Healthy Democracy

The future of involvement in health and social care

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Acknowledgements

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Foreword

Since its introduction in 1948 the NHS has formed the bedrock of healthcare in Britain, offering access to treatment free at the point of need for all. This principle has been at the heart of this Government's programme for the NHS since it came to power. That is why since 1997 we have delivered unprecedented levels of investment and introduced reforms to modernise the NHS. These have enabled us to reduce waiting times drastically so that they are the lowest since records began, and to secure improvements in key healthcare outcomes, including dramatic increases in the survival rates of those with cancer and heart disease across the British population.

Yet we know that the challenges faced by the NHS during the first sixty years of its existence are very different to the ones it will face in the next sixty years. New technology, new drugs and new thinking continually revolutionise the possibilities in healthcare provision. We also recognise that healthcare cannot be left to the professionals alone. Each of us must play our part in securing better life chances and a healthier nation.

In this context, this joint publication by Involve and the new National Centre for Involvement is both timely and significant. Britain needs an NHS that can adapt and respond to the changing needs and demands not just of today's public but of future generations too. A modern healthcare system needs to offer both choice and voice, making the NHS more responsive to the public rather than to Whitehall and involving patients as active partners in their own healthcare.

Already in the past decade we have started the process of reform to reconnect the NHS with its users. Most recently, the Department of Health published A Stronger Local Voice which proposes a radical overhaul of how patients and the public are engaged. We want to see Local Involvement Networks (LINks) in local areas that can harness the commitment and knowledge of both interested individuals and the voluntary and community sector in order to influence and improve local health services. We also want to see a forum for patient voice on the national level.

These developments are just the start of what I hope will be a wider process of change within our health service. Both NHS staff and patients have a shared interest in developing new ways to improve standards in the treatment and prevention of health problems. This means we have to look at new ways to involve patients in designing and determining their own care.
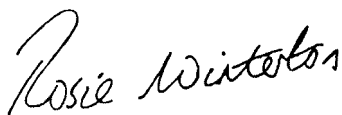
By bringing together some of the leading thinkers in the field and asking them to discuss the present and future of involvement in health, this anthology helps develop our thinking and our practices around patient involvement. The articles in this book demonstrate the wide variety of activities going on in the public, private and voluntary sector to involve patients and the public in the NHS. I believe that these examples of good practice are truly inspiring and offer us a template for how the NHS can evolve as it seeks to meet our ambitions for patient and user involvement.

I would also like to wish the new National Centre of Involvement the best of luck in its future work. This key body will play a major role in realising the vision of a patient centred NHS by giving encouragement to those organisations which lead the way in PPI, and support and advice to those who need it. This is the Centre's first major publication and I hope many more will follow.

As an organisation that works to understand and promote participation in all areas of society and not just health, Involve provides a vital part of the puzzle. Indeed, the need to offer a greater voice to the public within democratic decision-making across all public services is vital to resolving the policy challenges of our age. The lessons this anthology offers and the work that Involve does in improving our understanding of the role of public participation in securing social change resonate far beyond the health sector itself.

Finally, I want to acknowledge that I am continually impressed by the good work being undertaken to involve patients and the public in the NHS which is carried out across the country every day. This work is vital in order to provide better, more effective care to those in need and to ensure that our hospitals are responsive to the needs and wishes of their local communities. Yet too often this work is done 'under the radar', without the formal recognition that it deserves. The new National Centre for Involvement and the proposed LINks will redress this and enable us to make the involvement of patients and the public even better in the future.

This anthology offers us a vital insight into the future for patient and user engagement practices in our NHS. Our shared challenge for the years ahead as both patients and public service providers is to build on these examples as we work together to develop services of which we can all be proud.

The Rt Hon Rosie Winterton MP
Minister of State for Health Services

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Introduction

Edward Andersson, Jonathan Tritter and Richard Wilson

On 5th July we start together, the new National Health Service. It has not had an altogether trouble-free gestation! There have been understandable anxieties, inevitable in so great and novel an undertaking. Nor will there be overnight any miraculous removal of our more serious shortages of nurses and others and of modern replanned buildings and equipment. But the sooner we start, the sooner we can try together to see to these things and to secure the improvements we all want... My job is to give you all the facilities, resources and help I can, and then to leave you alone as professional men and women to use your skill and judgement without hindrance. Let us try to develop that partnership from now on.
Aneurin Bevan, The Lancet (1948)

It is sometimes difficult for those born after the creation of the NHS to comprehend the change it made to the lives of British people. Under the auspices of Aneurin Bevan, the Government revolutionised the health of the nation. Overnight the fear of not being able to afford treatment that scarred the lives of so many was banished. The day that the NHS began, 5 July 1948, did not bring one extra doctor or nurse. Instead it created a nation of patients, each secure in the knowledge of their right to seek expert medical advice.

The principle of universal healthcare, based on need, free at the point of delivery regardless of ability to pay epitomised the post-war welfare ethos and became a cornerstone of British society, one which remains strong today. Yet the NHS in its modern incarnation is a very different institution to the one first created by

Bevan and the post-war planners. Theirs was a system based on a command structure heavily dominated by those providing the services. Partnership then meant between experts in medicine and the contract managers in Government. Patients were to be the passive recipients of care, dependent on the intervention of the expert doctor. The healthcare challenges of the age the NHS faced were broad and relatively homogeneous, such as epidemic disease prevention and improved public hygiene.

Today, we are a nation living longer than ever before, in conditions that are more affluent than our predecessors could ever have imagined. Many of our major healthcare challenges are not epidemics, but chronic conditions such as heart disease, cancer and diabetes. And they are often related to behaviours such as diet and smoking. Accelerated technological developments now offer a dazzling array of drugs and treatments for conditions previously thought beyond the reach of human intervention – but at a cost. Primary healthcare has come to the fore, as we seek to prevent illness and promote well-being in the community far from the hospital bed. And above all, we recognise that involving and engaging patients in their own health choices is critical to their health outcomes. Tackling poor health today is as much about the lifestyle choices people make, as the number of doctors and nurses in our hospitals.

Every generation has sought to adapt the NHS to cope with the changing circumstances in which it finds itself and ours is no different. In the last ten years alone the NHS has undergone a period of unprecedented reform, reflected in the introduction of Foundation Hospitals, the restructuring of the Strategic Health Authorities and the introduction of patient choice, as well as the largest increases in state support for the NHS for decades. Each of these measures reflects a concern to provide a health service fit for purpose, one which can uphold the ethos of the NHS whilst facing complexities of health provision in the modern age.

Previous reform has been dominated by an inward focus on delivery structures, whether in introducing an internal market or increasing numbers of doctors and nurses. Yet many patients now no longer accept being simply spectators, but expect to actively participate and to be partners themselves in their own healthcare provision. Indeed, today's public are increasingly healthcare experts themselves, armed with the internet and a concern to know not just what but how and

why treatment is prescribed. It is within this context that moves towards patient and public involvement (PPI) have taken centre stage.

A central plank of the current Government's modernisation agenda for the NHS, PPI has become somewhat of a catchall term, covering initiatives from service improvement through to creating new models of accountability in health. It is not a new idea in itself: the first Patient Participation Group was set up in the 1970s, as were Community Health Councils, but never before has PPI been such a political and policy priority. The recent consultation paper 'A Stronger Local Voice' published in July 2006 reflects this concern, proposing important changes to the main structures for PPI locally and nationally. The paper recommends that the existing Patient and Public Involvement Forums (PPI Forums) be replaced by Local Involvement Networks (LINks).

This publication seeks to contribute to precisely this changing context. It offers both a critique of developments so far and proposals for progress. Each of the authors was asked to address three critical questions:
— What are the key challenges currently facing PPI in England?
— What are the good examples of overcoming these challenges?
— What are the implications for the future and the imminent
   reforms to the PPI system?

This publication is divided into five discrete sections, each reflecting a different and vital aspect of the debate around PPI. It brings together a range of practitioners and public policy makers from across the PPI field to outline their vision of the way forward for public engagement. In the first section, the authors consider the theoretical questions at the heart of PPI. Andersson, Creasy and Tritter provide an overarching analysis of the key guiding principles that must inform the future of PPI. The next three chapters show how the concept of PPI is a broad one with a large number of very different activities taking place under the banner.

In his chapter Harry Cayton proposes a fundamental shift, from a healthcare system based on the passivity of patients to a system that embraces patients as entrepreneurs. The contrast between Angela Coulter's and Albert Weale's chapters shows there are clear differences between activities which aspire to empower individual patients in their own care and structures put in place to al-

low the public to hold the NHS to account. Weale emphasises the importance of involving people as citizens, looking at the public good. Coulter on the other hand views the empowerment of patients in making decisions about their own care as a key area, without which citizen engagement means little.

The second section then moves to looking at the existing structures in healthcare and examines how PPI can be integrated into service delivery and service decision-making. Jonathan Tritter and Ian Brittain's chapter examines the support and development needed for effective involvement and considers how the new NHS Centre for Involvement plans to provide this in the future. They detail how, at present, the evidence-base on effective methods for involvement is also limited. Models of how to integrate PPI exercises into strategic and operational planning in NHS organisations are not readily available. Anna Coote's chapter demonstrates that a wide range of involvement approaches is often necessary in order to hear all voices. Together, these two chapters demonstrate how efforts to promote PPI in the past have sometimes struggled due to a lack of clarity about the purpose and nature of PPI. Jane Martin's chapter covers the experience of health overview and scrutiny committees and discusses the important role that elected representatives can play in articulating local concerns around health care.

The third section moves the debate around PPI on to look at the role that organisations outside the traditional confines of the NHS can play in promoting public engagement. Present and past PPI policy has emphasised the role played by Voluntary and Community Organisations (VCOs) in providing increased choice in healthcare provision and also in articulating patient voice. Belinda Pratten's chapter points out that, whilst both feature prominently in public rhetoric, it is proving hard for charities to fund their advocacy activities. Most money is spent on service delivery, while the ability of VCOs to articulate the needs and wants of users remains taken for granted. Frances Hasler's chapter looks at the experience of user involvement in social care. This is increasingly relevant, as the proposals for PPI emphasise the linkages between health care and social care. From different perspectives, Pratten and Hasler both discuss the capacity difficulties faced by those in VCOs in making the principle of public engagement a reality.

The fourth section of this publication is focused on involvement at the general practice level. This is the place where the majority of interactions between the

NHS and the public take place, and, as such, it is a key arena for involvement. Current reforms are shifting commissioning decisions about local health services from Primary Care Trusts down to the practice level. Brian Fisher's chapter examines this and describes the opportunity it provides for increased patient and public influence over local services. Graham Box looks at practice level patient participation groups, arguing that the current reforms make these groups increasingly relevant and useful.

The final section of this publication looks to the future, and considers new innovations in PPI and healthcare provision that will shape the NHS in the years to come. Sue Slipman describes the experience of foundation trusts and draws the conclusion that, as membership organisations, they have created closer links between NHS trusts and local communities. In comparison, Paul Hodgkin discusses how modern web technology provides citizens with new tools to influence health services. He describes the way that online user reviews and reputations are currently contributing to a more responsive NHS.

This publication is a joint venture between Involve and the New NHS Centre for Involvement. The NHS Centre for Involvement is led by a consortium of the University of Warwick, the Centre for Public Scrutiny (CfPS) and LMCA and is committed to supporting the NHS as a whole, at local provider, regional and national levels to lead and sustain patient and public involvement. Involve is a not for profit organisation dedicated to understanding and promoting better civic participation, not just in the health sector but across all issue areas. A key part of its role is encouraging the debate about what actually works.

