

PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

Patients will wait longer for better hospital care

New research shows that faster treatment does not necessarily impress

Patients are willing to sacrifice faster access to treatment in favour of better hospital care, says a new report published jointly by RAND Europe, the King's Fund and City University.

The study reveals that patients are more likely to choose to be treated at a hospital with a good reputation rather than one that has shorter waiting times. Patients who were surveyed for the study were also willing to trade off longer waits for operations if the NHS was prepared to pay for and arrange travel.

The report says the findings raise questions about the Government's policy on patient choice, which, so far, has only offered patients a choice of quicker treatment.

Lead researcher Peter Burge said: "This study shows that waiting time isn't everything. Some patients will be prepared to wait considerable amounts of time in order to obtain treatment at a hospital with a better reputation."

The findings are based on an evaluation of the London Patients Choice Project (LPCP) - one of the first government schemes to offer patients on waiting lists quicker access to hospital treatment. The project was established in June 2002 and ran until March 2004, with patients first being offered a choice in October 2002. During this period 22,500 patients were offered choice in five specialties covering 35 operations. Of these, 15,000 patients accepted treatment at another hospital rather than their local one. Their care was paid for by the LPCP.

The study found that less wealthy patients are more willing to accept being treated at hospitals with a poor reputation. "The reality of these differences in choice raises uncomfortable questions about how best to provide a health service that ensures equal access for those in equal need," said Burge.

The research also identified the lack of existing information available to patients on hospital reputation to help patients make informed choice.

"If the Government is serious about offering real choice to NHS patients, then it has to start providing the right sort of information to help patients choose," said Prof John Appleby, another key researcher involved in the evaluation. "Unfortunately there is little or no adequate information currently available on reputation or quality of care."

Finally, the research finds that the Government's decision not to pay, or at least organise, patient transport to hospitals beyond their local area will reduce the range of opportunities for patients to exercise choice in some cases.

Prof Nancy Devlin, key researcher in the study, said: "Our research shows that if transport were provided and paid for by the NHS then this would increase patients' willingness to choose hospitals out of their area. However, in its roll out of choice across the country, the Government has decided not to organise or pay for transport."

Policy implications of the study could lead to better-informed decisions and improvement in NHS healthcare delivery, with the research providing useful lessons that are highly relevant to the NHS 'Choose and Book' initiative.

The final report of an evaluation of the London Patient Choice Project is available at: www.rand.org/randeurope or www.kingsfund.org.uk

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Brighton Rocks: Jane Bolding talks about Brighton & Hove's Expert Patient programme – a finalist in this year's Health & Social Care Awards

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Letsgo Tesco

Hasn't shopping chaged over the years?

I can remember the time when it was highly personalised and low tech. My mother would scrawl a semi-legible note and wrap some money in it. Sometimes the note would contain the low tech equivalent of the modern storecard. She would write something like "I'll pay you on Wednesday when I get my family allowance". I would scurry down to the shops and have to suffer the wrath of some white coated shopkeeper with names like Fred Aberdeen, Eileen O'Keefe or Mr Nevershut, who amazingly was married to Mrs Everopen.

Then they would respond personally to your needs by asking you a series of clarification questions. "Is that cooking cheese or eating cheese?"; "shall I cut the bacon thin like paper?"; "Do you want 'roady' bacon". This would indeed have been very personal service, had I only known the answers to some of these questions. Even to this day, I still don't know what 'roady' bacon is. I somehow bluffed my way through.

This level of personal service though could have its drawbacks. Your every request was instantly transmitted throughout the shop. 'Hardwired' to everyone in it. I noticed this as I grew up in a tough neighbourhood where having an extensive vocabulary meant that you knew

more swear words than anybody else.

I was always interested in words, and as a ten year old I was sent to the shop to get one of those tiny packets of coffee. I waited for my turn and got to the counter and asked for a 'sachet' of coffee.

You would have thought that I had broken wind in the reading room of the British Library. The shopkeeper, Mr Nolan, silenced the shop as he peered down at me. "A sachet?" he queried. "What the ***** is a sachet". I quivered as I explained it was a small packet.

Even though the service was personal, I never enjoyed going into Mr Nolan's after that.

Today, shopping is done in supermarkets. Though they don't know about us personally, they spend a lot of time trying to profile us, to understand how are needs are changing; what trends are emerging; and how we have different needs at different stages of our lives.

I wouldn't have dared to complain to Mr Nolan about his treatment of me, or about anything else for that matter, but Tesco treat a complaint as a gift.

It is interesting that in a recent interview with Andrew Billen for The Times, the Chief

Medical Officer wants the NHS to become more like Tesco. He says "I once heard Terry Leahy of Tesco saying that customer feedback was hard-wired into Tesco. I think patient feedback should be hard-wired into the NHS because it is absolutely vital. We do do it but it is not yet a strong part of the culture."

He says that he welcomes informed patients who challenge their doctors? "I do. At medical conferences, the awkward bit is often question time but, quite often, an irate doctor will stand up at the back and say, 'You're raising patients' expectations. Stop doing it'. And my response is that we want people to have high expectations because it's only by stretching ourselves and being ambitious and comparing ourselves to other countries that we find ways of doing things differently."

That's good because that's what we try to do at PPI Monitor. In this months edition we are pleased to bring you not just practical tools from the UK, but also ideas from overseas as well.

Raising patients expectations is the equivalent of getting Mr Nolan to move from small packets to sachets. Some people won't like it. Those of us committed to PPI must front them out.

Health care just like shopping, must change.

EDITORIAL ADVISORY BOARD

Chris Dabbs

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

Nick Bosanquet

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

Zenna Atkins

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

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

Malcolm Stamp CBE, DCL, FRSA, MIHM, MMS

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

David Gilbert

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

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News items

Essex Pack

As part of a drive to publicise PALS more effectively, the Essex Network held a PALS Awareness Week across the county. Using funding from the National PALS Development Group they produced a promotion pack for each PALS within Essex.

The idea of the pack is to ensure everything is immediately available when making presentations and has made cross border working much easier.

Each pack includes a pull up banner printed with the individual Trust's logo and contact

details, and presentation materials in a carrying case printed with the nationally recognised PALS logo.

For more information on the pack and how to get the best from a PALS Awareness Week, please contact: Nicky.Hart@cpr-pct.nhs.uk

Health watchdog urges NHS to improve dealings with dissatisfied patients

The Healthcare Commission has urged the NHS to improve its dealings with dissatisfied patients and service users. The Commission, which handles complaints the NHS cannot resolve, makes the call as it publishes figures which show the NHS is not doing enough to resolve grievances locally. The figures show over 25% of complaints referred to the Commission are sent back to the NHS because the Commission's investigators believe the trust has not done enough to resolve the issue.

Unresolved complaints sent to the Commission are mainly about: poor communication with patients and relatives, poor clinical practice, an unsatisfactory patient experience, poor staff attitude and poor complaints handling. Complaints managers report that a significant number of complaints are being made about the poor handling of bereavement and unsatisfactory care of the elderly.

To improve complaints handling, the Healthcare Commission is:

- developing new criteria for good complaints handling which will be used to assess trusts in their annual performance rating
- calling on strategic health authorities to more effectively manage the way trusts in their area resolve complaints

- providing advice on good complaints handling
- offering training for the trusts who send us the greatest number of complaints to try to achieve local resolution.

Marcia Fry, Head of Operational Development at the Healthcare Commission, said: "The NHS has got to get better at handling complaints, which are an important tool for improving services. In the coming months we will be working with the NHS to improve handling of NHS complaints. However, if the situation doesn't improve, trusts will feel the effect in their annual rating."

She added: "We are working as fast as possible to get the very large number of unresolved complaints seen to as quickly as possibly. These people will already be frustrated with the response the NHS has given to their complaint and it is essential that we address their concerns as quickly as possible.

