and a scribe.
- Planning the groups so that people don't all sit with others they already know is really worth the time.
- We can do far more working together than we could ever do separately.

What next?

As well as informing the preparation of the Statement of Case, this work has also given us food for thought in relation to development of more local, primary care-based services. It generally supports the notion that people expect most of their health care to be available as close to home as possible, whilst accepting that for specialist treatments/interventions, more distant facilities are inevitable and indeed desirable to ensure the necessary levels of expertise.

The East Berkshire PPI Group is now well established. We continue to discuss future possibilities for joint working with patients and the public, to share experiences and information and to pursue the aim of ensuring that we can say with confidence that we have consulted, listened and acted upon what has been said.

This work has been a huge learning curve for all of us. We are very happy to share our lessons.

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Case Studies

Case study

From Vision to Reality

Influencing change and improvement in health services people through patient and public involvement

In Greater Manchester, redesign of secondary health care services has been the subject of debate for many years. It has been widely recognised that things need to change if high quality, modern health services are to be developed for children and young people in the area. The Greater Manchester, East Cheshire & High Peak Children and Young People's Network was set up by Greater Manchester Strategic Health Authority in March 2003 to oversee the development of primary, secondary and tertiary health services for children and young people. The Network has been working to create child-centred health and social care services that meet the needs of the 21st century and to make sure that there is a cohesive and consistent approach across the Network area.

Although considerable consultation about children and young people's health services had taken place over the years in Greater Manchester, many of the discussions were characterised by the sense that patients and the public were not involved from the start, that decisions may already have been made, and that the debate was often overtaken by the voices of pressure groups and lobbyists with a particular interest or viewpoint. Importantly, the voices of children and young people were missing. A new approach was required.

Challenges and Opportunities

It was apparent that there would be some major challenges to overcome if the involvement of patients and the public was to have a genuine impact on policy and practice.

- The size of the geographical area covered by the Network, with its varying populations, and socio-economic groups, presented difficulties for a cohesive approach.
- Comprehensive patient and public involvement had to reach all age groups, cover all the geographical areas, and ensure that the needs of all children and young people were understood, from the well child to those who used services regularly and may have disabilities. There was a perception that it would be difficult to engage with children and young people, although we were optimistic that we would achieve this.
- Organisations had different levels of development in, and commitment to patient and public involvement, with varying network contacts and expertise on which to build. Although partnership working was a priority for the NHS, there was a wide variation in the history of cross-boundary working at sector level and right across the Network.

Do something different

"If you always do what you always did...you always get what you always got."

We expected to hear from those activists with an interest in the way health services for children and young people should be developed, and we had heard from the experts in the field. We wanted, however, to listen to a broad cross-section of people, including children and young people. The two initiatives highlighted here are indicative of our willingness to explore different ways of working and act on the priorities local people identified.

The voice of the people

To ensure objectivity, a Manchester-based social research company, Vision 21,

was commissioned to develop a Citizens' Council. The process ensured that we were able to hear people's authentic voices. The 17 Council members came from a wide geographical area, and reflected the varied socio-economic background of the population in the Network area. At various times over three days, they came together to hear from a range of witnesses who gave their different perspectives on the issues for children and young people's health services. The Council members asked questions and deliberated on what they had heard. On the final day, the Council members developed their recommendations and priorities for change. The people involved were asked what the experience of being a Citizens' Council member meant. One person told me "It built up my awareness of how things needed to change...this empowers the public. Even though it was a demanding three days, we felt really informed...it was a positive process for me and I believe that we have influenced the Health Authority's thinking."

Children and young people influencing change

We recognised that building on the enthusiasm and skills of people with experience of involving children and young people was the way to meet this challenge. We worked with an expert team from Central Manchester and Manchester Children's University Hospitals NHS Trust, including a therapeutic play specialist with specific skills in using innovative methods such as interactive play, art, therapeutic puppetry, text messaging, using disposable cameras, and writing stories. The consultation explored the views of children, young people, parents, carers, and staff to find out about expectations and issues in using A&E services and day case surgery. The work has been a major success in identifying common themes, we have built up new relationships across

for children and young

organisational boundaries, and the results have started to influence existing practice. Most importantly, there has been a genuine respect for the value of the contribution that children and young people can make to decision-making and the planning of health services.

Learning the lessons

The experience of building this programme has resulted in a number of key lessons that will have a major influence on future methods for involvement.

- I was recently asked how to get people involved who would not normally take part in public meetings or join in workshops or focus groups. From our experience, I suggested that it was often best to “talk to people where they are.” Rather than try to recruit members of the public to join in a meeting, we have found that the people already working and communicating with local community groups or initiatives such as Sure Start were best placed to listen to views.
- As one member of the Citizens’ Council said when we promised to feed back what we would do as a result of their recommendations – “We know your name now.” In other words, there was no escape when we promised to act on the recommendations of the Council. Too often people who give their time to patient and public involvement initiatives never hear what happened as a result. We have responded to the Citizens’ Council by detailing how their recommendations have influenced our thinking, and what we propose to do as a result. Importantly, we are involving the Council again once the proposals are developed to see how they meet their priorities.