Just as Bevan saw the 'understandable anxieties' in creating a national healthcare service before him, so this publication reveals the difficulties and tensions in creating a modern responsive healthcare system which can truly engage with all those it seeks to serve. Yet it also reflects the promise of public participation, illustrating that when it works it can be a key part of securing improving healthcare for all. By working together to produce this book, Involve and the NCI show how, despite their different backgrounds, a commitment to improving public participation practises can reap dividends for both service delivery and democratic decision-making. The challenge now for all concerned is to take forward the debate about how this can happen on the ground in the health service as we seek to create an NHS fit for the 21st century.

Overview
Does Patient and Public Involvement matter?

By Edward Andersson, Stella Creasy and Jonathan Tritter

This section seeks to contribute to our understanding of how public participation in healthcare is evolving and engaging both the public and service providers. It offers an overview of the issues patient and public involvement (PPI) processes must address if they are to contribute meaningfully to the future of the NHS.

Key points
— Each PPI activity needs to have clear objectives, realistic timeframes and a shared sense of purpose communicated to all participants, whether patients or service providers.
— PPI must be a motor for greater equity in service provision, not an excuse for increased inequality.
— PPI needs to be seen as the job of all involved in the NHS, integral and not incidental to service provision.
— Successful PPI requires building the capacity of NHS staff to engage users as well as support for individual patients and the public to get involved.
— The distinction between the community and voluntary sector as service providers and advocates for users must be clarified within any PPI initiative.

The evolution of Patient and Public Involvement in the British Health Service
Throughout its history the NHS has sought to encourage PPI and in the past three decades Governments have gradually institutionalized the role of users in the healthcare services. The first formal arrangements were created through

Community Health Councils (CHC), established in 1974. Despite their achievements, CHCs were criticised for geographical variations in working practices and an inability to reflect the diversity of local communities.[1] As a result, at least indirectly, they were abolished in 2002. Other developments over the last decade have responded to the growing pressure to be proactive in seeking community views.[2] For example, the Patient's Charter focused on responsiveness to individual expectations by using the rhetoric of patient's rights to clarify service aspirations nationally and from local providers.[3] Despite these changes, there has been continuing pressure for more direct local mechanisms and demand-led care to ensure patient-centred services. In part this has also been prompted by public response to cases of NHS scandals and in particular the Report of The Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary (2001).[4]

In response to this, new Government legislation mandates more direct forms of user involvement, particularly Section 11 of the Health and Social Care Act 2001. This requires all NHS organisations to make arrangements to involve and consult patients and the public in service planning and operation, and in the development of proposals for changes. These reforms make clear that this means consulting and involving the public not just when a major change is proposed, but continually in service planning and development. The recent High Court case of Pam Smith v North East Derbyshire Primary Care Trust and the Secretary of State for Health reaffirmed the duties under this Act and concentrated the minds of Senior Management of NHS organisations.

Building on the power of local authority Overview & Scrutiny Committees (OSCs), this legislation also established a new role for elected members of local authorities to scrutinise health on behalf of local people. The NHS Reform and Healthcare Professionals Act 2002 established the bodies responsible for implementation while Shifting the Balance of Power set out the organisational changes needed to deliver The NHS Plan.[5] All of this set significant challenges for more effective and inclusive PPI.

Further stress on the need for a changed relationship between the public and NHS staff is apparent in the Health and Social Care (Community Health and Standards) Act 2003, which established Foundation Trusts. These new bodies are accountable through local members of the foundation and an elected board

of user governors. The Act describes user governors as 'empowering patients collectively by increasing the accountability of local health services to local communities,' but they have very limited and curtailed powers.[6] In addition to this, the latest DH consultation document, A Stronger Local Voice seeks to locate PPI in communities defined by local authority areas, rather than linking them to a specific health organisation.[7] For these local authorities, all of which commission social care services, this creates the opportunity for greater integration between health and social care services. Other planned NHS reforms will increase the opportunities for patient choice over the location of treatment and create significant changes to the commissioning of services, increasing the role of GP Practices. These reforms will also increase direct user involvement in healthcare provision.[8]

The evolution of PPI within healthcare reflects how public involvement has now become a critical mechanism for change within the NHS. Today the term PPI is used loosely to refer to a range of initiatives and a number of ways of working that all share a commitment to involving the public. Yet amongst these different ways of working it is clear there is a range of expectations from different actors – politicians, public policy makers, academics, patients, service providers and the public – about what PPI can achieve for the NHS. These can be categorised as follows:

1 Increasing patient choice: the role of citizens as consumers of healthcare services

Many forms of PPI have been portrayed as an opportunity for individual patients to express their personal preferences in how they want to receive their healthcare.[9] The concept of 'patient choice' has dominated recent discussion of the NHS, both in the services offered to the public and the role that PPI can play in facilitating the expression of preference. Evaluation of services by individual users has become common place. Simple satisfaction questionnaires and more robust investigations are now part of many audit exercises. Along with information from Patient Advice and Liaison Service (PALS), these are all important avenues for ensuring that the views of the public and patients can inform strategic and operational decision-making. The evolution of consumerism in health policy has been justified as promoting patient-focused care and as the logical extension of informed consent. Similarly, consumerism is presented as a mechanism for redressing the power inequality between health professionals and patients.

'NHS care has to be shaped around the convenience and concerns of patients. To bring this about, patients must have more say in their own treatment and more influence over the way the NHS works.'[10] Yet in seeking accountability for healthcare provision there is a tension between increasing personal choice and the role of the predominantly collective forms of patient engagement. In particular, the promotion of individual 'patient choice' as the best way to ensure responsiveness and flexibility in services potentially undermines the argument for user involvement as a more egalitarian mechanism for securing these outcomes.

2 Increasing patient voice: the legitimacy and accountability of healthcare service provision decision-making

In parallel to the interest in extending individual patient 'choice', has been an emphasis on PPI as a way of extending collective patient 'voice'. Some authors have argued that this has emerged from a decade of neo-liberal inspired public sector reform.[11] This has created a culture amongst policy makers and politicians of concern to show the public 'value for money' in spending decisions. Others on the political left argue 'voice' in public service provision is a mechanism for social equality because it opens up decision-making to those previously seen to be excluded.[12] In truth, the record of PPI initiatives in getting more people involved in making decisions about healthcare services has been mixed. This is at least partly due to the rapid succession of PPI structures over recent years. As some of the authors in this book argue, the abolition of Community Health Councils in favour of Patient and Public Involvement Forums, which are themselves now to be reformed, has made evaluating PPI activities as a form of 'voice' difficult.

3 Hearts and Minds: Changing working practises and lifestyle choices through PPI

Another expectation made of PPI processes is that involvement will influence all those who participate, not just in shaping particular services but also in the way in which they approach healthcare as a whole. In his review of the healthcare service for the Treasury, Derek Wanless argued that co-production – getting patients involved in taking a more active role in their own health – is the only way that the NHS can be economically sustainable for the future.[13] There is thus a growing presumption that public engagement will also create public education, leading to a better public understanding of the difficulties facing the heath service and the need for individuals to act to improve their own life chances by

choosing and promoting healthy behaviours. This was particularly clear in the recent 'Our Health, Our Care, Our Say' White Paper.[14] This capacity for engagement to influence people is also evident in the way in which healthcare professionals work. The promotion of randomised controlled trials as the gold standard research methodology has increased calls for greater user involvement in research strategies.[15] The advice on research governance in the NHS identifies the involvement of users in developing good practice.[16] Users, as patients, have been involved in teaching medical students through testimonials about their own experience and, more recently, through participation in curriculum development.[17] Here, then, PPI is a mechanism for changing the relationship between NHS staff, patients and the public and moving towards a model of partnership. Thus, PPI holds the potential to change the culture of the NHS.

Setting a Future Course for PPI

In setting out these three distinct expectations for PPI our intention is not to prioritise one over the other or dispute their validity. Rather we believe transparency about what any PPI process is intended to achieve is vital, if is to be of benefit to providers, patients and the public. Whilst each of the three expectations may appear complementary, this publication argues that the reality on the ground has been very different. Its chapters reveal how mixed messages about what PPI is for have created tensions and service inefficiencies that have often limited the effectiveness of PPI initiatives. Responding to this and planning for the future of PPI in healthcare we argue requires all those concerned to address the following four key questions:

1 How can service providers ensure productive participation by the public?

PPI at present is often planned with the interests and needs of the institutions at heart rather than those of the intended participants. Consultation exercises tend to be shaped around organisational priorities, rather than the concerns those in a local community identify as important. Whilst there is awareness of the difficulties for today's public in balancing family lives with work pressures, there is less recognition of the competing demands for time and resources made by those organising PPI activities. Recent research revealed that it is time and not money which most people find scarce, a concern partially addressed by the introduction of compensation for users for the time they commit to involvement.[18] Put simply, service providers need to stop taking the time of patients and the public for granted.

In order to retain the interest of present and future participants, service providers need to plan around people, not policy areas. Different forms of PPI need to be flexible enough to adapt to people's lives rather than expecting the public to fit into the processes set up. PPI in healthcare also now competes for interested parties alongside public forums for neighbourhood renewal, the police and local democratic structures as well as leisure pursuits, employment obligations and family commitments. A greater focus on the issues that the public are interested in and on creating processes which fit into today's time-squeezed lives will be critical to the success of future public engagement in any area of public service provision. Indeed, this is why closer co-operation in public engagement work between the NHS and local authorities will be vital to using the public's time more effectively and efficiently.

2 How can we encourage local innovation but also ensure equity of provision?

Current NHS reforms reinforce locality as a key basis for involvement. Local Authority boundaries, rather than NHS Trust areas may be a more important organising principle in the future. So, too, practice based commissioning will see many decisions made at the local practice level.[19] Such a focus accords with common sense, as neighbourhoods are the arena in which most people access healthcare and where change can be visible and meaningful. It also encourages a joined-up approach, helping connect healthcare concerns to other govern-ment initiatives, such as structures for neighbourhood management and Local Area Agreements.

However, there are also trends towards more centralisation within the NHS. And these include the merging of Primary Care Trusts and the reorganising of Strategic Health Authorities. It is inevitable tensions will arise from creating fo-rums for local people to contribute to NHS services and decisions, if centrally set targets have already pre-determined what can be done. As the case of the Commission for Patient and Public Involvement (CPPIH) demonstrated, centrally driven attempts to prescribe how, when and where PPI should take place have not been successful. If we believe that local people have key knowledge about their own health needs, then we need to give them the freedom to experiment. Some will fail but others will succeed. The alternative is what Harry Cayton in his chapter calls 'the equity of the mediocre'.

That is not to say concerns about equity are unfounded. If patients and the public are to have a real say on what the NHS does locally, it follows that services will differ across the nation just as the needs and concerns of population do. What works in inner city Manchester will be different from what is needed in rural Somerset. Done well, PPI should enable our healthcare services to identify and meet the diversity of needs that exist rather than be an excuse for overlooking them. It is likely some areas will struggle in taking the opportunities PPI offers and that some of these will be areas that are already worse off, where low levels of social trust hinder effective involvement. This, however, strengthens the case for targeted support to aid engagement in these areas rather than limiting the role that PPI plays in service provision per se. So, too, partnerships with voluntary health organisations, patient groups and the local authorities will be a vital channel in overcoming exclusion and empowering a diversity of local voices to participate.