"We are determined to crack this, but it can only be done if everyone else does their bit. Everyone loses if complaints are not dealt with properly at a local level – patients, ourselves and the NHS."

Since taking over the review of second stage complaints last August, the Healthcare

Commission has received an unprecedented number of requests from people wanting their complaint reviewed. Nearly 7,000 requests to review complaints about the NHS have been received in the first 10 months of the service's operation, compared to less than 3,000 per annum under the previous NHS system.

Steps being taken by the Healthcare Commission to improve its complaints resolution service include taking on more staff, hiring an external partner to handle high volume periods and increasing the number of early resolutions through discussion with both parties without going to full investigation. The Commission is also trialing a mediation service which will give both parties an opportunity to sit down together at an early stage to reach an agreement.

Contact Creina Lilburne in the press office on 020 7448 9439 for further information.

News items

New guide aims to 'join up' patient and public involvement in health

The Centre for Public Scrutiny (CfPS) has published a new guide for health overview and scrutiny committees (OSCs) and patient and public involvement forums (PPIFs). The guide clarifies the distinct roles of OSCs and Forums and suggests ways that they can work together to maximise their influence on decisions about health and healthcare.

The guide is part of the package of measures to provide further support for patient and public involvement that was announced by the Minister for Health Services, Rosie Winterton, in March. Other parts of the package include reducing the number of Forums and creating a "resource centre" for patient and public involvement.

Tim Gilling, Health Scrutiny Programme Manager at CfPS, said "successful patient

and public involvement relies on developing good relationships between individuals and organisations. Much can be achieved through co-operation and gaining an understanding of different priorities and constraints. The guide suggests a number of practical ways in which OSCs and Forums can work together as equal partners in the patient and public involvement framework."

The guide:

- Summarises the powers of OSCs and Forums and explains how they are accountable to local people for the work they do
- Considers why working together is important to enhance patient and public involvement
- Suggests ways that OSCs and Forums can work together around:

- building relationships with the NHS
- communicating with the public about their work
- tackling proposals for major service changes
- consulting on other health issues
- contributing to the Healthcare Commission's annual 'health check' of NHS bodies

The Healthcare Commission has identified OSCs and Forums as key groups that can provide a 'reality check' on behalf of patients and the public about the performance of NHS services. From October 2005 both parties will be able to comment on local services as part of the Commission's new 'health check' assessment process.

Foundation trust governors struggling to make hospitals more accountable to public, says King's Fund

Foundation hospitals were supposed to be more accountable to their local communities but the local elected governors are struggling to make the new system work - one year on2 from the launch of the flagship health reform.

This is the finding of a King's Fund report published today, which warns that foundation trust governors need more support and guidance in working out their role if they are to help hold foundation hospitals to account for their actions.

The report, *Governing Foundation Trusts: A new era for public accountability*, explores possible roles for governors drawing on evidence from a national workshop which for the first time brought together foundation trust governors from all over England.

Fourteen of the 20 'first wave' Trusts were represented at the event organised by the King's Fund.

The workshop revealed that less than half of governors had a clear understanding of their role and less than a third felt they had made a difference. The good news is that most governors (70 per cent) felt confident that they would be able to make a difference in the future.

Report author Richard Lewis said: "The key question is whether the governors of the new foundation trusts will have enough power to achieve results or whether they will be purely tokenistic and have little impact. Our work suggests that some governors are unsure of their role and do not feel empowered by board directors. This needs to be remedied. If governors and directors are not clear about governors' roles, the result is likely to be poor accountability on a local level."

Better communication between governors and members - the people who elected them - is crucial, according to the governors who

took part in the workshop. Nearly half said they had no effective route to communicate with the members. The governors would also like to be able to network with each other, a national training programme and a national framework setting out in more detail the respective roles of governors and directors.

King's Fund chief executive Niall Dickson said: "The Government promised that foundation hospitals would make the NHS more accountable. These are early days but our report suggests that as things stand governors are struggling to make this vision reality. Governors will need support to be effective."

For further information or interviews, please contact the King's Fund media and public relations office on 020 7307 2585, or 07831 554927.

News items

'TOGETHER WE CAN' action plan Launched

A new action plan to pass more power from Central Government to local communities has been produced as a joint effort between six government departments, including the Department of Health.

Together We Can is:

- an approach where government and citizens work closely together to make a difference to their communities;
- about a national drive to pass power,

influence and control over local services to local people;

- about listening to local people and working in partnership and bringing government and people closer together; and
- The detailed action plan embraced by twelve Government departments is the first step towards a significant shift in the balance of power between local communities and Central Government.

It outlines eight key policy areas:

- citizens & democracy;
- regeneration & cohesion;
- safety & justice;
- health & sustainability

These will be carried out by twelve Government Departments to strengthen citizens' engagement in delivering success. The action points in the plan represent the start of this work.

UK's rich and poor 'still live in different worlds despite the welfare state'

Poor people with the greatest need for good health care, education, jobs, housing and transport continue to have the worst access to opportunities and services 60 years after the founding of the welfare state, according to a new assessment of 21st century Life in Britain.

A series of ten analytical studies for the Joseph Rowntree Foundation, launched this month use data from the millennial Census to uncover the continuing 'inverse care law' whereby poor communities have the least access to essential life chances and resources.

Comparing people and places across England, Northern Ireland, Scotland and Wales, the researchers at the Universities of Sheffield, Bristol and Edinburgh report on key examples of the inverse relationship between need and supply for specific services including: -

- **Doctors and nurses:** Areas with the highest levels of poor health have the lowest numbers of doctors, dentists and other health professionals living and working there. Only nurses, midwives and health visitors tend to be more concentrated in areas of higher need.
- **Teachers:** Areas with the greatest proportions of young people with no qualifications have the lowest availability of working teachers per head of population. The areas doing best have four times the density of teachers and one-third the rate of unqualified young people.
- **In sickness and in health:** For the first time, the Census made visible the work of 5.9 million people providing care and support to others on an informal basis – including 1.2 million contributing more

than 50 hours of care a week. Unlike the 'inverse care law' that applies to doctors, there is strong geographical link between informal care provision and need. The proportion of people with limiting long-term illnesses and informal care providers increases to the west and north of the UK, with the highest rates in the Welsh Valleys, parts of Scotland and areas around Tyneside and Merseyside.

Life in Britain: Using millennial Census data to understand poverty, inequality and place by Ben Wheeler, Mary Shaw, Richard Mitchell and Danny Dorling is published by The Policy Press and can be purchased online at www.policypress.org.uk <https://www.policypress.org.uk/catalog/product_info.php?cPath=10043&products_id=1092> or from Marston Book Services, PO Box 269, Abingdon, Oxon OX14 4YN, price £49.99 plus £2.75 p&p.

WHO seeks patient & consumer partners

Patients for Patient Safety, one of the World Health Organisations six action areas, is seeking applications to participate in a workshop.

The event, to be held between November 27th and December 1st is in London and aims to recruit and develop a core group of people from around the world to become champions in advancing patient safety in their region.

Patients and consumers interested in applying can obtain details and an application at www.who.int/patientsafety/patients_for_patient/en or by calling 0207 7721 7549.

Challenges and rewards!

Already mainstreamed, with people feeling more in control of their lives, the Expert Patients' Programme in Brighton and Hove was a finalist for long-term conditions in the South Region of the Health and Social Care Awards 2005. Jane Bolding explains how the success has come about and how it has gone beyond the basic course.