- One size does not fit all. Around 100 separate projects have taken place at sector, local and Greater Manchester wide level, with over 6500 people involved. The work has been relevant to the diverse communities and geographical areas across the Network. The work includes role play, citizens’ panels, competitions in the local press, workshops, video boxes, one-to-one interviews, focus groups, surveys, discussions with families from ethnic minority communities, activities with children and young people with non-verbal communication, and more ...
- The learning from the many approaches to communication will ensure that future involvement reflects what worked best. Importantly, we have learnt from the Citizens’ Council that “the Health Service needs to communicate better with the public so that they understand why things need to change.” The opportunity for the Council members to hear about the issues facing children and young people’s health services in detail meant that they made genuinely informed decisions. The wider public now deserves the same chance.

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Case Studies

Case study

Travelling the Journey Together

Our journey into ensuring patient, carer and public involvement within the Sunderland modernisation process began in 2002. Before then, the joint planning process had been carried out through the Health Improvement and Modernisation Programme.

This consisted of a number of multi-agency groups focusing on specific service areas with uncoordinated levels of patient, carer and public involvement. The process was reviewed during 2002 by the Multi-Agency Chief Officers Group, comprising the chief executives of the three Sunderland trusts and the Director of Sunderland Social Services. This resulted in the establishment of 12 Modernisation and Reform Groups (MaRGs) to cover service areas including cancer, older people, mental health, inequalities, children; and four additional groups on capacity, workforce, information management and technology, and patient, carer, service user and public involvement, were formed to “cross-cut” the other groups. Each health and social care organisation in Sunderland is appropriately represented on all of the sixteen MaRGs and every group has agreed terms of reference and action plans on which performance is reported to chief officers on a rolling programme throughout the year.

The Patient, Carer, Service User and Public Involvement MaRG rose from the dying embers of a group which, though not formally constituted, had evolved to monitor the implementation of Chapter 10 of the NHS Plan. The lack of formal standing of this group prompted the recommendation by Chief Officers to include patient, carer and public involvement in the MaRG process. Thus the Group was born.

Initially, the formula for all MaRG’s membership was used, with a chair nominated by one of the partner statutory

organisations and membership drawn from each of those agencies. In addition, the Patient, Carer, Service User and Public Involvement MaRG retained members from organisations who had been part of the earlier group, including the Community Health Council and Princess Royal Trust for Carers, in order to provide lay, volunteer and community input to the Group’s development.

Initial meetings of the Group were searching and probing to determine the role of the MaRG and its role within the modernisation process. A “time out” session in January 2003, facilitated by the Head of Patient, Carer and Public Involvement from the Strategic Health Authority, addressed these issues and established the group as a dynamic and forward thinking group.

Terms of reference were drafted and principles drawn up and, in consequence, the membership reflected upon. Senior staff from each statutory organisation are members, including clinical governance leads and the Chair of Sunderland Teaching Primary Care Trust. It was agreed that at least 50% of the membership should be from non-statutory organisations or groups and, to date, recruitment has been from the voluntary sector, Trust patient groups and community health groups. It was also agreed to institute Co-Chairs, with one from the statutory sector and one a lay member of the community, equal in their inclusion and contribution. The title of the group is intended to demonstrate the inclusivity, though it is certainly not short and snappy!

Members quickly recognised that they knew very little about each other or their organisations and held a “Getting to Know You” event. This began with an “ice breaker” focusing on people as individuals and gradually homing in on members’ expectations of the role of the Group in the modernisation process. Everyone agreed how useful this had been, including officers from the statutory organisations, and feedback has been shared with other MaRGs as a way of

promoting effective working relationships.

One of the first roles addressed by the Patient, Carer, Service User and Public Involvement MaRG was to establish a baseline measurement of patient, carer and public involvement across the other MaRGs. This was accomplished by asking all the Chairs to complete a broad, qualitative questionnaire covering

- aims of patient, carer and public involvement in that MaRG
- practicalities involved, including resources
- improvements planned to ensure a positive contribution of patient, carer and public involvement
- evaluation of patient, carer and public involvement.

We agreed that there was no common way to involve people as it depended on the “client group” involved and whether there were existing mechanisms.

From the questionnaire, some MaRGs noted they had plans to improve inclusivity and active involvement. Others were struggling with the practicalities and examples of good practice and practical support were offered. A few MaRGs saw little opportunity for patient, carer and public involvement within their scope and the Patient, Carer and Public Involvement MaRG plans to discuss their particular situations and offer practical, constructive support.