These concerns reflect the need for learning and support that is locally responsive but also incorporates a core curriculum of necessary PPI skills and knowledge for all NHS staff as well as users.[20] It requires local PPI champions to expand their horizons and operate at a regional and national level. Moreover, capacity building needs to go further than merely equipping individuals with better leadership skills and resources. As Tritter and Brittain argue in their chapter, beacons of good practice in PPI need to be embedded within development teams that in turn are linked into organisational priorities. With the steady accumulation of evidence, through examples of good practice, documented patient experience, formal evaluation and research findings, we can develop effective approaches, methods and tools that can be adapted and applied when and where they are needed.

3 How can we embed a culture of PPI into the NHS?

PPI must be mainstreamed. This can only happen if it is part and parcel of the process of commissioning and embedded in the contracts that define the nature, volume and quality of services. Too often, PPI is seen to refer to specific events, such as consultations on service changes, rather than an ethos. As a result, involvement is often added to the end of an existing decision-making process, after many key decisions have already been made. This can then lead to high levels of conflict, as has been seen with several recent hospital closures

and reconfigurations. For PPI to contribute to the future of the NHS there needs to be a culture shift. It cannot be not seen as something which is begun – and ended – depending on service priorities. It must be seen as a way of working that is central to achieving outcomes.

Evidence shows that better results can be had by involving participants through-out the institutional planning and decision-making cycle and by placing an em-phasis on building and maintaining relationships with local communities rather than on delivering specific events. Indeed, the type of community development work identified by Fisher in his chapter in this book is an example of involvement in a cyclical fashion, where events are recurrent features in a process of relation-ship and capacity building rather than a goal in themselves.

The need to mainstream PPI is not confined to direct healthcare service pro-viders. National organisations responsible for inspection, monitoring, validating health professional training, developing protocols, licensing healthcare prod-ucts and safeguarding public appointments must also involve patients and the public in their deliberations and decision-making. Accountability to patients and the public is not simply dependent on involvement flowing upward from the grassroots. It also flows outward to locally and nationally elected officials and the public sector at all levels. As PPI develops within healthcare provision, it is critical that people as citizens are also involved in these formal modes of gover-nance and accountability.

4 What role should the community and voluntary sector play in PPI?

The role of the voluntary and community organisations (VCOs) in public services has changed substantially over the past decade, as their role as both service providers and user representatives has expanded. As these twin roles become more of a priority in policy thinking across all sides of the political spectrum, it is clear there is a danger they will become blurred with a resulting impact on both service outcomes and public engagement.

This blurring creates problems for both the health service and VCOs. As Hasler identifies in her chapter, many VCOs find it difficult to deliver to centrally de-termined NHS specifications whilst at the same time remaining innovative and patient focussed. As representatives of patients, it can be very difficult for an organisation to remain an independent voice when much of its income comes

from delivering services for those it may wish to critique. In contrast, Pratten's chapter shows how VCOs that focus on advocacy often struggle to find the time and resources to respond to an increasing number of consultations and partnerships. Without clarifying the role we want for the VCOs in the future of public services, we run the risk of creating a two-tier system, biased towards funding choice but not voice.

The reality of using the VCOs to engage the public in local decision-making across public services has been mixed. Recent research highlighted how many of the same people from VCOs are asked to participate in different public engagement forums at a local level.[21] A common critique of the former Community Health Councils and present Patient and Public Involvement Forums was that they were not representative because they were the 'usual suspects'. There is also a need to explicitly differentiate between using VCOs to encourage advocacy and public involvement. Advocacy refers to the relationship that a user has with a particular service or patient group whilst involvement refers to a broader engagement in issues around healthcare provision. Both roles are vital, but both are different and will require differing forms of PPI to be productive and increasing emphasis on one role may compromise the other.[22]

Critically, PPI should be seen as producing benefits from involving people more directly in service shaping and decision-making. It should not be seen as an alternative source of legitimacy and power for other bodies, such as local authorities or even national Government. Across all public services, it is vital that public engagement is seen as a complementary process to democratic decision-making, not its successor. As Coulter reminds us in her chapter, the number of people who volunteer to give up substantial amounts of time to sit on NHS PPI structures will always be very limited, and these people tend also not to reflect the age, socio-economic and ethnic balance of society at large. The fact that these volunteers are so rare makes their commitment valuable, but only if their role is correctly understood. There are issues around which it is important to have a demographically accurate sample and, in these instances, other means should be used to make service decisions. As PPI is built into healthcare services, members of PPI bodies should be viewed as advocates or advisors rather than spokespeople or representatives for a wider group. Otherwise the future structures that replace PPI Forums could also quickly be deemed failures.

Conclusion

High quality PPI can truly change things for patients and carers, both in their experience of services and the quality of their care. It can also enhance the working lives of health professionals, helping them to increase service responsiveness, deliver improved health outcomes for all and improving job satisfaction. As this discussion has shown, there are many difficulties and decisions still to be made about how PPI can work in practise in our healthcare system and resolving these will be crucial to making PPI work for all concerned. However, as the authors in this publication all agree, getting PPI right will be critical to the capacity of the NHS to secure improved health outcomes for all members of British society.

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Theory and overviews
1. Patients as entrepreneurs: Who is in charge of change?

By Harry Cayton

Harry Cayton argues that health services are still controlled and run in the producer's interest. Only through the entrepreneurial engagement of patients and the public will real change come about.

Introduction: 'The equity of the mediocre'

The organisation of health services is predicated on the passivity of patients. This is particularly so in the United Kingdom. Until the publication of the NHS Plan in 2000, our publicly funded and provider managed system had concentrated on command and control, on demand management, on the restriction of choice and the restraint of supply.[1]

To a great extent this was possible because patients and the public have long accepted their role as grateful beneficiaries of a paternalistic National Health Service. Within recent memory the British Medical Association was able without irony to run an advertising campaign asking patients to 'Be patient'. Doctors were busy doing their best, we were told and waiting was inevitable. And we believed it. We tolerated lost notes and long delays and waiting lists of a year or more because we accepted that if we had to wait it was because the NHS was busy looking after someone else. The Health Service justified this to us on the grounds that it was fair. I have called this the 'equity of the mediocre' and it remains a strong element in the arguments of those who resist the opening up of choice in the NHS because they fear that choice and equity are incompatible.[2] The argument seems to be that the NHS is good enough and that at least we

have an equitable share in its inadequacies. This counsel of inertia ignores the fact that health inequalities continue to grow and that the rich and the well-connected have always been able to jump the queue.

A recent comparative study by the Picker Institute (Coulter 2006), covered in more detail in Angela Coulter's chapter highlights how ingrained this culture of passivity and paternalism is in the NHS.[3] Despite higher levels of expenditure per head on health in Northern Ireland, Scotland, and Wales and an explicit policy commitment to patient and user involvement in England, the Picker study found no significant difference between the four home countries. This underlines how strong the prevailing attitude is and how difficult it is to shift.

The NHS Plan and the subsequent Wanless reports envisaged a patient-centred NHS in which people both as patients and as citizens were actively engaged in their own health and well-being and in helping to shape the quality and structure of health services through public participation and some limited forms of consumer choice (Wanless 2002).[4] A series of policy papers, Building on the Best (2003), Choosing Well (2004), and Your Health, Your Care, Your Say (2006) have aimed to put these ideas into practice.[5] Alongside policy there has been great effort put in locally in the NHS to service redesign, improved information for patients, better patient experience, choice of provider, support for self-management and for people for long-term conditions. And yet little has really changed.

Recently Sir Derek Wanless himself has warned that movement towards the 'fully engaged' public he described in his 2002 report as essential for the future of health and the health service has been slow.[6] He highlighted obesity in particular as getting worse rather than better.[7]

A new role for patients
This is disappointing for those of us who seek an NHS which works more effectively for the people who pay for it and use it. However, many of the mechanisms we need to bring about change are in place. What we need now is to recognise that for the first time patients really can be active partners in the system and to allow them to be so. We need to have the courage of our convictions and turn a 'patient-led' NHS from idea to action.

'Social entrepreneurs' are people who bring about change and innovation not to make money but to improve society. Entrepreneurs are active, decision making, and self-motivated. These are the very qualities that as citizens we need to apply to our healthcare. Patients must become the entrepreneurial force for change using the opportunities available to them and creating the social energy for more. Having put the mechanisms in place in the NHS, we need to start believing in patients as agents of change.

If you travel from Whitehall to Newham in east London, you lose a year of life expectancy for every Underground station you pass. Newham is the most diverse borough in Britain but that very diversity is being turned into a strength by a remarkable programme called 'Communities of Health' which starts with the reality of local communities and supports and encourages them to create their own health and well-being.[8]

Concerned about diabetes in the south Asian population, Newham's NHS Trusts launched a programme offering tests in public places such as markets and shopping centres. High levels of diabetes were found and the people tested were advised to see their GP as a matter of urgency. There was no real increase in people seeking help. It seemed that people were powerless to act on the information they were given. Medically defined, professionally delivered public health information was not meaningful to them, so they could not use the knowledge to change their behaviour. The Newham Trusts adopted a different approach. They went to talk to the communities, to faith groups, to housing associations, day centres, schools and workplaces. They went where people were and found in those settings the motivation to improve health and the community leaders who could do it.

'Communities of Health' is the opposite of the usual approach: traditional public health interventions are professionally provided, knowledge-based and structured. Communities of Health promotes variety, culturally specific and citizen led action. It has clinical involvement but it is not clinically led, its strength and direction comes from the leaders of community groups and activities.

The Expert Patients Programme is another model of patient-led change created in this case by people with long-term conditions for people with long-term conditions. Supported self-management programmes, such as the Expert Patients

Programme, focus on personal motivation, decision making, goal setting, dealing with pain and fatigue and getting the best out of health professionals. They can produce measurable health improvements but primarily they increase self-efficacy and thus well-being and quality of life.[9] The tutors who run Expert Patients Programme courses are volunteers who have long-term conditions themselves and this is central to its success. Tutors model behaviours that participants aspire to and demonstrate in their lives that health is achievable. They are the epitome of 'do as I do, not do as I say'.

This year the Expert Patient Programme has become a community interest company. It is now a not-for-profit business, liberated from the restrictions of government accounting and Department of Health bureaucracy. It will seek new markets with employers and in social care and it will escape from the illness centred NHS to promote well-being.

A culture in need of change
Professionals are often uncertain about the Expert Patients Programme. They fear 'expert' patients as a challenge to their own expertise. But the programme doesn't attempt to impart professional knowledge. It seeks to enhance the person's expertise in their own life. Professionals often continue to behave towards self-managing patients by directing them. They undermine rather than re-enforce their autonomy. Or they want to take the programme over, suggesting it would be better delivered by clinical professionals who would 'know what they were doing'. Of course, this misses the point entirely.

And we are still missing the point entirely in much of the implementation of a 'patient-led' NHS. If 'patient-led' means anything it means that the way people using the NHS choose and act should shape the service. Some rudimentary tools have been provided: there is choice of provider, some information to help make those choices and payment by results to provide incentives for providers. In social care we have direct payments and soon will have personal budgets. Early reports suggest that choice of provider is popular and that it is working.[10] Even if only small numbers of patients change their provider the payment system has a significant effect. However, doctors' organisations remain mainly resistant to choice for patients, though doctors have always exercised it for themselves and their families. GPs remain the gate-keepers to the system controlling access to choice. And most of the clinical specialties continue to resist the publication

of information on quality or comparative data. The Society for Cardio-thoracic surgery is an admirable exception. Individual surgeons outcome data, adjusted for case mix, is now published by the Healthcare Commission on its website.[11]

So there are real examples of change but these are small scale – as social entrepreneurial activity often is – and they are as yet peripheral to the vast majority of activity in the NHS. Patient engagement, patient choice, self-management are not seen as the radical revolution they could be. Instead they are perceived as yet another intervention to be imposed on patients. When patient choices do start to have an impact under the new arrangements, the instinct of the service is to resist and not to follow where patients lead.