The Expert Patients' Programme (EPP) originated in the United States, and was piloted in England from 2002. It has since been rolled out nationally, and provided locally through primary care trusts (PCTs). In its basic form, the EPP comprises self-management courses people living with any physical or mental long-term health condition. Courses, lasting 2½ hours a week for six weeks, are delivered according to a tried and tested approach by trained volunteer tutors, who themselves live with long-term health conditions. Topics include:

- overview of self-management
- dealing with anger, fear and frustration

- liaising with health professionals
- appropriate nutrition and exercise
- relaxation and distraction techniques
- medicines management
- looking to the future

The basic tools of the course are goal setting and action planning, which are done by the group with the support of the tutors.

National evaluations have shown that participants are more assertive with health professionals, make fewer visits to GPs and A&E, make more use of the pharmacist as a source of information, have fewer and shorter hospital admissions and have improved medicine adherence.

45% of participants surveyed in 2003-5 reported increased confidence that they would not let common symptoms – such as pain, fatigue, depression and breathlessness – interfere with their lives. In short, the EPP is a course that benefits both participants and health services!

So, what is different in Brighton and Hove?

One of the problems faced by EPP coordinators in the Surrey and Sussex area and, I suspect, nationally, is the lack of priority given to the Programme in the face of so many other competing needs and requirements. In Brighton and Hove, we are lucky to have the support of the PCT Board and the Professional Executive Committee (PEC), who have shown their commitment by agreeing adequate funding. This covers not only EPP courses but also increasing the base of volunteer tutors. It is vital to support them as much as possible as they give their time freely and generously, often when they are feeling under par. It is the least we can do to refund expenses promptly, offer training to increase their skills and, for example, offer to pay for meals when they are on EPP business at these times.

We are lucky to have 12 tutors, ranging from our two original tutors – one of whom has progressed to becoming an EPP assessor – to six fantastic newly trained tutors, who are very enthusiastic about delivering their first course!

Crucially, the funding has allowed the appointment of a full-time Administrator.

In many areas, EPP is an 'add on' to other work – commonly Patient Advice and Liaison Services, but health promotion and some clinical roles are not unknown. This was perhaps fine in the pilot phase, but the scope of the Programme really necessitates dedicated staff to do it justice.

We have regular PCT/tutor meetings to make sure tutors are happy, discuss any problems, share ideas on venues, eat nice biscuits ...

We have set up a 'buddying' scheme for new tutors where they have the opportunity to be linked with an experienced tutor. This gives them the chance to ask questions about delivery and for advice on any problems that come up in the course, and to receive support in addition to that from the PCT and the small team of regional trainers.

We are arranging training for our tutors, not only to improve their skills in terms of EPP – providing, for example 'dealing with difficult people' and 'mental health awareness' sessions – but also thinking about how they want to develop their skills, possibly to return to paid work at some stage. We have offered information technology skills workshops, assertiveness and stress awareness and, in response to tutors' ideas, we are arranging cultural diversity and 'suicide awareness' training. We are working with a community chef who will provide basic cookery and nutrition sessions, with the aim of improving awareness and thus influencing health.

Don't forget carers.....

Many times the health of carers is overlooked, when there are day-to-day demands of caring for a loved one. We heard about a pilot EPP programme for carers, called Looking After Me; fortunately, with a bit of arm-twisting, we were able to offer this course run by a local EPP trainer plus another tutor who travelled from London each week. The strong relationship the PCT has with the local Carers' Centre was the base for partnership working to provide this course in Brighton, which was full to capacity. This was a huge success! One carer commented:

"We laughed and we cried. It changed my life - I realise I'm no good as a carer if I don't look after myself."

On the wave of this success, we secured funding from the Friends of Brighton and

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Hove Hospitals for two more carers' courses. Not only does this cover the course, but also any alternative care the carer might need to put in place, carers' travel costs and lunch (the Carers' Centre felt that the opportunity to socialise after the course would be invaluable).

... or participants!

Some areas have problems with recruiting

tutors, and others have tutors but a trickle of participants. We are lucky to have both, with a waiting list of participants. Many now contact us having heard of the Programme by word of mouth; some of our best advocates are NHS staff who have been on the course! Health professionals such as GPs and nurse specialists are now suggesting that patients find out more about the Programme. We are planning awareness days for NHS staff and for the voluntary sector in the Autumn to spread the word further.

Of the more than 200 participants who have benefited from the EPP in Brighton and Hove so far, 38 different health conditions have been declared – which really shows how far we are reaching.

A captive audience

EPP tutors and participants are all potentially high intensity users of health care. Who better to give us feedback on services?

All participants are sent an evaluation after the course, which includes a form asking if they are interested in giving their feedback about health services. Those who are can join the HUB (Health User Bank), a database of people who are interested in being involved in health services. The HUB members are supported as a group – invited to an initial event to discuss how they would like to be involved and the feedback they would like to give. They are given the opportunity to choose an area they are interested in (such as mental health or staff training) and are matched to various involvement opportunities when they arise.

We are also planning the second EPP participant reunion. This is a half-day event where former participants are asked to feed back about EPP – the gains from the Programme and life changes they have made – plus more general work on their views on and experiences of health services. Our most recent reunion coincided with a local consultation on health care, so we were able

to elicit the views of our participants with long-term conditions. This time, we will be able to include carers' views as well!

For our next trick ...

As well as increasing the number of courses we offer, we hope to be involved with some new initiatives – including EPP Online and courses for parents of children with long-term conditions. We are also looking at work targeting deprived areas (which have a high incidence of long-term conditions), and increased working with the voluntary sector.

To wrap up ...

So, what is so different about EPP in Brighton and Hove?

We are not so special; there is fantastic work going on in many other areas. We are fortunate in having the unconditional support of the local PCT and the resultant funding. We have a great team of regional trainers who are unstinting in their advice and support. We have fantastic tutors, who are astounding in their energy, enthusiasm and commitment. And a ready pool of people with long-term health conditions ...

We have made the link between offering the EPP course and the wealth of experience offered by the participants in terms of health service usage, and are harnessing feedback and enthusiasm. The mainstreaming of EPP into the managing long-term conditions agenda will draw in the views of service users and carers, facilitating feedback and provide meaningful ways of using their experience to shape services.

Jane Bolding

PALS Manager

Expert Patients' Programme

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As one of our participants commented:

"I have been able to make the small changes that have really made an impact. I understand my symptoms better, and listen to my body more. Distraction techniques have proved invaluable! My GP is very impressed ... not that I see her that much any more"

A month is a long time

Writing in August for September publication ought to be easy. But the continuing uncertainty about future arrangements for PPI means Ian Hayes fears that the passage of a month will invalidate what he says!

So what do we know? We have not had any significant public announcements about future arrangements for patient and public involvement (PPI) – it is August! – but some information has emerged from replies to Parliamentary Questions and Early Day Motions towards the end of July.

An Early Day Motion in Parliament on 20 July expresses concern that reorganising the system as early in its life as this could:

“destabilise a system before it has the opportunity to develop properly and show its full benefits leading to a loss of confidence amongst forum members; and further notes with concern that the abolition of the Commission for Patient and Public Involvement in Health, without any single national body to replace it, may impede the ability of patients and the public to influence decision making on health services at a national level.”

This is one of the first, and strongest, public expressions of concern about the current situation I have noticed, and it was good to hear. There may be very good reasons to change parts of the system but the speed of change and lack of time for the system to bed down are a real problem. PPI is about cultural change within organisations and lasting changes in the relationships that patients and the public have to those organisations. These take time and will be impeded by continued changes to structures.

We have also had further confirmation of the continuing importance Ministers place upon the role of PPI forums. In a written reply dated 18 July, the Minister reiterated the functions of forums and stated:

“These functions provide forums with a role to influence health policy locally by finding out what their community thinks about health provision, taking action and encouraging others to get involved.

The functions will contribute to building an NHS that is increasingly prepared to respond to the needs of the communities it services, as well as the creation of a patient-led NHS.”