MaRGs are invited to discuss their approach at the Patient, Carer, Service User and Public Involvement MaRG meetings to enrich feedback which could not be accomplished via a questionnaire. Some have been accompanied by lay delegates, who provided a very real view of their involvement.

In recognition of the practical difficulties experienced by lay group members, the Patient, Carer, Service User and Public Involvement MaRG has developed

- guidance and a claim form for expenses on behalf of all the MaRGs

Case Studies

- a glossary of common health terms to help when staff inadvertently slip into abbreviations and to supplement specialist glossaries that the other MaRGs are developing
- a pre-meeting for our lay delegates to allow free discussion on agenda items for people who are not familiar with the topics under review; this is still in its infancy and, whilst first comments are very positive, we will review to ensure its usefulness

The terms of reference include “influencing a whole systems approach to the work of different bits of patient, carer and public involvement” in the City. So, to begin this process, the Group hosted an event drawing together lay delegates and officers from all three Patient and Public Involvement Forums, the Overview and Scrutiny Committee, all three Patient Advice and Liaison Services, the Independent Complaints and Advocacy Service, lay delegates involved in the MaRG process and staff from the statutory organisations who have responsibility for promoting patient, carer and public involvement. Each other’s roles and responsibilities were explored, identifying where the links and partnerships are and the role of the Patient, Carer, Service User and Public Involvement MaRG in enabling cohesive development.

We haven’t got to our destination yet – far from it – but we do feel we are on the right road and, most of the time, travelling in the same direction. From this point we feel that we can take forward patient, carer and public involvement across the City partnerships.

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PATIENT, CARER, SERVICE USER AND PUBLIC INVOLVEMENT MODERNISATION AND REFORM GROUP

PRINCIPLES

- Involvement is everybody’s business
- Listening and having representation
- Relevant Involvement to particular group
- One size does not fit all
- Stakeholders need to be informed
- Understanding of why we / they are there
- Clear accountability – two ways
- Avoiding tokenism
- Requires evidence of appropriate and real involvement
- Mutual trust
- Inclusivity
- Tailored support if needed
- Equal partners and status
- Will be monitored
- Should be evaluated
- Be as innovative as possible
- Be transparent
- Feedback to the public involved regarding contribution / what difference did their input make
- Timely

Listening to young children: a participatory approach

Y.Penny Lancaster focuses on how and why we should listen to what young children are trying to say.

Coram Family, a charity that has been caring for disadvantaged children since 1793, with the support of the Esmée Fairbairn Foundation and Bernard van Leer Foundation, has recently completed a three-year research and development project to understand why and how we should listen to what young children are trying to say. This culminated in the development of Listening to Young Children, a resource that focuses on the arts to enable young children to express their views, feelings, and concerns about matters that affect their lives and supports parents and professionals to relate more effectively to the children they work with and/or care for. The non-prescriptive and creative nature of the resource facilitates practitioners to connect with the objectives, for instance, of the National Service Framework.

“If we see the different standards and targets that practitioners need to meet as boulders and stones in a river, then Listening to Young Children is like the flowing water that passes around these. It’s not something extra to try and fit in, but rather it supports practitioners to connect with what they already have to do.”

An early years advisor

The UN Convention on the Rights of the Child (UNCRC) has played a significant role in promoting the notion that children’s views must be taken seriously. Recent developments across children’s services in education, health and social welfare have also reflected the importance that Government and service providers place on this basic human right. These initiatives are

intended to ensure that listening to children, enabling children to express their views, feelings and concerns is paid more than lip service. Nevertheless there are still too many children who are not accessing decision-making processes in matters that affect their lives. One group of children that tends to be overlooked are those who are under the age of eight. There appears to still be an assumption that these children are too young to meaningfully participate in matters that affect their lives. And yet, if we are to learn from the tragic death of Victoria Climbié, it is important that change is achieved so that young children are no longer excluded from decision-making processes on account of their age.

Socially inclusive relationships promote a view of children as already living and accomplishing rather than simply learning and practicing to exist for the future. As active participants, children not only have something worthwhile to say about their lives, but they are also able to communicate their views about matters that concern them. Our view of childhood impacts on whether children’s voices are heard or silenced. Recognising young children as social people in their own right, as experts in their daily lives but with different skills, experiences and capacities helps to break down traditional views of children that exclude them.

Listening to Young Children promotes that the starting point for listening to children up to the age of eight is in socially inclusive relationships. These are relationships which promote mutual encounters, respect for one another and which provide children with the listeners that they need.