After the introduction of the new GP contract and the introduction of waiting time targets for Accident and Emergency attendance at A&E increased by 27 per cent between 2001/2 and 2004/5.[12] This was not what was meant to happen. It was seen as a problem; discussions were had about how people could be stopped from going to A&E. But isn't this exactly what patient-led should mean? GPs had abandoned their patients by ceasing to provide out of hours services. The alternatives were mistrusted. A&E had improved: it was available twenty fours hours a day and no matter how minor or serious your problem you knew you'd get treated eventually. Instead of trying to stop people attending A&E, a patient-led health service would be investing in new forms of urgent care services which meet the needs and preferences of patients.

Embracing patient initiatives

Instead of constantly resisting their impact, we ought to welcome patients as agents of change. A cultural change is needed. This is demonstrated by people with chronic pulmonary obstructive disease, or long term breathing problems in plain English, who took part in an innovative project with the Meteorological Office and their provider trusts. COPD is directly affected by the weather: the colder and damper, it is the more severe the symptoms. Trusts knew that cold damp weather meant an increase in in-patients and they wanted to plan their availability of services around this. 94% of patients knew that the weather affected them. The Meteorological Office provided weather forecasts to help providers. But the patients affected took control. Give us the information you have on the weather and we will use it to manage our own illness, planning our shopping so we can stay in doors, taking our drugs at the right time, turning up

the heating. By allowing the service to be patient-led the effect was better for everyone. Providers no longer had to prepare for an influx of seriously ill patients: the patients by their actions, with the support of clinical professionals in the community, kept themselves out of hospital. Hospital admissions were reduced by over 20 per cent.

From Canada comes a powerful example in the field of mental health.[13] At McMasters University in Hamilton, families with children needing mental health services face long waits of six months or more. During that time children's mental heath deteriorated and family stress increased. Some of the more assertive parents asked the clinicians, 'What can we do to help ourselves and our children? We are wasting this waiting time.' Working with the families in a systematic study of their information needs and the barriers to their effective use of information they designed a self-managed home-based programme providing step by step solutions for parents to use. This was backed up by a telephone helpline and coaching service. The results were dramatic. At the end of the six month waiting time for professional help 87 per cent of families had solved their own problems and no longer met the referral criteria for the service. This was better than clinically based interventions where the recovery rate was 63 per cent.

The entrepreneurial patient

These examples illustrate what I mean by patients as entrepreneurs. This is why it is so important that we stop thinking of patient and public engagement as a new way of getting people to do what the NHS. We should understand it as a real force for getting the NHS to deliver what patients and the public want. In particular, we need to stop managing patient behaviours at every level and start responding to patient choices. We need to do less of some things and more of others. Policy makers need to give up trying to control the system rather than just saying that they have. Everyone needs to recognise patients and service users as a new force in the system and we need to continue to bring health and social care closer together.

The opportunities that people have to be entrepreneurial about their own healthcare are still inadequate. Choice is still mostly dependent on exit. That is, it depends on leaving a GP or leaving a hospital and going elsewhere. Such choices may be difficult and inconvenient and therefore not real choices at all. So choice must be matched with voice; with effective, influential consumer involvement

and real community engagement. We also need to think over time about new mechanisms for entrepreneurial patients such as personal budgets in heath or choice of commissioner.

As patients and citizens we need to seize the opportunities given to us to shape healthcare, small though they are and become entrepreneurs for change in our own interests and those of our fellow citizens.

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Theory and overviews
2. Patient engagement: why is it important?

By Angela Coulter

Angela Coulter argues that to date collective public involvement has been prioritised over the empowerment of individual patients in their own care. She suggests it makes little sense to encourage people to get involved in collective action, while treating them merely as passive recipients of healthcare in their day-to-day interactions with the NHS.

Policy goals

Improving responsiveness to patients has been a goal of health policy in the UK for several decades. The most obvious manifestation of this has been the emphasis on reducing waiting times, a cause of great public concern that until recently had proved relatively intractable despite numerous policy initiatives.

The government's stated aim is to encourage active participation of patients in their care and to engage members of the public in the planning and management of health services. In 2000 the government made promoting patient-centredness the central theme in its new plan for the NHS. The NHS Plan described the problems in the following way:

The relationship between service and patient is too hierarchical and paternalistic. It reflects the values of 1940s public services. Patients do not have their own health records or see correspondence about their own healthcare. The complaints system in the NHS is discredited. Patients have few rights of redress when things go wrong. The patient's voice does not sufficiently influence the

provision of services. Local communities are poorly represented within NHS decision making structures. Despite many local and national initiatives to alter the relationship between the NHS and the patient, the whole culture is more of the last century than of this. Giving patients new powers in the NHS is one of the keys to unlocking patient-centred services.[1]

Patients and citizens
The NHS Plan lumped together the concerns of patients and those of citizens, but it is worth considering the differences between the two viewpoints. All of us are both patients, or potential patients, and citizens, but a distinction can usefully be made between what we want when we are using the health service and what we hope for as citizens or taxpayers (see box below).

Healthcare aspirations of patients and citizens[2]

Patients	Citizens
Fast access to reliable health advice	Affordable treatment and care, free at the point of use
Effective treatment delivered by trusted professionals	Safety and quality
Participation in decisions and respect for preferences	Health protection and disease prevention
Clear, comprehensible information and support for self-care	Accessible local services and national centres of excellence
Attention to physical and environmental needs	Universal coverage: geographical and social equity
Emotional support, empathy and respect	Responsiveness, flexibility and choice
Involvement of, and support for, family and carers	Participation in service developments
Continuity of care and smooth transitions	Transparency, accountability, and opportunity to influence policy decisions

In general, patients care more about the quality of their everyday interactions with health professionals than about how the service is organised, whereas citizens often care passionately about perceived threats to the NHS and the values it is seen as representing. Involving citizens means opening up debate about the pattern and nature of service provision, while engaging patients involves tackling the clinical agenda and changing the culture of care. Since the publication of the NHS Plan, patient and public involvement (PPI) has become part of the everyday rhetoric in the NHS. Considerable efforts have been expended on consulting local people about planned service developments and securing lay membership on a raft of committees and policy-making bodies, but progress in respect of involving patients in their care has been disappointingly slow.

International comparisons

The Picker Institute recently analysed data from two population surveys in carried out in 2004 and 2005 in six countries – Australia, Canada, New Zealand, Germany, the USA and the UK. Our analysis focused on six indicators of the extent to which patients are engaged in their own care.[3] The UK performed worse than the other countries on almost all the indicators. Fewer patients in the UK were involved in treatment decisions, and they were less likely to have been invited to take part in a review of their medicines or to have been given information about medicine side-effects than those patients in the other countries. British patients were given less help to cope with recovery and rehabilitation and fewer than one in five of those patients with chronic conditions had been given a self-management plan. Even more alarmingly, the UK had the highest smoking rates of the six countries, the heaviest alcohol consumption, and the second worst record on obesity (after the US). Yet British patients were the least likely to report that their doctor had given them advice on preventing ill-health.

None of the countries in the study, which involved telephone interviews with more than 15,000 patients in the six countries, excels in promoting patient-centred care, but it appears that British patients receive even less support for engagement with their healthcare than those elsewhere. Findings from the national patient surveys confirm that while there have been improvements in waiting times and in the quality of care provided to patients with priority conditions such as cancer and heart disease, there has been little or no improvement in the everyday interactions that most patients have with health professionals.[4] Information provision, involvement in decisions and support for self-care are still at a low lev-

el for many patients. Before tackling the question of why this is the case, it's important to understand why patient engagement is considered worth promoting.

The case for patient involvement

A growing body of evidence demonstrates that patient engagement in treatment decisions and in managing their own health care can improve appropriateness and outcomes of care.[5] Information and involvement is at the heart of the patient-centred approach, but communication failures are the most frequent source of patient dissatisfaction. If clinicians are ignorant of patients' values and preferences, patients may receive treatment which is inappropriate to their needs. Patients cannot express informed preferences unless they are given sufficient and appropriate information, including detailed explanations about their condition and the likely outcomes with and without treatment. There is good evidence that sharing treatment decisions with patients can lead to better decisions, and better, more cost-effective outcomes.[6]

There is also good reason to believe that the active involvement of patients could improve safety and reduce complaints and litigation. The landmark inquiry into failures in children's heart surgery in Bristol identified the need for substantial change in the way in which health professionals interact with patients and their carers.[7] The committee made 198 recommendations. Amongst the most important of these recommendations were the calls to involve patients (or their parents) in decisions, to keep them informed, to improve communication with them, to provide them with counselling and support, to gain their informed consent for all procedures, to elicit feedback and listen to their views and to be open when adverse events occur.

Another reason for promoting patient involvement has to do with improving value for money. Engaging patients in their health care and encouraging people to take responsibility for protecting their health are seen as the best way to ensure the sustainability of health systems. In a review of future funding needs for the health service carried out on behalf of the Treasury, Derek Wanless called for a new focus on moderating demand by investing in effective health promotion and supporting self-care.[8] Wanless believed that patient engagement should be a key component of the strategy to keep future healthcare spending within manageable limits. In other words, the sustainability of the NHS will depend on the effectiveness of efforts to eliminate the unhealthy paternalism that still characteris-

es patient-professional relationships in the British health system. This theme was echoed in the recent White Paper on community services, which promised to help patients to take responsibility for their health, support their independence, put them in control and focus on the promotion of health and well-being.[9]

In addition to the potential for achieving greater efficiencies in resource use, encouraging patients to take more control when they are ill may also prove to be an effective tool for improving public health. Traditional paternalistic practice styles undermine people's confidence in their ability to look after themselves. So, replacing paternalism with a partnership approach could help to enhance a sense of self-efficacy, thus encouraging them to take more responsibility for reducing risk factors and preventing ill-health.

It is important to understand that the potential benefits of involving individual patients are different from those one hopes for when seeking the involvement of members of the public or citizens (see box below).

Why encourage patient and public involvement?

Patients	Citizens
To ensure appropriate treatment and care	To improve service design
To improve health outcomes	To determine priorities for commissioning
To reduce risk factors and prevent ill-health	To manage demand
To improve safety	To meet expectations
To reduce complaints and litigation	To strengthen accountability

What explains the UK's poor performance?

Factors that may be important in explaining the disappointing UK performance in relation to patient engagement include shortcomings in professional education, a low level of expectation from the Royal Colleges or regulatory bodies such as the Healthcare Commission, the General Medical Council (GMC) and the Nursing and Midwifery Council, who may not have given sufficient priority to

the topic, and a failure on the government's part to offer incentives to clinicians to engage their patients.