But, at the same time, a number of replies confirmed the intention to abolish all but the primary care trust (PCT) PPI forums. So, while we can welcome the continuing importance placed on the role of the PPI forums, there is continued reason for concern about how they will work with individual providers of health care. In addition, given that the future of PCTs seems likely to involve a significant reduction in numbers we need to be concerned about:

- the additional uncertainty which these further changes will bring to PPI arrangements, and
- how PPI forums, even with larger memberships, will manage meaningful community engagement “locally” across such large geographical areas.

These concerns, especially those around the number of PPI forums and whether they should focus on geographical areas or on provider Trusts, have been around since long before the creation of the Commission for Patient and Public Involvement in Health.

So what do we know? We have not had any significant public announcements about future arrangements for patient and public involvement (PPI) – it is August! – but some information has emerged from replies to Parliamentary Questions and Early Day Motions towards the end of July.

We really do need to revisit those discussions and avoid ‘re-inventing wheels’. It might be time to recognise that we are where we are because decisions were taken too quickly in the past in order to meet unrealistic timescales.

A considered view needs to be taken but, with less than a year left until the planned transfer of functions, it seems less and less likely that this will be possible. It is arguable that the mechanism for taking such a considered view is yet to be put in place.

The role of the proposed national PPI Resource Centre is, in part, to consider arrangements and make recommendations. Its brief will extend across the whole range of PPI activities, not just those currently carried out by CPPIH. As an independent body, it would be ideally placed to consider the options and suggest a way forward for the system as a whole.

This consideration could be based on evidence since more and more evidence is emerging from the operation of the current system, it could also include a proper review of the cost of PPI.

I have been thinking about the cost of PPI a lot recently. We know what running the CPPIH system costs, but much of this lies outside of that within the budgets of Trusts and PCTs. I would be happy to be proved wrong, but I suspect that no one knows the total cost, or the comparative cost of PPI for different NHS bodies. Without this kind of information, it is impossible to take a view on whether the current, or any proposed system ‘adds value’.

But, of course, the PPI Resource Centre will not be in place until after the decisions are made and implemented.

Ian Hayes

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Drugs Futures 2025

Experts from many fields have explored how scientific and technological advancement may affect our understanding of addiction and drug use over the next 20 years. As Martin Ince explains, they also engaged the public, but found that the more people knew, the more they challenged scientific opinion.

Can the public be consulted about medical developments that could be decades in the future, may never happen and whose outlines we are only starting to appreciate?

That was the challenge for the UK Office of Science and Technology's (OST) Foresight project on Brain Science, Addiction and Drugs. Over an 18-month period, the project consulted over a hundred experts on the future of drugs and the brain. They discussed drugs for pleasure, both legal and illegal, and drugs for therapy, as well as new types of drug such as cognition enhancers that are only now beginning to emerge.

The project's own work involved scientists, economists, historians, medical practitioners and a wide range of others including people involved in drug treatment and law enforcement. But a decision was taken at an early stage that it was also vital to engage the public in its work.

For an issue such as this, there is no such thing as "the public." A wide range of people have an interest in drugs, mental health and the other topics that make up the project, and they come at it from many perspectives. So the people consulted included users of illegal drugs as well as others whose knowledge of them is less direct. One group was drawn from people with ADHD (Attention Deficit Hyperactivity Disorder), their parents and carers. A school in Hounslow near London was the source of a group of children consulted by the project. Other groups were held across the UK, in Derry, Glasgow, London and Swansea.

Even more tricky is the fact that the people being consulted had to comment on possible future scenarios, not current developments. Even today's scientific discoveries are regarded with scepticism and uncertainty by the public, let alone those that have yet to occur.

However, the consultation, run by the Office of Public Management (OPM) for OST, was a success.

It used discussion groups, workshops and a final forum to get at public attitudes to the project's top-level question, which was how the use of psychoactive substances could be managed in the future for the best advantage of the individual, the community and society.

One view that emerged strongly is that individual freedom and autonomy is the source from which everything else flows. As one participant put it: "If drugs are designed to combat deviant behaviour, where does it stop?"

One of the areas explored in the consultation was the possible use of preventative medicines to reduce the harms from recreational drugs. There are many practical reasons why vaccination against drug use may be difficult, but the public was also concerned about the idea of a treatment that might restrict an individual's freedom by removing the option to use the substance in the future. They preferred an approach in which people whose genes might predispose them to addiction were offered support and counselling. The ADHD carers were particularly keen on this approach as a preventative measure.

In the same spirit, the groups consulted were alarmed about the possibility of a "normalised" society where people were offered psychoactive substances to treat behavioural conditions at the fringes of behavioural norms merely to deliver community safety.

These findings are consistent with a more general view expressed during the consultation that although science is largely a force for good, it needs to be seen in an ethical context. BSE, MMR, the possible radiation hazards of mobile phones and – perhaps surprisingly given the long time lag – thalidomide are all regarded as examples of science being misused. The pharmaceutical industry has a particularly poor image despite the general recognition among the public that it has developed successful treatments for previously fatal conditions.

In addition, the participants called for more public dialogue about future legal and illegal drugs and their effects. Some of the channels they suggest sound obvious, such as school lessons or sessions with GPs and pharmacists. But they also asked for more community involvement in projects on the effects of drugs, and for the findings that result to be made widely available online.

The Government has now asked the Academy of Medical Sciences to look at issues relating to society, health, safety and the environment raised by the report. Part of this work will include public dialogue where experts and members of the public can debate the issues that advances in brain science, mental health treatments and addiction may raise. The project's wide range of reports, called Drugs Futures 2025? and including Public Perspectives, which describes the consultation, are available at www.foresight.gov.uk

There is evidence from many lines of research that lay people with a direct personal interest in complex topics can find out about them in detail. This consultation showed that carers for people with ADHD had a particularly highly developed awareness of drugs such as Ritalin (methylphenidate) that are commonly prescribed to ADHD patients.

They want the media to report on new research and new drugs more reliably, while being keen to avoid over-hyping every new drug that comes along.

They also call for the health system to discuss drugs more openly. They point out that facts that might seem useless to some drug users could be vital to others, such as their exact chemical names as well as brand names.

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For more details about the Brain Science, Addiction and Drugs project, see www.foresight.gov.uk/Brain_Science_Addiction_and_Drugs/Index.html

Health Check

One way that the Healthcare Commission is seeking to promote improvements in the quality of healthcare and public health is by creating an entirely new approach to assessing and reporting on the performance of healthcare organisations. Anna Coote explains the role of PPI in making it happen.

Healthcare organisations across England are preparing declarations for the Healthcare Commission that say how well they think they have performed against standards set down by Government. This is the first stage of the 'Annual Health Check', a new system of assessment that will lead to the award of ratings next summer. It replaces the old system of inspection against targets and 'star ratings' undertaken by the Commission for Health Improvement (CHI), the regulatory body that was replaced by the Healthcare Commission last year.

Are you still with me? I am not going to try to defend the endless reshuffling of functions and institutions to which all governments seem to be addicted, except to say that the new Commission is less concerned than the old Commission with routine inspection and more with getting health organisations to improve their performance - in my view a good thing. What I want to do here is explain how the Healthcare Commission involves patients and the public in the 'Annual Health Check'. I have been with the Commission since February as Head of Engaging Patients and the Public. With colleagues I have been working to bring this new system of assessment closer to the people it is supposed to benefit. I will freely admit that what we have put in place is not perfect. But, given the brisk pace at which we have had to introduce these changes, the complexity of the whole task and our finite resources, it is the best we could do for year one.

Earlier this year, we carried out extensive consultations with members of PPI forums and others, including workshops with people whose voices are seldom heard in general consultations, such as those with learning difficulties, gay men and lesbians, and black and minority ethnic groups. These have helped to shape the system of assessment so far. From here on, we intend to learn as we go and hope we can make significant improvements in the ways we involve patients and the public in year two and beyond.