Even babies communicate and have something to convey. For instance at a baby massage class a first-time mother arrived with her six-month-old baby boy. The class had been recommended to her because she was finding it difficult to build a relationship with her child, “he is so fractious and will not settle. I feel such a failure – I don’t think he likes me”. She was returning to work within the next three months and was not happy that she had not built a loving relationship with him. With her consent their ‘baby massage’ experience was videoed which included time in which she gave her son his bottle. Afterwards the mother viewed footage at slightly slower than normal speed. It was only at this speed that we saw that while she held him close to her he was calm and for the most part intently gazing at her. For the first time this mother, to her delight, ‘heard’ her son interacting with her, communicating that he wanted to build a relationship with her.

For children’s views, interests, experiences, feelings, concerns and aspirations to be heard then listening needs to become the ‘subtle thread’ of all that we do when working with and/or caring for them. Supporting children to express the meanings that they are searching for in different social contexts, encouraging them to ask questions, giving them undivided attention and valuing their perspectives helps children make sense of their experiences, enables them to contribute their ideas in their own way, highlights their diverse realities, and supports adults gain an understanding of the world through the eyes of children. Facilitating these kinds of interactions empowers children to take part in matters that affect their daily lives, to be at the centre of their schooling, and social and health care.

Listening to Young Children contributes towards rethinking the way we relate to children through the notion of RAMPS. It is a

tory approach

RAMPS involves adults:

- Recognising a child's many visual and verbal languages that children use to express themselves. These include their use of fantasy, play, and visual and performing arts, which helps children to explore and represent their perspectives in their own terms.
- Assigning space for children's voices to be heard. To have spaces, in which they can communicate and be heard, and which provide tangible proof that their views, feelings and concerns have been valued and are taken seriously.
- Making time to give children information that is relevant, makes sense to them and focuses on what they want to know so that they can make informed decisions, and ensure that the context is one in which children can ask questions and negotiate understanding.
- Providing genuine choice to participate in decision-making processes in which their perspective, their feelings, aspirations, concerns, views about their learning, social and health care are taken seriously. Genuine choice also relates to ensuring that children have the option of choosing not to participate and that the context is appropriate for children to comfortably contribute.
- Subscribing to a reflective practice to ensure that our attitudes, values, assumptions and prejudices and practices empower young children's expression of their feelings, experiences, views, concerns and aspirations rather than hinder them. Subscribing to a reflective practice involves checking that young children's voices are taken seriously in matters that are relevant to them.



framework that is analogous with the ramps that have been constructed so that people who use wheelchairs can gain access to spaces that had been previously denied to them. It reflects a changing view of childhood – one that sees children as people who are acquiring competence to consider matters that affect their lives while acknowledging that some need support in order to participate in their learning, social and health care.

The notion of RAMPS is embedded in the set of eleven creative, flexible and non-prescriptive shared experiences or activities that are included in the resource Listening to Young Children. The shared experiences provide a range of different opportunities, based on the arts, to enable young children to express their views, concerns and feelings. They are a springboard from which to work with children rather than doing things to them. They provide an environment for children to work in ways that are familiar to them for instance through their talk, play, creativity and actions, and all the subtle ways in which very young children can represent their views, feelings and concerns. The shared experiences are part of a holistic approach in relating to the children we work with and/or care for.

The youngest members of our society need sensitive listeners. They need our commitment to build power-sharing ramps so

that they can actively participate in matters that affect their lives, in having their direct voices taken seriously.

The Listening to Young Children project is now offering a training and consultancy service to support parents and practitioners in listening to children under the age of eight.

For further information about the Listening to Young Children training and consultancy service please contact Penny Lancaster on 020 7520 0357 or penny@coram.org.uk. The Listening to Young Children resource pack is published by Open University Press, Tel: 01628 502 700 or www.openup.co.uk/listening

RESOURCES

DfES Children and Young People's Unit - <http://www.cypu.gov.uk/>

National Children's Bureau - <http://www.ncb.org.uk/>

Listening, hearing and responding : Department of Health : involving children and young people - <http://www.dh.gov.uk/assetRoot/04/07/20/62/04072062.pdf>

DIALOGUE WITH THE PUBLIC

Practical Guidelines

Recent legislation means that all Primary Care and NHS Trusts must consult widely as part of their decision-making processes. Consultation has been a feature of NHS practice for some time but the legislation means that there will need to be changes to current practices. To begin with, the wider public, as well as patients and carers need to be included. And both the range of issues and the point in the decision-making process at which consultation must now take place have changed. Those who are only just beginning to get involved in consultation are looking for good sources of support. Even those experienced in consultation will need to draw on new approaches to meet this brief.

One important issue is the new requirement to involve and consult the public on what might be thought of as 'technical' topics. This includes scientific topics but there are others where special expertise or experience might be thought of as a pre-requisite before people can contribute to debates and decision-making.

The NHS is not the only institution trying to open-up to more lay input. Research scientists have also been trying to engage the public, spurred on recently by events such as BSE, cloning, nuclear waste and a shortage of skilled scientists and engineers.