Another key to the conundrum may lie in the fact that most NHS organisations have seen promoting patient and public involvement as synonymous with the requirement to consult the public and obtain direct involvement of lay people in planning and service development. Their efforts have met with some success, but as yet they appear to have done little to tackle the quality of the interactions between individual patients and the clinicians (GPs, nurses, specialists, therapists) who form the front line of the service. In other words, they have made the mistake of assuming that if they tackle the goals outlined in the second column of Figure 2, the desired changes listed in the first column will automatically follow. Unfortunately, this is a fallacy: if you want to engage and empower patients directly you have to change the culture of clinical practice.

It is this face-to-face contact with individual clinical staff that the majority of patients care most about. Usually, people who use health services are seeking help for a specific health problem. They want advice from professionals who are good communicators and have sound up-to-date clinical knowledge and skills; they expect their views and preferences to be taken into account; and they want to be given reliable information about their condition and the treatment options and assistance they need to help themselves. This is the type of engagement with health services that most people want. Only a small and unrepresentative minority want to sit on policy committees or be consulted about complex service developments that don't affect them directly.

Many of those most actively promoting the patient and public involvement strategy are concerned to tackle the 'democratic deficit' in the NHS and beyond. They hope that encouraging people to get involved in collective activity to re-shape the NHS will help to reduce alienation and promote a new type of community engagement. This is a worthy aim, but they have chosen the wrong starting point. It makes little sense to exhort people to get involved in collective action, while treating them merely as passive recipients of healthcare when they are ill. If people are disengaged and disempowered when they are patients, they are unlikely to feel encouraged to participate as active healthy citizens. Most will just want to forget about their experiences of the NHS and get on with their everyday lives.

The way forward

Moving forward must involve engaging clinicians as well as patients, encouraging them to see patients as their partners in the process of treatment and care, not simply as passive victims of ill health. Outdated professional attitudes are preventing patients from playing the active role that most want. Such an active role could greatly increase the efficiency and effectiveness of healthcare. All health professionals should be encouraged to recognise their responsibility to promote health literacy, support self-care and self-management, and involve patients in treatment decisions. The best way to judge their effectiveness in this regard is to obtain feedback from their patients. Currently this is addressed, as least partially, in the national patient survey programme for England led by the Healthcare Commission. However, these surveys are carried out at the organisational level and do not produce results that are specific at the level of clinical teams or individuals. The Department of Health and the GMC should require patient feedback as part of planned revisions to professional appraisal and revalidation systems.

Fostering a culture of partnership between clinicians and their patients requires clinicians to develop a new set of skills and competencies that hardly feature in current training programmes. In order to engage patients more fully in their care, they must learn about the theory and practice of developing health literacy, of enabling shared decision making, and supporting self-care, all of which demand excellent communication skills (see box on next page).

So the general direction of policy is clear, but implementation has been weak so far. This is partly because initiatives taken under the banner of Patient and Public Involvement have tended to focus more on democratic accountability than empowerment and have neglected the 'patient' component, and partly due to a reluctance to confront the health professions. The UK cannot afford to miss opportunities to redress the balance, because its performance in relation to patient engagement is poor compared to that of other countries.

If it is to succeed in its goal of empowering patients, the government must be bolder about challenging the professional organisations to modernise their attitudes and approach to training. Commissioning bodies should reinforce this, using patient feedback as part of their performance monitoring activities. And Local Involvement Networks should make effective use of existing data on pa-

Competencies for patient partnership

Clinicians need to learn how to:
— Guide patients to appropriate sources of information on health and healthcare
— Educate patients on how to protect their health and prevent occurrence or recurrence of disease
— Elicit and understand patients' preferences
— Communicate information on risk and probability
— Share treatment decisions
— Provide support for self-care and self-management

tients' experience, including that from the national patient surveys, to hold local organisations to account. Engaging patients more actively in the decisions that affect them directly and ensuring that their efforts at self-care are well-supported by health professionals are the basic building blocks for PPI. Without them the PPI strategy will fail.

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Theory and overviews
3. What is so good about citizens' involvement in Healthcare?

By Albert Weale

There are important differences between involving people as patients in their own care and as members of the public. Albert Weale looks at different roles people can play in PPI and argues that in most cases there is a need for a wider citizens' perspective along side the voices of interest groups.

Introduction: the distinctive contribution of citizens

To help find an answer to my central question, 'What's so good about citizens' involvement in health care?' let us remember all the reasons why there should be public involvement in health policy making. Public consultation helps with planning the location and configuration of services. It provides evidence on the patient's quality of experience. It develops the accountability of decision makers. It contributes to the legitimacy of decisions. It clarifies the choices that policy makers face.

But none of this explains why citizen involvement is valuable. Why is it good to involve the public as citizens? After all, people can stand in a wide variety of relationships to health services. Most obviously they are users of those services. Or they can be suppliers of important resources that the health services need, as blood donors are. They can be patients enrolled in clinical trials. They can be relatives and friends of users. They can be voluntary workers. They can be neighbours. In short, there are many publics in relation to health services. What, if anything, can citizens contribute?

To sharpen the question, consider an example. There is a well-known trade-off in the planning of specialist services between centralisation and accessibility. If services are accessible, they are geographically spread, but this makes it difficult for specialist teams to develop the case load and expertise to improve the quality of what they do. Conversely, when services are concentrated, skills improve, but accessibility declines. It therefore seems natural to ask, say, users of specialist cancer services how much they would be prepared to incur the disadvantages of travelling in order to get a better service. This was exactly the question posed to one of the early King's Fund citizen juries.[1] But why citizens? Why not just users? Why not the users of just the specific services? If we are thinking of breast cancer services, why ask men their views? If we are thinking of prostate cancer services why ask women? Why have a citizens' jury?
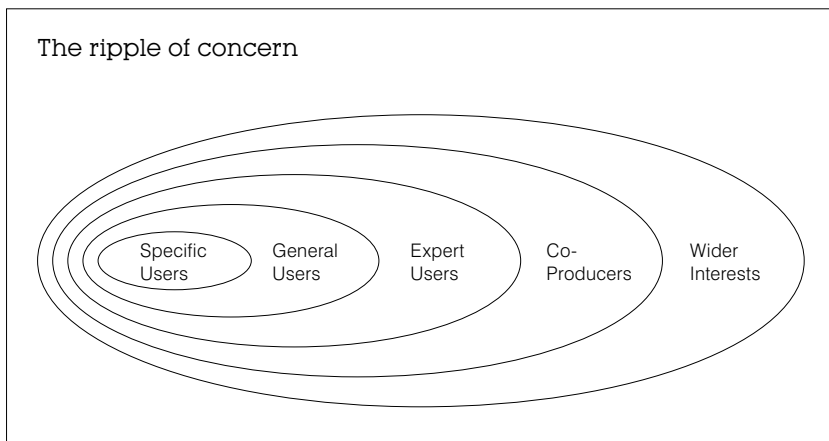
The answer to the question, I shall suggest, is that the broad public perspective of citizenship is an aspect of even the narrowest user's point of view. This does not mean that all forms of public involvement should be aimed at citizens in general. Some may quite properly target a more limited range of groups, in order to understand their point of view. But we do need to understand how different points of view necessarily involve a more general perspective. 'If I am not for myself, who will be for me? If I am only for myself, what am I?'

To pursue this, I shall lay out a list of reasons for public involvement. They can be thought of as a ripple of concern, like the proverbial stone thrown into the water. At first we begin with reasons for public involvement that concern only a limited number of people. As we go through the reasons, we see a widening circle of concern that links the particular publics with the broad public interest that citizens require (see box on the right).

Reasons for Public Involvement
1 Planning Services from the user point of view.
The first and, in many ways, the most obvious reason why the public should be involved in the planning of health care is that they are users or potential users, and the services will be better if policy makers take into account the user point of view. The example of the location of cancer services, which I have already given, is an instance of this. The health services cannot know how people will judge the quality of care unless those people are asked. Only the wearer of the shoe knows where it pinches.

The ripple of concern

| Specific Users | General Users | Expert Users | Co-Producers | Wider Interests |

In such cases, it would seem, there is a case for the involvement of the core group who are affected, rather than citizens in general. But note two qualifications to this simple conclusion. In the first place, there is seldom one user viewpoint. Instead, different users will have different viewpoints, and they cannot easily be combined. So even if we are considering a core groups of users, such as the men who use prostate services or the women who use breast cancer services, we need methods of involvement that enable those users to understand that there are competing perspectives. Understanding that common decisions have to be made for different people is in itself one of the elements of citizenship.

The second reason why users' consultation expands towards a more general consultation depends upon the generality of the service being offered. Specialist cancer services concern relatively small proportions of citizens, but even for specialist services there is an interest from potential users. In principle this also covers citizens as such. More obviously, the location of walk-in centres is of concern potentially to everyone. So user involvement extends to citizen's involvement when the users are potentially everyone.

2 Improving the technical quality of decisions
It is one thing to make a contribution as a user, where the question for participants is: how does this service look from the point of view of my priorities and values? It is another thing to make a technical contribution, one which enables

professionals to understand better the evidence on which they make decisions. Yet, there are examples where such contributions are important. Consider the identification of side-effects from pharmaceuticals. Advocates for those suffering from schizophrenia have argued that the seriousness of the side-effects of traditional therapies has been downplayed as part of the argument for resisting more expensive therapies. Their contention is that those taking the drugs are in a unique position to understand their effects.

In this sort of example, the ability to make a technical contribution is dependent upon the direct experience of those who are patients, and it is difficult to see how any other perspective could substitute. Many patients, particularly those suffering long-term conditions, build up a considerable technical knowledge, and arguments for participation can be derived from the fact of this knowledge. More generally, the skills of policy analysis are widely dispersed in a modern economy. These skills consist of abilities such as data analysis, option appraisal and the bringing together of diverse types of information. On such questions as the public transport implications of moving a health service facility from one location to another, members of the public may be in a better position to make a contribution than busy health care professionals.

3 Consulting co-producers

For blood and tissue donations, some citizens are co-producers of health care. Their interests then have a standing that needs to be represented in policy discussion. Consider a topical example.[2] There will soon be a blood test to check whether someone is a carrier of vCJD. When it is developed, it is clear that the National Blood Services will have to use it. At present, donors currently consent not only to having their blood tested for a range of conditions, but also to their being told the results of the tests, should they prove positive. With a vCJD test, however, the results may not be highly accurate, and there is no clinical care that can be provided for those carrying the prion protein. Should the policy then be one that requires donors to consent to knowing the results of the test?

There are many issues to be discussed here, but it is easy to see how it makes sense to consult donors on this question. This is not least because if the reasons for making known the test results are not understood, there could be a short-fall in donations from those who feel that their gift is being compromised. Consultation here is an expression of a general principle that, if citizens give

freely to the common good, then they should be treated as responsible agents to whom the implications of their donation is explained as fully as possible.

4 Rectifying an imbalance of policy influence

One of the most established rationales for public participation is to rectify an imbalance of policy influence, particularly in a service that is virtually a monopoly provider and in which there is a worry that concentrated producer interests may dominate the policy process.

It goes without saying that the need to secure a balanced representation of user and producer views in the design of services is important, but it is also important to be clear about the problems of defining where the public interest is. Consider the case of patient groups concerned with the provision of particular therapies or services. To a large extent, the system of priority setting depends upon such groups advocating their case vigorously. However, under circumstances in which leading pharmaceutical firms are delaying disclosure of the patient groups whom they help fund, there is a need to ensure that the balance is struck not only between users and producers, but also among the set of users and their representatives.[3]

Here again there is a need for a citizens' perspective, in the sense that the public interest cannot be assumed to emerge simply from the pluralistic competition of different groups advocating their own – entirely legitimate – interests, but has to be considered from a more dispassionate point of view.