Because the system is new, we have introduced a pilot phase for year one only. This should give people a chance to get used to it and iron out glitches. Accordingly, healthcare organisations are asked to submit a draft declaration in October 2005 and a final declaration in March 2006. In subsequent years, they will submit a single declaration in March.

The Annual Health Check covers NHS hospitals (including NHS foundation trusts), ambulance services and primary care trusts. The standards test performance in seven areas:

- Are these organisations safe for patients?
- Do they provide services that are clinically effective and value for money?
- How well are they run?
- How far are they patient-focused?
- Do they provide accessible and responsive care?
- Is the environment in which people receive services well designed and maintained?
- What is being done to improve, promote and protect the health of local people?

In each area, there are 'core' standards, which are basic requirements that all organisations should meet, and 'developmental' standards that encourage improvement. Year one of the Annual Health Check focuses mainly on the 24 'core' standards. The Healthcare Commission has drawn up criteria to show what healthcare organisations need to be doing to meet them. It has also issued guidance on how to draw up the draft and final declarations. This includes guidance on how to involve patients and the public.

Every organisation is required to invite PPI forums and local authority overview and scrutiny committees (OSCs) to contribute their own comments to the draft and final declarations. Neither PPI forums nor OSCs are obliged to comment, but if they do, what they say must be included unedited. Wider involvement of local user-led and community-based groups in preparing the declarations is also encouraged.

We have issued separate guidance to PPI forums and OSCs and are holding events with them, in partnership with the Commission for Patient and Public Involvement in Health

(which supports the PPI forums) and the Centre for Public Scrutiny (which works with the OSCs), to explain the process and build their capacity to contribute effectively. We encourage them to comment on aspects of performance that relate to the standards and that can be supported with practical examples gathered in the course of their own work over the year. So, for example, if a PPI forum comments that its local hospital has dirty toilets, we would expect that to be based on a documented site visit.

Once the declarations are submitted, they are cross-checked against everything else the Commission knows about each organisation, including complaints, staff and patient surveys, and investigations and research. If there is a substantial mismatch between the declaration and any of this data, including the comments from PPI forums and OSCs, the Commission will consider an inspection. It also carries out random spot checks with unannounced visits.

Looking ahead, we are developing more inclusive approaches to PPI at two test sites, one in the South West and one in the North of England. Here, we are working with local healthcare organisations and with community-based and user-led groups, and we hope to establish viable, locally grown models for engagement that can be used in future years.

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For more details about the Annual Health Check, go to www.healthcarecommission.org.uk/InformationForServiceProviders/AnnualHealthCheck/fs/en?CONTENT_ID=4017483&chk=ub2qrx

It is important to the Healthcare Commission that the people who benefit from our work continue to be part of it. The Commission therefore values feedback and input from patients and the public. If there is an aspect of our work that you would like to become involved in, please contact Lea Pickerill on 020 7448 9413 or email feedback@healthcarecommission.org.uk

Spread the word

Epilepsy is a common, but misunderstood condition. Liz Champion describes how volunteers are spreading the word.

More than 450,000 people in the United Kingdom have been diagnosed with epilepsy, making it the second most common neurological condition after migraine. Despite this, epilepsy is one of the most stigmatised and misunderstood conditions: many people do not know what epilepsy is, or how it is caused.

What is epilepsy?

Epilepsy is a tendency to have seizures – caused by a brief and temporary disruption in the electrical discharges of the nerves within the brain. It is like a very brief short circuit, which results in the brain's messages becoming temporarily halted or mixed up.

What causes epilepsy?

Anyone can develop epilepsy, at any age and from any walk of life. In most cases, there is no known cause, and in other cases, epilepsy is caused by damage to the brain. This damage can occur because of a blow to the head or brain damage before, during or after birth. As we get older, other possible causes are strokes and circulation problems. For six out of 10 people there is no known cause.

Getting an accurate diagnosis

Diagnosing epilepsy can be difficult as there is no single test to determine if you have the condition. Hospital investigations commonly used are blood tests, an EEG (electroencephalogram), a CT (computer tomography) or MRI (magnetic resonance imaging) scan.

The most important information the doctor will rely on when diagnosing epilepsy is a description of what happens to you during a seizure. An eye witness account can also be very useful. There are many different types of seizure, so it is important to get an accurate description of the signs and symptoms experienced.

What a person experiences during a seizure will depend on where in the brain the epileptic activity begins, and how widely and rapidly it spreads. During a seizure, some people may black out, while others experience a number of unusual sensations or movements. Seizures generally last only a few seconds or a few minutes.

Some seizures affect the whole brain (generalised seizures) and some affect just a part of the brain (partial seizures).

Occasionally seizures can spread from one part of the brain to the whole brain. Seizures can happen when someone is awake or asleep.

In recent years, the medical names given to various types of seizure have changed so you may hear one seizure referred to by different terms.

Types of seizure

Ask anyone in the street to describe an epileptic seizure and they will probably talk of someone going stiff, falling to the ground and having convulsions. This is a tonic-clonic seizure and is only one of around 40 different types of epileptic seizure, which include:

- **Absence seizures:** These seizures involve a brief loss of awareness for several seconds. They can occur many times a day, every day. They may be accompanied by eyelid fluttering or lip smacking.
- **Myoclonic seizures:** These involve sudden jerky movements usually in the arms or legs, but can affect the whole body. They are very brief.
- **Atonic seizures:** These seizures cause a sudden loss of muscle tone – usually resulting in a fall.
- **Tonic seizures:** These involve sudden stiffness of the limbs or the whole body. They may result in a fall.
- **Clonic seizures:** These involve repeated contraction of the muscles. They cause jerks or twitches of the whole body and last between 30 seconds and a few minutes. They can sometimes last longer.
- **Tonic-clonic seizures:** These involve sudden stiffness and a loss of muscle control, usually resulting in a fall – but some can last for more than 30 minutes – this is called status epilepticus, and is a medical emergency.
- **Partial seizures:** These can be divided into two types – simple and complex. During a simple partial seizure, the person's level of consciousness is not affected. The person may experience a change in sensation, such as a strange smell or taste, or a feeling of *déjà vu*.

Taking Action

Epilepsy Action acts as the voice for people in the United Kingdom with epilepsy. It provides help and information to those living with epilepsy, as well as their friends, families, carers, health professionals and the many other people on whose lives the condition has an impact.

Epilepsy Action, the working name of the British Epilepsy Association, was set up 55 years ago and now has around 16,000 members. As well as campaigning to improve epilepsy services and raise awareness of the condition, the charity assists people in a number of ways, including a network of branches, accredited volunteers, regular regional conferences and freephone and email helplines.

Changing attitudes towards epilepsy is a real challenge for the charity. Myths are hard to dispel, and for some people, epilepsy is still something they feel they need to fear and avoid. Education is the key to overcoming this attitude, and Epilepsy Action works hard to tell people the truth about epilepsy.

To help raise awareness and put an end to the many myths surrounding the condition, a team of dedicated Epilepsy Action volunteers tour the country giving talks and presentations to schools and local groups. The volunteers talk about epilepsy and what it is like to live with the condition.

People wanting to become a volunteer for Epilepsy Action are required to complete a training programme to develop the necessary knowledge and skill to be able to help people who have epilepsy. The charity provides continual support throughout the training period and has a conference and volunteer co-ordinator to answer any queries.

To pass the course you must successfully complete the nine modules, attend two designated training days, and complete the distance learning package. The training programme is designed to provide volunteers with information on the nature, causes, management, effects and social implications of epilepsy, as well as preparing volunteers for one to one contact work and group speaking.

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Common knowledge

The arts have a positive contribution to improving health, argues Mike White, but it is critical to get a collective commitment.