In 2000 a House of Lords enquiry concluded: "That direct dialogue with the public should move from being an optional add-on to science-based policy making and to the activities of research organisations and learned institutions, and should become a normal and integral part of the process."

There are clear parallels here to the NHS experience. But the history of communicating with the public is long standing and can be traced at least as far back as Davey and Faraday giving public lectures in the nineteenth century. The techniques that scientists are developing to consult the public provide a pool of knowledge that NHS consultation practitioners can draw on to inform their own practices.

The NHS is not the only institution trying to open-up to more lay input. Research scientists have also been trying to engage the public, spurred on recently by events such as BSE, cloning, nuclear waste and a shortage of skilled scientists and engineers.

The UK Research Councils, who between them receive £2 billion per annum to fund research (including medical research, in universities and in their own centres) commissioned People Science & Policy Ltd and TNS to produce "Dialogue with the public – practical guidelines". It can be downloaded from the Research Councils UK web site at <http://www.rcuk.ac.uk/guidelines/dialogue/>

Some professionals need help to move from delivering 'monologues' to stimulating 'dialogue', listening as well as talking. This is the focus of the guide, although it emphasises that there is no magic formula, no "right way" to conduct a consultation. Professional judgement, experience and knowledge of the constraints (such as budgets) are crucial to building a structure that will best meet set objectives.

The target audience is very much those just starting to interact with the general public on scientific topics and may be too basic for some. But it never hurts to take a moment from the day-to-day to refresh one's memory of the essentials. The approach is also useful for other complex issues such as finance.

There is a process that an organiser might expect to go through. In chronological

order, the stages are: setting objectives; understanding audiences; attracting audiences; encouraging dialogue within traditional formats; and identifying appropriate techniques to facilitate dialogue. It is also important to know how to evaluate a consultation exercise, which the guide also covers.

To assist the reader, the process associated with each topic is covered. Practical examples are used, developing the same three cases so that the journey made by the project manager can be followed through its various stages. For later use, an "Organiser's Checklist" appears for each subject, to offer an aide memoir.

For those with specific roles for patient and public involvement in the NHS, identifying appropriate techniques may be of particular interest. One section of the Guide draws together the key features of a number of methods and highlights their strengths and limitations. This should help in selecting the most appropriate tools to meet objectives within available resources.

Requests for the guide have been received not just from British scientists, but also from across the world. Indeed, the popularity of the Guide is evidenced by the fact that a Google search for Research Councils UK reveals the welcome page as the first result and the Guide as the second. It may therefore prove of particular use in working with clinical staff within the NHS.

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A CUP OF COFFEE WITH...

Peter Barrett, Chair of the Independent Reconfiguration Panel (IRP)

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

Nottingham was once the home of an idealist. His name was Robin Hood.

Today it is the home and professional base of Dr Peter Barrett – Chair of the Independent Reconfiguration Panel (IRP). A man also concerned with fairness and equity. A man who has spent his professional lifetime trying to help people.

I expect you are thinking much the same as I was. Dr who? Chair of what?

He laughs as I put this to him "A lot of people say that. The IRP was set up as part of the NHS plan. Its role is to provide expert advice on NHS reconfigurations and service changes".

Still a practising GP, he works three days a week in Nottingham, spending the other two days as Chair of the IRP. "I always wanted to be a doctor" he says. After training at Kings College, he thought about going into psychiatry, but instead opted for general practice vocational training in Kings Lynn.

He has no regrets "I found it fascinating and became very interested in people and how illness could affect their lives". After 27 years in his Nottingham practice he is still brimming with enthusiasm, he says "A lot has changed. People knock the NHS. They are often looking at the past through rose tinted spectacles. Since I started, the service is much different and better".

Today, he feels that patients rightly have greater expectations "They have a right to better standards, more informed, better focused staff. Once, the principle of doctor knows best was paramount. Now we have developed a willingness to shut up and listen. It's more about partnership"

He became increasingly interested in strategic health issues, and chaired Nottingham Health Authority then Trent Region. This experience eventually led to him taking the Chair of the IRP.

Explaining the IRP in layman's terms, he says "It's comprised of a panel of nine people. Three senior NHS managers, three clinicians and three lay people. We work openly and transparently. All of our advice is published. It is not a badge of honour to be referred to us. We try to give help so that NHS organisations do not end up being referred to us".

The IRP may be asked to give advice when a local reconfiguration or major

I expect you are thinking much the same as I was. Dr who? Chair of what?

service change is opposed and reaches stalemate. Local people or professionals can ask their Local Authority Overview and Scrutiny Committee (OSC) to look at a reconfiguration issue. If there is still unease about proposals (or consultation), the OSC may refer the matter to the Secretary of State. Before deciding on the matter, the Secretary of State may ask the IRP to step in and provide advice.