5 Avoiding unnecessary confrontation and creating the conditions for consensus

Sometimes the setting of priorities can become a matter of hard choices. Examples of this include the decision to close a local hospital unit or the denial of expensive drug therapies to a minority group of patients. One hope for new forms of public consultation is that they will be mechanisms for generating a process by which these hard choices become easier to implement.

There is no need to assume that a good process will lead to a consensus. Indeed, even if we are only concerned with the citizens' perspective, rather than, for example, the interests of particular patient groups, there will still be differences of opinion. The hope is that a fair and open process will foster a sense

of greater legitimacy for the decision among those whose opinions have been over-ruled. To have had the opportunity to register a voice in a fair and open process in which you have lost the decision is better than simply to have had one's voice ignored completely.

6 Identifying competing perspectives on issues, particularly in respect of their moral dimensions

Public participation may help to identify to policy makers what are the competing moral considerations that are relevant. For example, in the public consultation by the Wellcome Trust (2000) on cloning, there was a clear consensus across many different groups that therapeutic cloning is regarded as morally acceptable but not reproductive cloning.[5] In matters of bioethics, it is often important to draw clear lines in obscure places. No one can be sure that they are drawing the line in the right place, unless they are prepared to test their intuitions with a widely representative range of citizens.

The role of citizenship

What then is the place of citizens' participation in the making of decisions? We have seen that, even in cases where there is appropriately a narrow focus on the particular users of a service, elements of citizenship are still present. As we move to the broader issues of resource allocation or the principles of bioethics, the role of a citizen's perspective becomes more important.

One way of putting this is to say that in a democracy those who exercise political power should be able to justify their decisions in open argument. Public involvement provides a test for whether this condition is met. In other words, the ability of decision makers to explain to a consultative forum the rationale of their decision provides some test that a publicity condition has been met. This function seems to have been behind NICE's decision to establish its Citizens Council. Sir Michael Rawlins is reported as saying that the Council 'is designed to provide a backdrop against which we and the independent groups that advise us can make their recommendations'.[5]

This position is not without its critics. There are those who will argue that in sharing decision making with citizens decision makers may be avoiding their own accountability as elected representatives or appointed professionals. Thus, it has to be a worry that the recommendations of the Department of Health Review

on Patient and Public Involvement for a flexible framework of public involvement will make the design of accountable decision making even more complex when they are implemented.[6] Where in the maelstrom of voice and choice is the accountability of officials for spending public money and delivering effective public services?

There is no easy answer to this question. But it is worth noting that a democratic society is broader than the institutions of electoral democracy, important though those institutions are. It involves a civic culture in which there is openness to those citizens who wish to contribute to the process of public reasoning about what should be collectively done. Unless there are well-functioning institutions of public discussion, there will be deficiencies of public policy. What is so good about citizen involvement is that it is the expression of a democratic civic culture in the vital interest of health care.

1   S. Davies, et al., Ordinary Wisdom: Reflections on an Experiment in Citizenship and Health (London: King's Fund, 1998), 102–11.

2   Health Protection Agency 'Consultation on vCJD Test for Blood Donors' (2006), at http://www.hpa.org.uk/infections/topics_az/cjd/consultation.htm.

3   Andrew Jack, 'Two Companies Delay Disclosure of Patient-Group Funding', Financial Times, 20 June 2006, p. 4.

4   Wellcome Trust, Public Perspectives on Human Cloning (London: Wellcome Trust, 2000), available at http://www.wellcome.ac.uk.

5   J. Kelly, '"Citizens Council" to Make Health Decisions', Financial Times, 19 August 2002, p. 4.

6   Department of Health, 'Concluding Review of Patient and Public Involvement. Recommendations to Ministers from Expert Panel', 12 May 2006, available at http://www.dh.gov.uk/

Structures in Healthcare
4. The NHS Centre for Involvement: building excellence in patient and public involvement

By Jonathan Tritter and Ian Brittain

Past attempts to involve patients and the public in the NHS have sometimes failed due to inadequate or inappropriate support and resources. Jonathan Tritter and Ian Brittain explore the role of the new NHS Centre for Involvement in supporting NHS staff and making true involvement a reality.

Introduction

The concept of a patient-led NHS is part of a wider government agenda aimed to promote the role of service users, and give power to local communities in order to better shape the delivery of the public services which affect them. The commitment to a patient-led NHS necessitates more and better involvement with patients and the public in order to improve services, make them accountable to the public and ensure that they are patient-centred. Patient and Public Involvement (PPI) must be at the heart of the NHS, whatever structure, organisational form or diversity of providers makes up the Service.

The role of the NHS Centre for Involvement

In order to support NHS staff and organisations to deliver this central reform, the NHS Centre for Involvement was launched in 2006 to help NHS organisations and staff to respond to the need to develop services that are directly shaped by the views and experiences of patients and the public. The Centre also has a remit to define excellence in patient and public involvement, generate knowledge from research and experience, promote good practice and support health and

social care organisations in developing mechanisms that lead to better quality services, better decision making and better relationships with those they serve.

The NHS Centre for Involvement operates through an innovative collaboration between academia (the University of Warwick), the voluntary sector (LMCA – the umbrella body for national voluntary organisations working to meet the needs of people with long-term health conditions) and local government (the Centre for Public Scrutiny). All three organisations have had extensive practical experience in working with patients and the public, PPI Forums, the voluntary sector, NHS staff and NHS organisations to develop PPI. Hosted by the University of Warwick, the Centre adopts a multidisciplinary approach that bridges traditional boundaries within and across the NHS, local government and the public sector. It also helps to ensure excellence in the identification and generation of evidence and its translation into practical intervention in order to best support NHS organisations and staff to build a new culture that integrates PPI into all their work.

So that the Centre is equipped to deliver this agenda, a number of high level strategic interventions have been initiated. These 'tools' will enable health and social care organisations to respond proactively to the increasing volume and intensity of involvement activities that is being promoted within current policy and reform.[1] The NHS Centre for Involvement will build on practical experience across the public, private and voluntary health sectors, bringing it together with expertise and excellence in organisational development, clinical and social science research. This interdisciplinary approach will generate and distill the research evidence base, produce evidence based learning and underpin work with NHS organisations, PPI Forums, Forum Support Organisations, health Overview and Scrutiny Committees and Non-Executives across the health sector to develop their capacity and systems for effective PPI in service planning, commissioning, delivery and evaluation.

The structure of the NHS Centre for Involvement
The work of the National Centre for Involvement is primarily organised around four interdependent domains: three creative – Organisational Development, Learning and Support, Research and Best Practice – and one to ensure effective transmission of information, Communications. Key features of the Centre include:

1 Organisational development

The Organisational Development Domain will help organisations and health communities to turn PPI into everyday practice and become 'mainstream' involvement. Involving patients and the public has mostly been confined to particular services or topic areas. Most organisations, however still aim to spread, sustain and integrate project-based activities in a way that creates a whole organisation approach, one that links grass-roots communities to organisational strategic decision making.

The NHS Centre for Involvement is unique in being able to bring together expertise in:
— Working with patients and the public
— Operational and strategic approaches to PPI
— Leadership and organisational development

Rather than a lending library of methodological toolkits or mere advisor, the NHS Centre for Involvement will work with NHS organisations to link to local people. Engaging with PPI Forum members, the voluntary sector, those working on local citizenship ventures, health professionals and local partners, this approach will help to ensure that reports of engagement exercises are moved off the shelf and into practice.

2 Learning and research

In order for patient and public involvement to be effective, there needs to be a comprehensive approach to the development and delivery of learning programmes and learner support. Within the Centre, the Learning Domain will support the research and development work and will be fully integrated into the organisational development work and the creation of the People Bank. A disproportionate amount of resources in the area of learning has been aimed at helping the involvement of patients and the public. The National Centre for Involvement focuses on NHS staff and will ensure that learning and training is developed that helps them undertake PPI activities and build on the findings to ensure that PPI has an impact.

Although there is much to build on in this area there has been no single assessment of the range of learning available under the heading of PPI. The Centre will continue earlier work by the NHSU PACE Team in mapping provision across

England. This approach will use the resources available within the Ui advice and information service and the national Information, Advice and Guidance service for learners.[2] The latter has national quality assurance frameworks and a network of staff based locally and regionally.

3 Research and best practice

PPI, like other aspects of the NHS must be based on evidence and best practice that has been demonstrated to work and make a difference. The key aims of the Research and Best Practice Domain are to:
— map and review existing evidence about PPI and identify knowledge gaps
— distil this information and translate it into guidance, implementation plans, training and support programmes
— undertake or commission work to fill the gaps in the evidence base

One of the key issues that the Domain will tackle is developing and disseminating key PPI concepts in a consistent and coherent manner. This will form the basis of a rational approach to all the work in the Centre and be embedded in the learning and support programmes it provides. It will help ensure that all those involved in PPI activities have a common point of reference for discussion and implementation. The Centre will develop clear operational definitions for key concepts in PPI building on the components of the PPI cycle and develop and validate evaluation frameworks for PPI building on previous work of members of the collaborative team. In addition, the Research and Best Practice Domain will publish readily understandable digests of evidence on PPI to help support PPI professionals and researchers.

4 Communications

This domain will act as the Centre's primary external interface, ensuring effective delivery of all products for its stakeholders and the appropriate targeting of dissemination for the other three domains (Research and Best Practice, Learning and Support, Organisational Development). As such it must ensure the delivery of knowledge and tools to the diverse relevant audiences of practitioners and policy makers in the most appropriate form. In other words it will be the translator for the work of the NHS Centre for Involvement, the link connecting the internal work of the Centre and its application in the field.

Practicing what we preach: Patient and Public Involvement in the Centre

A number of structures have been devised so that the Centre's strategic direction, work agenda, practice and delivery are not only shaped by key stakeholders, patients and the public but, where possible, actively involve them in its work.

1 The people bank

In accordance with the Centre's inclusive principles, a People Bank will be created and developed which will lie at the heart of the Organisation. Composed of a group of PPI champions – staff and non-staff – it will help to lead the work of the NHS Centre for Involvement and support and develop that work.

Experience of PPI is the best form of training and the People Bank will provide a means of sharing experience and supporting and developing PPI professionals. This means NHS staff with a formal responsibility for undertaking PPI work. The People Bank will consist of two groups: a pool of high quality, well-supported and trained patients and members of the general public and PPI professionals. The Centre envisages that the People Bank will co-produce the outputs of the NHS Centre for Involvement. They will help deliver the work of the Centre as equal partners. Over time, the Centre will consider whether national agencies might be able to access the People Bank and its members for particular projects. Members of the People Bank will be considered as the patient and public advisors in the Centre's development projects, will become trainers for various learning programmes that the NHS Centre for Involvement might offer and/or oversee research.

2 The patient-citizen exchange

A key role for the NHS Centre for Involvement will be to support patients and the public who fill many and varied roles involved in the governance, management and delivery of healthcare. The success of the Centre will depend on building the understanding and capacity of patients and those members of the public who exercise a representative or intermediary voice on their behalf. The NHS Centre for Involvement will seek to develop the role of patients (and the public) as active citizens who play a role in ensuring accountability for the organisation and delivery of health services. The Patient-Citizen Exchange will provide a hub for sharing best practice and supporting and developing patients who play such roles. The Patient-Citizen Exchange will develop innovative methodologies in

conjunction with the other domains to enable maximum engagement with patient-citizens and others who support them. It will provide space for networks of people and groups to discuss involvement related issues and provide an avenue promoting better understanding of the work of the Centre. Whilst the NHS Centre for Involvement will not directly train or support individual patient-citizens, the Patient-Citizen Exchange and the Centre can build capacity and underpin the creation of a supportive infrastructure with appropriate partner organisations.