On the launch of the NHS in 1948, its political architect, Nye Bevan, observed: "The maintenance of health requires a collective commitment. Preventative medicine, which is merely another way of saying collective action, builds up a system of social habits that constitute an essential part of what we mean by civilisation".

Bevan acknowledged that there is a cultural base to the Health Service and that we need to make this visible for the public to fully engage with it. Yet it has taken half a century to realise that participatory arts could have an important role in bringing this to light. Collective creativity can make committed expressions of a community's health, simultaneously identifying and addressing their local and specific health needs. This is what distinguishes arts in health work from art therapy and connects it into social inclusion. Arts activity can also address a concern to maintain trust between healthcare professionals and the public. As a former Secretary of State for Health said, "the arts can play a very important role in ensuring that messages about healthy lifestyle, and about engagement between the Health Service and the communities they serve, can be enhanced." (Rt. Hon. Alan Milburn MP at CAHHM's Common Knowledge conference, Newcastle, 2001).

The arts in health field has grown exponentially in recent years. The National Network for Arts in Health (www.nnah.org.uk) currently has around 400 members. The field is now so diverse we are starting to see some emerging specialisms in differing approaches. Some projects may focus on the therapeutic benefits of the arts for individuals, some on environmental improvements to support health care staff in delivering services, and others on producing more creative kinds of health information. When doing arts in health work with communities, we may also focus on the concept of social capital where 'unity is health'. These are arts projects that start

There is a window of opportunity for arts development to help realise a social model of health. The move to multi-agency working is new to our reformed health services; the arts can have both an integral and a catalytic role in this. What used to be understood as the preventative approach to health care is increasingly about building capacity for change, externally in developing social capital and internally in improved training and holistic approaches.

from the point of using creativity to enhance social relationships, reflecting growing evidence that good relationships are a major determinant of health.

There is a window of opportunity for arts development to help realise a social model of health. The move to multi-agency working is new to our reformed health services; the arts can have both an integral and a catalytic role in this. What used to be understood as the preventative approach to health care is increasingly about building capacity for change, externally in developing social capital and internally in improved training and holistic approaches.

To demonstrate their effectiveness, arts in health practitioners need to share their practice within collaborative research programmes that will create the evidence base that is implicit in the qualitative testimony of participants in the projects. Building networks of arts in health projects is necessary to develop both the practice and its research agenda; this is what our research centre at University of Durham focuses upon and helps engender. There must also be a learning development aspect to networking, with action seminars on issues of common interest and 'apprentice' placements on projects. For example, the Common Knowledge programme we have run for Tyne and Wear Health Action Zone convinced us that arts in health is essentially about building capacity, not just with artists but with staff in all the other sectors engaged with this work and, most importantly, directly with communities and patient groups themselves.

Common Knowledge has coordinated a major programme of work over the last four years using arts-based approaches to examine health. It aims to draw together different perspectives to increase capacity for arts-based approaches to health by engaging artists, health professionals of all kinds, teachers, local government and the voluntary sector to devise and deliver imaginative health interventions.

Common Knowledge has worked in real contexts to address such major questions as: 'what does health mean?' and 'how can engagement with the arts improve health status and lead to health gain?' Participants have to date completed over 50 pilot projects. 'Revelation days' have been held to explore new ways of working (such as arts-on-prescription schemes, participatory evaluation and emotional literacy for health). Most of the projects so far completed have been documented and many present 'stand alone' insights into working on health issues via the arts. There is a wealth of stories that are currently being mined to understand more about the relationship between art and health – see Smith, T., *Common Knowledge: An Evaluation of Sorts*. Centre for Arts and Humanities in Health and Medicine (CAHHM), University of Durham (2003). This approach is now also being applied in the East Midlands through a partnership between CAHHM, the Arts Council and the regional public health directorate.

One of the Common Knowledge projects is an annual lantern procession on the theme of 'happy hearts'. The Wrekenton area of Gateshead has an unemployment rate higher than the national average and there are many single parent families and high levels of drug abuse. The area also has one of the worst morbidity records for heart disease in England. The lantern procession through the streets is organised with the collaboration of the local school and the health centre. The lanterns are made by adults, young people and children, some to carry themselves, some for friends to carry. The workshops and the resulting procession create a strong sense of community. In the two-week preparation period of lantern making, information on both mental and physical health is imparted and shared in a relaxed and domestic manner. The project's coordinator grasped the potential of this from the outset:

"The link that we found between school, lantern workshop and Health Promotion Bus is that each can induce wariness. To step over the threshold into unfamiliar territory can seem a daunting challenge. By holding the lantern workshops in the community rooms of a school, and by including the Health Promotion personnel in the team, we could help demystify the unknown, and maybe create a mutual healthy experience. The lantern workshops became a congenial space.

Slowly, a gang of women and the occasional man became involved. No longer threatened, the power of chat became the conduit for discussion of health, life and death that was sometimes serious, at other times hysterical. At the centre of it all was the art and activity of lantern making. Parents would come to help their child make one and would still be coming days after that one had been finished. From simple materials came magical objects."

From the outset, responses from participants have annually been collected and documented:

"When you came here and said 'We're all going to make lanterns out of sticks and glue, and walk down the streets with them', well, I thought you were mad. I'd never have believed what I've seen tonight. Look, it's Friday night in Wrekenton and everybody's eating brown bread and soup - and enjoying it!"

Deputy Head of local primary school.

"When the lanterns light up, everyone turns into my friend."

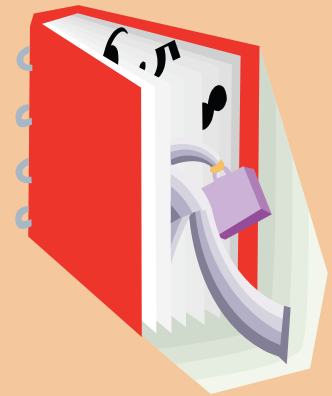
9-year-old boy.

In collaboration with CAHHM, this project is currently devising methodologies to evaluate the impact of the arts in the development of emotional intelligence within the life of the school and wider community.

There are now many arts in health projects in the UK like this that are attempting to establish a continuum of support for people to improve both their well-being and creative skills. Much of the practice and learning going on in this field can usefully contribute to wider health promotion strategies and the development of participatory arts with the general public. They need not be seen simply as specialist services for excluded minorities, but rather as core applications of the arts to encourage a healthy culture in a healthier nation.

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Leading by example

The patient and public involvement challenge is usually focused on the NHS, but what is the voluntary sector doing on service user and carer involvement? Kristina Staley and Bec Hanley have been finding out.

Voluntary sector organisations have been telling the NHS for sometime how it should be doing more to involve patients and the public in its work. But they know that if they want to be more persuasive, they need to be 'putting their own house in order' and involving service users and carers more effectively in their own organisations. This may be why, in a survey carried out by the Long Term Medical Conditions Alliance (LMCA), member organisations identified service user and carer involvement as one of the key areas where they are looking for guidance. They are aware that if they want to push for more patient and public involvement in the NHS, they need to lead by example.

Unlike working in the NHS, people working to promote and support service user and carer involvement in the voluntary sector have limited amounts of specific guidance and even less supportive infrastructure, such as learning networks or training programmes. But what they do have is a tremendous amount of experience from 'learning by doing' – many organisations are simply getting on with it – and are now looking for opportunities to share their experiences and learn from others.

The Long Term Medical Conditions Alliance therefore commissioned TwoCan Associates to develop a set of three guidelines on service user and carer involvement, securing funding for this project from the Lloyds TSB Foundation. They consulted their members for a second time to find out exactly what topic areas they would find most useful. What people said they wanted was:

- Help with developing a strategic approach to user and carer involvement. Some people were not sure about how to get started or how take their work up a notch. Others were already involving users and carers in different projects and were looking for ways to link up this activity and feed it in to the mainstream agenda of their organisation.
- Advice on good practice – while taking into consideration the challenges of

working with people who have a long-term condition, finding ways to meet their needs as well as being flexible enough to adapt to changes in people's circumstances.