Though the IRP is relatively new, it has already had a successful role in unlocking a reconfiguration stalemate in East Kent, where he says "We made fourteen recommendations and all were accepted, including the abandonment of an expensive multi-million pound PFI scheme".

There were so many agencies with a stake in this complex reconfiguration it seemed almost like a no win situation, yet all fourteen recommendations were

accepted in full. He feels the reasons why the IRP proposals were accepted were clear "People saw it was open and transparent. We gather and assess information. We visit and make sure that everybody knows we are coming. We are quite happy to take oral information and we try to balance individual needs against needs of all the people".

Citing an important lesson for everyone involved in PPI he said "We found that it's not always the people who shout loudest that have all the answers. It's not the volume it's the quality that counts."

Looking to the future Dr Barrett expects the reconfiguration business to continue to be brisk "There's a lot going on. In the NHS there is no such thing as stability, and a lot more service changes will be forthcoming."

He makes it clear that the IRP also has a role in giving guidance "We are building up a background of good practice and sharing it with health communities as they begin to think about service changes. If they follow it, they should not have to be referred to the IRP".

PPI is high on the list of good practice for the IRP "We are concerned about the quality of consultation. Is it real or a sham? Is it just ticking boxes? Like my GP consultations they should be meaningful and influence the outcome".

But today is Tuesday, and for Dr Peter Barrett it is a day for general practice. As he prepares to head off, he reveals yet more of his enthusiasm for the day to day, saying "Today we can do more for people. We have fantastic students. They are idealists and it's a wonderful thing to see".

Robin Hood would have been proud.

For more information on the Independent Reconfiguration Panel go to www.irpanel.org.uk.

Living well...

From patient to person

Six years ago, I started working for a small charity called the Long-term Medical Conditions Alliance (LMCA). The Alliance was then made up of around 50 organisations supporting people living with long-term conditions, and the LMCA staff (all three of us) spent much of our time trying to get long-term conditions on the map. How times have changed! LMCA representatives are now in great demand as every other conference, seminar and policy initiative is addressing itself to the health care 'time bomb' that is long-term conditions.



There are estimated to be 200 million people worldwide living with one or more chronic conditions. In the USA this figure is 70 million and in the UK 17.5 million. Two out of three Americans not currently living with a chronic condition think they will get one. If they are lucky they will get just the one, because two-thirds of adults in the US living with one of the five most common chronic conditions also live with two or more illnesses (they also make up half of all physician and hospital visits). In the UK around a quarter of the people with a long-standing illness have three or more conditions.

The increase in chronic disease represents a challenge to the health care system, individuals and communities. The NHS Plan signalled a move towards a more patient-centred NHS in which individuals and communities contribute to the "co-production" of health. This has been followed by a raft of policy initiatives such as the National Service Frameworks, the general medical services (GMS) contract, the National Programme for IT, the 'choice' agenda and, of course, patient and public involvement (PPI). More recently, the Secretary of State for Health announced a three-pronged approach to addressing chronic disease through self-care support, good disease management and case management.

People living with long-term conditions have always known that their well-being is determined as much by their social and psychological world as it is by the medical care they receive. They are a 'patient' for a fraction of the time they are a person living with a long-term illness. Good self-care support in the form of lay led self-management is the means by which people living with long-term conditions can develop the necessary confidence and skills to take control of the daily management of their illness. During the 1990s voluntary sector organisations such as Arthritis Care, the Manic Depression Fellowship and LMCA pioneered the use of lay led self-management, and in particular, the Chronic Disease Self-Management Course (CDSMC) developed by Professor Kate Lorig and her associates at Stanford University in California.

During the 1990s voluntary sector organisations such as Arthritis Care, the Manic Depression Fellowship and LMCA pioneered the use of lay led self-management, and in particular, the Chronic Disease Self-Management Course (CDSMC) developed by Professor Kate Lorig and her associates at Stanford University in California.

For LMCA two of the most attractive features of the CDSMC are the fact that it was developed using the experiences of people living with a condition as its start point, and secondly that it is delivered in local communities by and to people living with long-term conditions. The aim of the CDSMC is not to impart medical information, but help release the capacity of people living with long-term conditions to attain the greatest possible quality of life. They do this by working in partnership with health and social care professionals to make the best use of all available resources.

The programme also had a sound evidence base. Short and longer-term outcomes demonstrate the positive effects of lay led self-management for people attending and delivering courses. International evidence from randomised controlled trials show that these approaches are effective in increasing

participants' self-efficacy, symptom management, use of self-management behaviours and improving some aspects of health status (i.e. depression, fatigue and anxiety).