The Centre anticipates five key audiences for the Patient-Citizen Exchange: health voluntary organisations, expert patient members, patient & public involvement forums, overview and scrutiny committees and non-executive governors. To complement this Exchange, a Health Voluntary Network will be organised to run in parallel and act as a conduit for support and advice in relation to the work of the Centre.

3 Health voluntary organisations
Increasingly the health voluntary sector is looked to for expertise in relation to specific conditions and in supporting and providing services to key categories of patients and the public. Some of the ways the Centre will work with the voluntary sector include:
— Working on substantive thematic issues at a national level with voluntary organisations
— Working with local voluntary organisations within the development work (i.e. a key part of the development projects will be to bring all local stakeholders together)

And an early priority will be to map the needs and expectations of the voluntary sector with regard to the NHS Centre for Involvement's work.

Developing PPI in the community: the emerging role for LINks
The Department of Health has already announced that the current PPI system of PPI Forums will be reformed and the Commission for Patient and Public Involvement in Health is to be abolished. Local Involvement Networks (LINks) have been proposed that will enable NHS provider organisations to engage with the local community to improve health and social care services. As a network of interested individuals and local voluntary and community organisations, LINks will set their own agenda and focus on issues of concern to local people and

seek to influence change. It is of central importance that LINks be integral in commissioning decisions to ensure they reflect the views of local people and guide the priorities and delivery of health and social care services within a local community.

Conclusions

Mainstreaming PPI has the potential to change the culture of the NHS. It could, if done properly, be the way that the NHS becomes truly centred on what matters to patients. And it could, if done properly, ensure that what patients say makes a real difference to people's health and lives.

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1 Department of Health, A stronger local voice: A framework for creating a stronger local voice in the development of health and social care services (2006).

2 Ui is an NHS online and telephone information and advice service based in the NHS Confederation.

Structures in Healthcare
5. The role of citizens and service users in regulating healthcare

By Anna Coote

Anna Coote looks at the diverse mixture of methods used to engage with patients and the public. She argues that regulation should promote improvements in the way health services are experienced by service users.

Introduction: the core question

What role should citizens and service users play in regulating healthcare? To address this question, we must first consider how recent reforms of the health sector bear upon the role of regulation, how changes in the regulatory regime affect the role of public involvement and how government policy on public involvement in health care affects the role of the regulator.

Changes in the health sector

Ostensibly, recent reforms of the health sector have been driven by four aspirations. First, power has been devolved from the centre to reduce bureaucratic controls, shift resources to front-line services and make these more sensitive to local needs. Second, the NHS has been opened up to independent providers to encourage innovation and efficiency in a service that – in spite of huge injections of new cash – remains in a perpetual financial crisis. Third, investment is being shifted towards community-based services to place greater emphasis on preventing illness, on early diagnosis and treatment, on linking health and social care and on caring for people in or near to their own homes. And fourth, the reformed NHS is supposed to give patients more say in how they are treated and cared for and more choice over where they get services.

The idea of regulating healthcare comes as part of this relatively recent package of health service 'reforms'. The main regulatory body, at the time of writing, is the Healthcare Commission, which assesses the performance of healthcare organisations against standards and targets set by government. In 2008 or thereabouts, it will be merged with two other regulators – the Commission for Social Care Inspection and the Mental Health Act Commission – to create a new body whose shape and character is not yet known. The merger is intended to cut costs, to streamline regulation and to reflect closer alignment between health and social care. It is likely that the new regulator will continue with the regime developed by the Healthcare Commission, which has three features that are important for this discussion.

The way the Healthcare Commission carries out its assessments is supposed to have a light touch and be 'risk-based', so as to make best use of its resources and avoid over-burdening healthcare organisations. Instead of inspecting each one at regular intervals, it tries to identify trouble spots and focus on institutions or service areas where particular risks are known or suspected.

It also seeks to promote improvements in services and not just find out what is going wrong. And it wants to improve the way citizens and service users experience health services, not just promote what health professionals and managers perceive as improvements.

To this end, the Healthcare Commission requires NHS trusts – that is, organisations that commission and provide health services – to complete a declaration each year setting out how well they think they are performing. It then cross-checks their statements against information from a range of other sources, including national surveys of patients' opinions about services. It inspects those trusts where it suspects a risk of poor performance, as well as a small, random sample. It issues an annual 'rating' to each trust, based on its performance assessed against basic standards, targets and financial information.

It also monitors trusts' performance against a further set of 'developmental' standards aimed at promoting better practice. It carries out a range of audits and reviews which look at services for particular groups of patients, such as those with diabetes, heart failure and learning difficulties, and at hot topics such as hospital cleanliness and healthcare acquired infections, including MRSA. It

handles complaints that have not been properly dealt with locally. And where it suspects serious failures, it conducts a formal investigation. Examples of this include one trust with unusually high death rates among women giving birth and another where patients with learning difficulties were being abused. It regulates private and voluntary health services in a different way, but there are plans to bring the two systems into closer alignment.

From all these activities, the Healthcare Commission accrues a huge amount of information about health services across the country, which is intended to help trusts improve their performance and to help members of the public to make informed decisions about how to use their services.

Changes in government policy on Patient and Public Involvement in health

The Healthcare Commission has declared its commitment to putting 'what matters most to patients and the public' at the heart of all its activities, in order to achieve its primary goal of improving their experience of health services. How far it realises these ambitions is a question that must be considered in the light of shifting public policy.

The idea of 'engaging' and 'empowering' citizens and service users has been an important feature of government rhetoric for at least ten years. This partly reflects an understanding that services will miss their mark and waste public resources unless they are properly attuned to the needs and circumstances of the people who use them. It is also a crucial dimension of New Labour's efforts to forge a fresh approach to social policy that differs from the old 'statist' model of the post war era and the market model of the Thatcher and Major years. A crucial element of this approach has been to encourage individuals and groups to help each other and themselves. It is hoped that this will keep costs down and build reciprocal relationships that help glue communities together. One way of doing this has been to 'involve' people in planning, designing and delivering their own local services. However, involvement is a rather more vexed issue in the health sector than in some other service areas. Everyone has an interest in health and healthcare throughout their lives. Yet there has been no local democratic control of healthcare organisations since local councillors were removed from health authorities in the early 1970s. There is also an enduring ethos of clinical autonomy, signalling that 'doctor knows best', which tends to cast 'patients' as passive

(and supposedly grateful) recipients of professional intervention, rather than as active participants in the management of their own wellbeing.

Partly because of these complexities, public policy on involving patients and the public in health has not run smoothly. In 2000, the Labour government abolished community health councils, and established the Commission for Patient and Public Involvement in Health (CPPIH), charged with setting up more than 500 Patient and Public Involvement Forums, one attached to each NHS trust. The quality of forums varied considerably. At their best they were vigorous advocates and watchdogs. At worst they were unrepresentative local cabals, destructively critical, or just weak and ineffectual. But before they'd had a chance to prove themselves, the government announced its intention to abolish CPPIH, throwing the future of forums into doubt.

In 2006, a new policy was announced, intended to learn from past mistakes and establish a framework for patient and public involvement that could accommodate further reforms in the health sector. The recommendations in A Stronger Local Voice have been set out elsewhere (see box introduction). , Responsibility for consulting and involving patients and the public will rest with trusts and how they do it will be largely up to them. But a key feature for the regulator is that the Healthcare Commission (and its successor following the merger with the Commission for Social Care Inspection) will be responsible for assessing their performance on this front.

The new arrangements are intended to encourage constructive partnerships between local people and trusts, rather than confrontation between 'us' and 'them'. The new Local Involvement Networks (LINks) are supposed to be flexible enough to cope with continuing change in the health sector, especially the new 'commissioning' powers of PCTs and new moves to let individual patients 'choose' services. Their establishment anticipates closer links between health and social care, as well as between the NHS and local government. The LINks will have to be inclusive, to find ways of reaching disadvantaged people, and to serve as a vehicle for as wide a range as possible of local groups to be heard and heeded by trusts. They are expected to build on existing channels for public involvement, including mechanisms set up by local government. This will hopefully reduce duplication and over-consultation.

Why and how the Healthcare Commission 'engages' patients and the public
The efforts of the Healthcare Commission to engage service users and citizens are being developed in a turbulent political environment with a rapidly-changing, increasingly pluralist health sector and a strong drive towards commodification of services and personal 'choice': its regulatory philosophy is in its infancy; its methods have yet to mature; its status is in flux; its future uncertain, and it must grapple with the latest upheaval in government arrangements for patient and public involvement in health.

Sir Ian Kennedy, the Commission's chairman, whose vision has been highly influential, has always insisted that the primary duty of the regulator is to the patient. The whole point of assessing performance is to promote improvements in the way health services are experienced by those on the receiving end. The main purpose of gathering information about the quality and availability of services is to pass it on to the people who use them.

One of the Commission's main objectives, therefore, is actively to engage patients and the public in its work. People are engaged in order to help assess the performance of healthcare organisations and review services; to shape and use the information provided by the regulatory body; to help identify ways of improving services; and, overarching these functions, to inform and advise the regulatory body about how to plan and carry out its work so that it best serves the interests of patients and the public.

At the time of writing, the Commission has five main channels for engaging them: working with local statutory organisations, consulting national voluntary organisations, tapping into 'seldom-heard' networks, involving service users in specific studies, and recruiting members of the public for deliberative events. It also carries out research into patients' opinions through regular surveys.

Working with local statutory organisations
From the Commission's inception, the main channel for engaging patients and the public has been through Patient and Public Involvement Forums and Overview and Scrutiny Committees. These are the locally based, statutory bodies charged with representation, inspection and scrutiny. Forums and OSCs are invited to contribute comments to the annual declarations in which trusts say

how they are performing against standards and targets. These 'third party commentaries' contribute to the annual ratings received by trusts, as well as to the Commission's local intelligence.

Comments are also invited from the lay members of Foundation Trust (FT) boards, who have been elected by a broader membership made up of people in the local community who have opted to join. Their comments are dealt with in the same way.

The declaration is an annual event, but forums, OSCs and other local organisations are encouraged to work with trusts and the Healthcare Commission's staff throughout the year to make sure that the voices of local people are heard and heeded, that their interests are understood and their needs met. At least, that's the idea. The Commission makes some effort to provide support and advice for Forums and OSCs, to develop constructive local partnerships and help them contribute useful commentaries. It has also been breaking new ground in finding ways to analyse the huge volume of qualitative data produced by these commentaries – all of which must be coded and weighted appropriately if they are to influence the ratings awarded to trusts.

One advantage of working with Forums, OSCs and FT board members is that they are easy to identify and reach. They have formal status and some resources to support their activities. One weakness is that they are far from inclusive; often the neediest groups have no links with them at all. Many individuals who belong to them represent valuable 'social capital' as experienced activists, but they alone do not give sufficient voice to all sectors of their communities.

The role of the OSCs is quite limited, not least because they are made up of busy councillors with other local interests to attend to. But the principle of scrutiny by elected local government gives the electorate some say in how their services are run in theory (and sometimes in practice). And in the never-ending revolution that afflicts the NHS these days, local government can seem an oasis of calm and stability.