- Opportunities to learn from others – about what they do in different parts of

Voluntary sector organisations have been telling the NHS for sometime how it should be doing more to involve patients and the public in its work. But they know that if they want to be more persuasive, they need to be 'putting their own house in order' and involving service users and carers more effectively in their own organisations

their organisation as well as what works and what does not.

Having prioritised these three topics, the guidelines were then developed in collaboration with service users, carers and staff from a wide range of member organisations of the Long Term Medical Conditions Alliance – from organisations that were large and small, that were user-led or staffed by non-users, that were based in different parts of the UK and that were supporting people with many different types of condition. In this way, LMCA members were able to define what each guideline needed to cover and were able to contribute to the detailed content by drawing on their own knowledge and experience.

What we have aimed to produce is a set of useful reference documents that can be dipped into rather than read from cover to cover. We have included information that is valuable to people who are just starting, as well as advice about how to improve what you do if you have more experience. We have emphasised that there is no single 'right way' to involve service users and carers – that it is best to start small, and to do something quickly and well before setting your sights higher. While targeted at people in the voluntary sector, we hope that many of the lessons will be transferable to others.

The guidelines are now available to download from the Long Term Medical Conditions Alliance website (www.lmca.org.uk) along with an invitation to provide feedback to the LMCA and to make recommendations about what other work should be taken forward in this area. It would be valuable for the voluntary sector to hear from the NHS what more they could do to promote effective patient and public involvement.

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A Fluid Response

An area of increased focus for Macmillan Cancer Relief in the last three years has been addressing issues of inequality of access to cancer services for black and minority ethnic communities. Melanie Lee describes how responses to African-Caribbean and African men can be improved.

One of the challenges in health information is ensuring the service can respond appropriately to the needs of a broad range of communities whilst ensuring equality of access where disadvantage exists.

Research undertaken by Macmillan Cancer Relief and the London School of Hygiene & Tropical Medicine demonstrated that black and minority ethnic communities face barriers to accessing cancer information and support services. This experience is, of course, not uncommon to many people affected by cancer but cultural, ethnic, religious, and linguistic diversities compound the issue. So it is important that cancer services develop collective, inclusive approaches which take account of these additional factors.

The Macmillan Black and Minority Ethnic Toolkit. Effective communication with African-Caribbean and African men affected by prostate cancer guides health and social care professionals in cultural diversity and equality to enable appropriate responses to African-Caribbean and African communities affected by prostate cancer.

Background

African-Caribbean and African men are three times more likely to be affected by prostate cancer than their white counterparts, although they have the lowest access to prostate cancer information and support services. The explanation for barriers to access for black and minority ethnic communities tend to be:

- in relation to health care staff :
 - an unwitting lack of awareness and understanding of the specific information and support needs of people from black and minority ethnic communities
 - a lack of recognition that exclusion occurs
- in relation to black and minority ethnic communities :
 - lack of awareness about cancer
 - fear and misperceptions about cancer

- taboos within communities which act as impediments to access.

In response to these findings, Macmillan formed a steering group of cancer partner organisations and users from African-Caribbean and African communities, to inform the Toolkit development. These partners include the African-Caribbean Leukaemia Trust, the Prostate Cancer Charity, CancerBACUP and Cancer Black Care and with help from the Igbo Cultural and Support Network, the Learie Constantine West Indian Association and the Anglo-Caribbean Domino League.

Hence, the principles of collaborative working, user and community involvement, outreach and evaluation were central elements of the production process. The final publication is a demonstration of a culturally appropriate resource in terms of content, design and layout.

The design makes it possible to 'dip in and out' of the Toolkit when particular advice or support is needed, or to go through the chapters in order. This element of choice ensures that the Toolkit becomes an 'active' document of regular use which provides guidance, reference and support.

Areas covered by the Toolkit

The Toolkit is comprised of five main sections and an index. These are:

- Getting to know African-Caribbean and African communities: Who are these communities? How are they defined and why? The importance of ethnic monitoring.
- Methods of establishing contact: The best methods to make meaningful links with African-Caribbean and African communities.
- Cultural pointers: Understanding lifestyle and culture, developing cultural competence, the role of women, cultural myths and attitudes, and the key issue of 'relational identity'.
- Communication and language: Principal languages in the Caribbean and Africa, body language, social and cultural etiquette, the use of advocates and interpreters.
- Developing materials: Options for developing resources, working with

a translation agency, multi-lingual resources, and the use of culturally appropriate images.

Throughout the document, the experiences of people affected by cancer from African-Caribbean and African communities are used to illustrate the points made. Focus groups were held with African-Caribbean and African men in Birmingham, Manchester, Rugby, and Brent and Haringey in London. The content of the Toolkit also highlights the diversity of method and process used, demonstrating that it is possible to access a wider breadth of people from African-Caribbean and African communities via non-health or non-cancer specific information routes. The importance of community networks and contacts, where trust and relationship already exists can be an effective avenue into discussions about cancer and cancer information in ways that African-Caribbean and African communities may resist in more conventional health environments.

Indeed, the community organisations that helped to bring the focus groups together enabled discussions about prostate cancer to occur amongst men (and their families) who had never before discussed the issues in a public forum although many had been affected by the disease. None of these organisations have either a health or cancer focus.

Conclusion

The purpose of the Toolkit is to provide a framework for understanding some of the issues involved in providing a cancer information and support service to African-Caribbean and African men affected by prostate cancer and their families. The Toolkit does not, however, intend to be prescriptive, so the concerns raised cannot be indiscriminately applied. 'Culture' is a fluid entity: there are diversities within all cultures and communities, so expectations, needs and their subsequent response will always depend upon individual circumstances.

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Free copies of Macmillan Black and Minority Ethnic Toolkit. 2. Effective communication with African-Caribbean and African men affected by prostate cancer are available from Macmillan Resources Line: 01344 350310.

Advocating for health

Advocacy has been rapidly moving from the fringes into the mainstream, but little is known about what it is and how it contributes to public involvement and the improvement of health, argues Baljinder Heer.

Government is committed to involving patients and the public in improving and delivering appropriate health care. For this to be successful, individuals need to be empowered to voice their concerns and express their views and the NHS needs to listen and act upon them. There are, however, many people who have limited personal power and resources to make themselves heard. This is especially true if they are very young or very old, have reduced mental capacity or do not use English as their first language. In addition, there are well documented inequalities in the availability and quality of services and care available to some groups of people.

Advocacy as an independent, community-based service is an effective tool for helping disadvantaged individuals, groups and communities to exercise their rights, access services, voice their own needs and obtain the information and support they need. More crucially, it is an effective tool for empowering individuals and communities to identify their own needs and implement their own solutions.

This argument has been gaining greater recognition within Government in recent years. For example, there have been several pieces of legislation and new initiatives that task statutory bodies with ensuring access to advocacy services, including:

- The draft Mental Health Bill 2004 proposes that all patients subject to compulsory mental health orders should have independent advocacy available to them.
- The Valuing People white paper stresses that people with learning disabilities should be able to access advocacy support.
- The Independent Complaints and Advocacy Service created as part of the 2001 Health and Social Care Act, and available to all users of health services on a regional basis.

- The Mental Capacity Bill 2004 is about enabling decisions to be made on behalf of people who lack the capacity to do so and introduces 'independent mental capacity advocate'

- The Choosing Health public health white paper introduces the concept of accredited community-based 'health trainers' to help individuals to change their behaviour and lead healthier lives, which has been modelled on the concept of advocates.