LMCA co-ordinated projects have supported the use of the CDSMC among voluntary sector organisations to the point where there are now over 20 engaged with the CDSMC in Britain. In 2001 the creation of the NHS Expert Patients Programme (EPP) ensured that this highly effective form of self-management became part of the menu of services offered by PCTs to their local community. Over the past three years the EPP and voluntary sector have delivered over 1,000 self-management courses across England. After a shaky start national and local partnerships between the voluntary sector and NHS are thriving. Voluntary sector organisations like the Multiple Sclerosis Society, British Polio Fellowship and Macmillan Cancer Relief regularly work in partnership with PCTs to deliver courses with EPP trained staff and volunteers, and there is an EPP Strategic Board with significant representation from voluntary sector organisations. As the EPP moves into the mainstream, we are at a point of unparalleled opportunity for stakeholders to model the future of partnership working between the voluntary sector and NHS.

Partnerships at all levels are the key to successful self-management. Effective partnerships between the NHS and the people who use its services is seen as the key to achieving improved health outcomes, which in turn leads to greater user involvement. The more people are involved the more likely they are to give. This is borne out by our experiences of working with self-management volunteer deliverers who are fantastic advocates for the programme and are willing to attend local and national events to share their experiences, even though they are often terrified. We have also found that people involved in self-management get involved in wider health care activity. A telephone survey of volunteer deliverers, two years after they trained, showed that many had gone on to become involved in shaping health care services and policy at a national and local level. These activities

included further self-management training, gaining full time employment as an EPP trainer, doing other voluntary work, public speaking and becoming a board member of the Commission for Patient and Public Involvement in Health. The overwhelming majority directly attribute this to their involvement in self-management courses. For one of the volunteers training as a self-management deliverer

"... has been an important part of my process to regain control over a life dominated by the treatments needed for my various illnesses. It also stimulated my interest in how patients might influence the health care system, which often dominates their lives. I believe that the skills and confidence gained by participants on lay led self-management courses make them ideally suited to a leading role in improving decision making in health and ensuring that real choice are available to everybody with a long-term condition."

Of course not every graduate of a self-management course will want to become involved in high profile activity. Lay led self-management is, however, an effective vehicle for enabling people living with long-term conditions to feel more in control and live a

better quality of life. It is a way of supporting individuals to become effective partners in health care both on an interpersonal level with their health care providers, and on a more strategic level as advocates and involved health care users.

Now when I sit at conferences and listen to the latest thinking around tackling chronic conditions and I listen to the expectations that are placed upon local service commissioners and providers (central to which is greater user involvement), I often think, if I were working for a PCT, a lead for PPI, a PALS manager, or had any responsibility for developing local user involvement I would be finding out everything I could about what was going on in my local area and grabbing self-management with both hands!

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For further information and contacts on Self Management and The Expert Patients Programme please refer to the list of References below:

Key references:

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Key web sites:

Expert Patients Programme - <http://www.expertpatients.nhs.uk/>

Long-Term Medical Conditions Alliance - <http://www.lmca.org.uk/>

National Electronic Library for Health - <http://libraries.nelh.nhs.uk/healthmanagement/>

Patient Education Research Center, Stanford University - <http://patienteducation.stanford.edu/>

Health Voice Network

This feature on the Health Voice Network is the second article in a short series from PPI Monitor on the help and support available from Networks for all those working in PPI.

What is Health Voice Network?

The Health Voice Network is a self-help network, part-funded by the Department of Health and run independently, firstly by Health for All Network (UK), and now by UK Public Health Association. Launched in March 2002, the Network is open to anyone who wants to help people to have more of a say in planning and improving services that affect their health. Over 1,200 NHS and Local Authority staff, community groups and individual members of the public are using the Network to explore ways of coming together to put the health back into health services.

Rationale

The key idea behind the Network is that communication between a wide range of people can benefit all. Just knowing that you are not on your own can give you the encouragement you need to go on. But people can also benefit from sharing experiences and ideas, and the Network enables members to get in touch with other staff, service users and support organisations quickly and easily.

Everyone has something they can share. It might be information about methods, campaigns or initiatives, or about training or funding resources. Or it might be an idea, or a request for advice – asking questions can be just as important as giving answers.

The Network has a flexible range of facilities to enable sharing between members. They can post up information on the Network's website www.healthvoice-uk.net, search for others with similar interests, participate in discussions on a variety of topics, and input into government policy and national decisions. We have a flexible keywords system so that members aren't overloaded with irrelevant information, and everyone receives regular summaries of what's going on across the country – events, campaigns, useful books and articles, tips and hints.

Independent evaluations have found that the Network generates social capital. It also

offers a uniquely important and cost-effective service, both to its members, and, potentially, to other related networks at national, regional and local level (reports available at <http://www.healthvoice-uk.net/pages/about/vn.asp#comments>).