Government is committed to involving patients and the public in improving and delivering appropriate health care. For this to be successful, individuals need to be empowered to voice their concerns and express their views and the NHS needs to listen and act upon them.

Little is known, however, about what the advocacy sector 'looks like', how many advocacy organisations there are, and how these developments would impact upon them.

The King's Fund recently set out to explore these issues through original research, including an extensive literature review, in-depth interviews with people working in the advocacy sector and analysis of government policy. The report, *Building Bridges for Health - exploring the potential of advocacy in London*, details the findings, which show that the advocacy sector in the UK has developed rapidly over the past 20 years. In London alone, there are now approximately 500 organisations providing advocacy to some degree. They have, however, developed in an ad hoc manner. Projects have been set up in response to the perceived needs of some of the most disadvantaged individuals and groups in society, rather than in a strategic way.

Some areas have high levels of provision, while others have little or none. They are often funded on a short-term basis and find it hard to survive, while they are largely uncoordinated and unregulated, relying heavily on untrained and unpaid volunteers.

In addition, there is no agreed definition of what advocacy is or does, and many models exist; sometimes in competition with each other. Many would agree that advocacy at its simplest means supporting and empowering disadvantaged individuals to have their views and concerns heard in order to secure enhanced rights and entitlements. Yet, even within the advocacy world there are differing views of what exactly this means and what roles and duties an advocate may perform.

Advocacy as an independent, community-based service is an effective tool for helping disadvantaged individuals, groups and communities to exercise their rights, access services, voice their own needs and obtain the information and support they need.

The research also found that there is a lack of awareness and identity for advocacy services. Advocates have been seen as an invisible workforce: they work behind the scenes in the most deprived areas with the most disadvantaged people. Yet they can often be the only link between the individual and health and social services. Their potential for improving health and well-being is enormous but there is little recognition or proper support for their work from statutory services.

Government is showing an increasing interest, driven partly by the need to ensure its choice, public participation and public health agendas reach disadvantaged and vulnerable communities and partly by a growing realisation of the opportunities for partnership with the voluntary sector. But some advocacy organisations are rightly wary of how they can best work with statutory services without losing their unique and

credible links to the communities they serve.

Furthermore, our analysis shows that the Government has also failed to take a consistent approach. Different models of advocacy and different approaches to key issues such as funding, regulation and professionalism have been applied – some of which are difficult, or even threatening, for many within the advocacy sector.

At the same time, there are huge strengths inherent in the sector. Advocates are committed, energetic, self-motivated and passionate about what they are doing. There is evidence that they make a real difference to the lives and health of disadvantaged individuals, groups and communities.

We believe, however, that a more strategic approach to the development of advocacy is now needed for it to fulfil its potential. Firstly, a clearer working definition of advocacy is needed, which not only encompasses its independence and its role in empowering individuals, but also recognises its potential for improving health and well-being, and promoting active citizenship in its widest sense.

Secondly, there needs to be a consistent and coherent strategy to developing advocacy services, and for advocacy to be available to all who need it. This needs to be supported by Government commitment and funding, preferably within a national policy framework, and by local planning and co-ordination. We strongly recommend the development of local advocacy plans, which should be drawn up by local authorities and primary care trusts in consultation with advocacy organisations and other stakeholders, to ensure equity of access, appropriate specialisation and adequate funding.

Thirdly, the advocacy sector needs to develop a strong identity and voice for itself, which will put it in a better position to influence policy and delivery at all levels. This could be achieved by the development of a national advocacy alliance representing the whole advocacy sector and through standard setting and evaluation.

Health advocacy appears to be a longstanding idea whose time has finally come. With recent developments it is gradually shifting out of the margins and moving centre stage where it can be a real force for change.

This is a crucial time for advocacy and the opportunities that now exist need to be grabbed with both hands.

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If you would like a copy of Building Bridges for Health, it can be downloaded free of charge from the King's Fund website at www.kingsfund.org.uk/pdf/buildingbridges.pdf

If you would like to find out more about advocacy contact:

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Action 4 Advocacy,

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www.advocacyacrosslondon.org.uk

The King's Fund and Advocacy

The King's Fund has a long history of supporting and funding the advocacy sector. Over the years, its support has included a major grants programme for health advocacy for black and minority ethnic communities in London, the development of a standards framework, funding of resource agencies and substantial investment in development grants for individual advocacy projects. This commitment will continue with a new funding and development programme looking specifically at mental health advocacy and the development of accredited standards, both in partnership with the advocacy sector.

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Last Word from Chris Dabbs



Dear Mrs. Buggins,

I am not a great fan of mobile phones – too much noise, and now almost unavoidable. It was, however, useful that we had one last week when we had to get your father into hospital. Having to negotiate with the district nurses, the social worker, the GP, the rehabilitation unit and then the ambulance service is challenging enough. Doing it where there was no easy access to a telephone would have been a nightmare – especially on a Friday afternoon.

The situation made me reflect on how quickly we take things for granted. The concept of a mobile phone was virtually unknown 20 years ago. Now, there are more mobile phones than people in the UK! Email and the Internet were cutting-edge developments 30 years ago. Little more than half a century ago, the leading figures in IT thought that the world might need five computers!

Things are similar in health care. Intensive care, now quite normal in the western world, was rare little more than a generation ago. The first heart transplant took place only in the 1960s. Things that are expected by people from modern health care systems would, at our age, have been dreams to our parents, and unimaginable to our grandparents.

Futurologists at BT have created a technology timeline for the next 50 years. This covers all areas of life, including health and medical issues. Electronic prescriptions are already here, but in less than five years, tooth regeneration will be part of the dental armoury.

By 2012, while lucky children might be entertained by video tiles in the bathroom, their bedrooms might have wallpaper changing appearance to promote feelings of

energy, happiness or calm. They might interact with a teddy bear that responds to their voice with matching emotions. We might all have to be careful, however; at about the same time, synthetic viruses will be a reality in our lives.

Only a decade away, each of us may have our individual DNA listed, before we take off for a stay at a hotel in orbit. No worries about the garden – the robots may tend the kaleidoscopic flowers. But if that sounds outlandish, some think that space elevators to moon villages could be here by 2040.

Adding to the Olympic excitement in 2020 may be the first bionic Olympics. But all this new technology will also bring new challenges: viruses may be crossing over from machine to human by 2025.

By the 2030s, the hi-tech games and entertainment of today will look as exciting as those of the 1950s to children now. People then could be playing sims games using real genetics, while their holographic televisions project 3D images to entertain custom designed pets.

Most challenging of all – it is predicted that the artificial brain may be with us by 2045.

It was good to see your father rested in bed in hospital early on Saturday morning. I wonder what technological developments might help us in the future, in the way that the mobile phone helped him.

Keep well

Chris

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

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EVENTS CALENDAR

True Costs of Participation

Aim: To ensure that the Involve research on the economics of participation reflects the reality on the ground. The workshop will also provide an opportunity to discuss the costs and benefits of participation more generally and to share and learn from each others experience.

Date: 15th September

Time: 2.00pm-4.30pm

Location: Involve's offices at 212 High Holborn, London

Contact Edward Andersson: t: +44 (0) 20 7632 0120 e: edward@involving.org

NICE Annual Conference

NICE's annual conference is taking place on 7-8 December at the International Convention Centre in Birmingham.

The conference programme and bursary scheme for patient/carer organisations are now available at www.nice.org.uk/page.aspx?o=conference05

Call 0151 709 8979 for a registration form or register online from Monday 15 August at www.nice2005.co.uk.

The Black Report and its consequences

What has happened to health inequalities since 1980? What happened to the recommendations made in the report? What further measures are needed?

Friday 9th September 2005

Manchester Town Hall

10am to 4pm

Lunch provided.

Martin Rathfelder
Director

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