How the network is used

We try to make the Network a welcoming place where members can have the confidence to be open about both their strengths and their weaknesses. We encourage members to send in requests for assistance, and these generally receive a good response. Here are 1 recent request, and the response they received:

Ethnic monitoring of complaints

A PCT worker asked how other PCTs monitor service complaints by ethnicity, and for examples of best practice.

The response:

"I got approximately 35 responses, which I thought was very impressive. In summary, the majority (about 75%) of PCTs were starting to ask the same questions about ethnic monitoring of complaints but had made little progress to date. About 20% had already introduced ethnic monitoring of complaints arrangement (post complaint letter) but had had poor responses from complainants. Two PCTs sent examples of post complaints letters that they sent out to complainants and Bromley PCT said that they had 9 out of 10 return responses. The two PCTs I cover have adapted the Bromley letter and are now using it to follow up complainants."

The Network has proved very useful as a 'reality check' for people working alone in new roles, and has actually enabled the survival of new ventures:

"Without Health Voice Network my organisation wouldn't exist" Carer and Director of eating disorders advocacy organisation.

The Network has also enabled visits to see best practice that have informed self-written policy documents. Events and courses advertised through the Network have guided staff in personal and organisational development. Small community groups have been linked into larger networks e.g. Youth Network to evaluate ways they were working with young people. Other benefits reported



by members have included:

- "Helped develop our Citizens Panel"
- "Engaging strategic partnerships to highlight the role of faith based organisations in health improvement"
- "Ensuring the events we hold are becoming much better at involving the community in policy and planning development"
- "Developed a Well Being Partnership which is being used by the Local Health Authority as a Consultative Forum".

The Future

Our next priority is to increase the diversity of the network by recruiting more community activists. We have a very strong membership among paid staff, and their pooled experience could be a great resource that supports community groups and individual members of the public to improve health. Activists can be encouraged and supported to go on trying, through finding out about and making contact with others in similar situations, or simply through getting ideas for new ways of influencing. And the benefits go in both directions - activists' stories of their experiences of health and health services, and of trying to improve them can also help organisations to understand how they can better include people in decision-making. Our challenge is to make community activists more aware of the network, and we are doing this by producing new publicity materials and asking existing members to make use of them.

Alan Boyd

Coordinator, Health Voice Network.

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Last Word from Chris Dabbs



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

Dear Mrs. Buggins,

To quote that great philosopher, Ken Dodd of Knotty Ash, "Happiness, happiness – the greatest gift that I possess." It is becoming clearer and clearer that the emotional experiences of patients and carers are critical to their perspective on health and social care. Yet it is not yet something given much formal recognition, except perhaps in the Expert Patient Programme, which has already benefited several of our mutual friends.

There is, however, a growing body of recent work by psychologists and even economists on what enables happiness. Politicians are beginning to take note of how the weight of happiness in the world can be grown.

One approach, "positive psychology", has used randomised control trials to see what works. This is the same way in which therapies and drugs are tested to check their effectiveness. The first results have just been published on the Authentic Happiness web site <www.authentichappiness.org>

The evidence suggests three positive interventions that not only make people significantly happier and reduce depressive symptoms, but also provide these benefits over a sustained period. Other things were tried but had little effect or did not last.

The first, "three good things", requires an individual to write down every night for one week three good things (big or small) that happened during the day. Next to each item, the person then answers the question, "Why did this good thing happen?" (By the way, why are there plenty of investigations in health and social care to find out why things go wrong, but no equivalent analysis of why things go right?)

The second, called the "gratitude visit", involves (with guidance) a person writing and presenting in person a letter of gratitude to someone they have never properly thanked.

This already works in places such as special care baby units. Maybe we might encourage staff and patients to do this more often (so long as it is genuine)? It might also be a good way of finding out what people really value in health and social care, to counterbalance complaints.

The third, using your "top strengths", meant that people completed a "signature strengths" survey (available on-line), noted their top five strengths and then – with detailed instruction – used them more often and in new ways. Mine were creativity, curiosity, enthusiasm, critical thinking and love of learning: essentially the things that I most enjoy.

In short, reflect on your blessings, appreciate others, and develop your assets. These elements are very similar to what other approaches have shown to work in improving staff satisfaction and retention. Perhaps managers and involvement staff might lead the way as role models!

Ken Dodd got one thing wrong – "I thank the Lord that I possess more than my share of happiness." There is no fixed amount – we can make more (or less) happiness than already exists! For people experiencing health problems, such production is a good (and inexpensive) thing. Maybe something that all of us engaged in involvement might consider when trying to improve the experience of patients and carers.

Keep well,

Chris.

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

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30 June 2004, Central London

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For more information and a booking form, please contact Rosa Napolitano, admin@newhealthnetwork.co.uk, or Tel 020 7407 1618.

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