The role of the FT board members depends largely on who they are, and how much independent clout they have on their boards. The jury is out on whether this model of local 'ownership' really does give some power to local people in

running foundation hospitals, or whether it is mainly window-dressing. As for the PPI forums, they will lose their statutory base and shut up shop when government policy is implemented over the next couple of years.

With an eye to these difficulties, the Healthcare Commission has set up two test-sites, one in the south-west peninsular and one in the Leeds/Bradford conurbation, where it is working with local patient-led and community-based groups to develop new ways of engaging people that suit local needs and circumstances. This has made it clear to the Commission that people want it to tap into existing groups and networks, and to make more use of local media, local centres of activity and local events to communicate with residents. The test site models could helpfully point the way to how the Local Involvement Networks (LINks) envisaged by government can work in practice.

Working with the voluntary sector

The Commission has set up a network of national voluntary organisations representing patients and citizens in order to seek their advice on how best to carry out its various functions. Some of these have networks that are also involved at local level. These groups have access to very considerable expertise. They may, for example, have members who are living with cancer, mental health problems or diabetes. They are, by and large, willing to pitch in and give advice, but are in high demand as consultees – and often feel over-burdened. They have made it clear that they don't want to be asked the same questions repeatedly by different government bodies, or to be roped into futile consultation exercises that drain their resources and show no useful results. Between them, they constitute a valuable resource for the health regulator, but their value is unlikely to be realised unless the regulator gets to grips with their strengths and weaknesses and appreciates the differences between them. Some are large and powerful in their own right, with formidable policy analysis and campaigning skills. Some are small and struggling. They represent widely varied constituencies and client groups. All of them have distinctive interests to promote or defend. A customised approach seems to work best, one which matches the skills and interests of different organisations with the Healthcare Commission's varying needs for input into its regulatory functions.

Working with 'seldom-heard' groups

Neither the local statutory organisations, nor the national voluntary sector give effective voice to people who are most vulnerable to ill-health because of social and economic disadvantage. This includes minority ethnic groups, people with disabilities or mental health problems, refugees, travellers, homeless people, ex-offenders, migrants who don't speak English and others who are socially excluded. Some of these groups avoid getting 'involved', but most simply don't get noticed by officialdom, except when they are in trouble. The problem for the Healthcare Commission is not just how to find them, but how to engage with them in ways that are meaningful and mutually rewarding. It is a big logistical challenge as well as a financial one. Comprehensive outreach in every community of place and interest would be prohibitively expensive. And yet any pledge to put 'what matters most to patients and the public' at the heart of regulation without including the most needy and vulnerable would be hollow indeed.

What the Commission has done, in effect, is to contract-out the challenge to the Centre for Ethnicity and Health at the University of Central Lancashire (UCLAN), which is building up a network of 'seldom heard' groups for just this kind of purpose. UCLAN identifies the groups and trains facilitators drawn from their number, who then organise local workshops for group members and help to facilitate them. The assumption is that disadvantaged or excluded groups must be involved on their own terms and in their own surroundings. Engaging directly with groups is thought likely to provide more authentic feedback than singling out representatives to attend mainstream events, although this may happen later if and when trust and confidence develop. This approach still needs heavy support from specialists in public engagement, who help prepare material for the workshops. Experience so far has demonstrated that there is a great deal to be learned from such groups. The process is slow, painstaking and labour intensive. It is not perfect and it certainly needs refining, but as a small, revealing step into territory previously uncharted by the world of healthcare regulation, it has to be worth it.

Involving service users in special studies

When the Healthcare Commission carries out a review, looking across individual trusts at how patients with particular conditions experience services, it usually invites service users to participate in planning the review and inspecting and assessing services. In some cases it enters into a contract with an appropriate

user-led organisation to recruit and train these lay reviewers. The mental health charity MIND has done this for reviews of mental health services.

This approach to working with people who are 'expert by experience' is being further developed by the Commission for Social Care Inspection and is likely to remain central to regulation in health and social care. But it raises some challenges. What weight is to be given to the views of 'experts by experience' if they vary from those of professionals in health and regulation? How far are professionals prepared to change their attitudes and ways of working in order to work constructively with service users? If service users are paid a decent rate for their contribution, what happens to those who are in receipt of benefits? How much effort should be made to involve severely disadvantaged service users, and how much training and support should the regulator pay for? There are no simple answers to any of these questions, but they certainly need to be addressed.

Recruiting members of the general public
None of the channels for engagement described so far extends to the 'silent majority' of unorganised members of the public, those people who don't belong to patient-led or community-based groups, or to social groups identified as disadvantaged or particularly vulnerable to illness. To engage people like this, the Healthcare Commission recruits members of the public using social research methods, in groups that broadly reflect the population profile. They are asked to participate in 'deliberative workshops' or panels that consider issues where the views of the general public are thought to be especially relevant. Examples of this might include determining the future priorities for the annual assessment of trusts: groups could be asked whether the Commission asking the right questions. Or this might include reviewing the way information is produced: groups could be asked whether it is what people want to know and whether it is presented in ways that are accessible and genuinely useful.

The same approach has been used to bring recruited members of the public together in 'collaborative workshops' with patients from voluntary organisations and clinicians, so that they can all address the same questions from their different perspectives, gain a better understanding of each others' views and, where possible, work towards a consensus.

These deliberative events can best be described as participatory research. They are more interactive than a focus group, and shorter and less intensive than a citizens' jury. Some last for a day, some for two or three hours. Materials are prepared and discussions structured as carefully as possible to enable participants to get enough background information and focus their attention on specific questions that are manageable within the constraints of the format. They are invariably run by specialist agencies contracted for the purpose, which record the proceedings and produce detailed reports.

The events cannot yield definitive results, but they do provide rich insights into public attitudes that cannot be found through quantitative surveys, as well as opportunities for dialogue that can't be found in focus groups and other qualitative studies. As long as the health regulator is serious about engaging 'the public' (that is, past or future patients) as well as current service users, it is hard to imagine a better way of doing so. The main disadvantage is the cost. The need to pay contractors to recruit, organise, facilitate and report on deliberative workshops makes them more expensive than other methods. So they have to be used sparingly and only where there is a reasonable expectation that other less expensive methods cannot engage the same kinds of people just as effectively.

Quantitative research

That said, by far the largest sums spent by the Healthcare Commission on finding out what people think (upwards of £4 million a year) are devoted to quantitative surveys of patients' opinions. These are administered by post to individuals who have recently experienced services, as hospital in-patients, emergency cases or users of primary health care. They are intended to give annual results for the whole country and findings are used to cross-check declarations from trusts for the annual ratings, as well as to identify trends and problems. The scale of expenditure on these surveys reflects the enthusiasm of the Department of Health for regular, robust quantitative findings. In the field, however, they have received mixed reviews. Some say they don't give enough information about what is happening in different departments of hospitals, some that they duplicate other surveys. There is far too little evidence of trusts using survey findings to help them improve services.

It remains doubtful whether this approach does as much to help assess and improve health services as it does to satisfy a desire for quantifiable informa-

tion. Arguably, if nationwide surveys were held every two to five years and combined with a range of smaller, more focused studies, the millions might be better spent.

Principles of effective engagement

Whenever and however the Healthcare Commission attempts to engage patients and the public, certain principles should apply. Engagement should happen as early as possible and be integral to planning and implementing the work in hand. The Commission should only ask people what they think if it is able to act on what they say.

The first step should be to find out what is already known about what patients and / or the public think about the issue under consideration. The method of engagement that is selected should be suitable for the purpose of the exercise. It must always be as inclusive as possible. It must be clear to everyone involved what is happening and why. Participants should receive as much background knowledge as possible to enable them to make an informed contribution.

The Commission must feed back to participants what it has learned and what it is going to do as a result; if it is not going to act on what it has learned, it must explain why. Its efforts to engage people should be in proportion with the scale of the issue at hand.

Barriers to effective engagement

That may sound quite promising, but it is not always easy to act according to principle. In common with most organisations in or near government, the Healthcare Commission is capable of putting up formidable cultural and institutional barriers to effective engagement. It remains to be seen how far or how soon the principles become embedded in practice across the organisation and all its functions. Much depends on strong, consistent leadership at the highest level.

Regulating involvement

If the Healthcare Commission finds it hard to turn its principles into action and change, the same is likely to be true of many of the organisations it regulates. The Department of Health has made it clear that the regulator has a key role to play in making a success of its new proposals for involving patients and the

public. These are looser and more flexible, shifting much of the responsibility to trusts, and relying on the regulator to ensure they meet standards. There are two core (basic) standards that relate to involvement, summarised in the box below. These are backed up by developmental standards, designed to promote improvement.

Core standards

C16 Health care organisations make information available to patients and the public on their services, provide patients with suitable and accessible information on the care and treatment they receive and, where appropriate, inform patients on what to expect during treatment, care and after-care.

C17 The views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving healthcare services

In order for these standards to have a positive effect on performance, several things are necessary. There must be clear and sufficiently demanding criteria set out by the regulator, so that trusts know what they are expected to do to meet the standards. The Commission's local assessment managers must know what to look for when they are sifting local data and conducting follow-up inspections. Everyone must know that this is matter of priority, not a second-order issue to be abandoned when the going gets tough. And the Commission should ideally have access to independently verifiable data in order to cross-check what the trusts say about their performance on this front. Meeting these conditions will be a major task for the Commission in the forthcoming year. The new National Centre for Involvement, funded by the Department of Health and recently established at Warwick University, is expected to help to build the capacity of healthcare organisations, so that they can rise to the challenge. The Department of Health is producing its own guidance on patient and public involvement, to be published in 2006–7, and this will help the regulator to establish clear and consistent expectations of healthcare organisations.

Conclusion: for the future

What are the necessary conditions for making tangible improvements, through regulation, to the way people experience health and healthcare services?

First, the current reforms of healthcare services must work in favour of involving patients and the public, so that their needs are recognised and met. Second, light-touch, risk-based regulation must be able sufficiently to influence the performance of healthcare organisations in this area of activity. Third, the government's new arrangements for involvement must be implemented in such a way as to achieve its main goal of giving a stronger voice to patients and the public. Fourth, the Healthcare Commission and its successor body must have sufficient resources and sustained commitment to involve patients and the public effectively in their work. Fifth, a range of factors – the reform of services and regulatory regimes, public policy on involvement in health and how the regulator involves patients and the public – must combine to ensure that all healthcare organisations adopt and follow the principles of effective engagement. And, finally, patients and the public must be able to feel the difference for themselves.

Structures in Healthcare

6. A new vision for local democratic accountability of healthcare services

By Jane Martin

Local councillors play a key part in holding the NHS locally accountable through health Overview and Scrutiny Committees. Jane Martin explores the vital role of local elected representatives as health champions for local communities.

The new framework

 A new vision for local democratic accountability of healthcare services has been built on modernised political management arrangements in local government. New powers of local authority 'overview & scrutiny', established in the Local Government Act 2000, have been further elaborated in relation to NHS bodies. What is now commonly referred to as 'health scrutiny' by non-executive councillors on the health overview & scrutiny committee (OSC) of the local authority was introduced in The Health and Social Care Act 2003 and applies to the 150 'top-tier' local authorities providing social services (these were all county councils and unitary local authorities with responsibilities for social services provision). They can do this by determining whether decisions about health and healthcare reflect local needs; whether health inequalities are being tackled; and if proposals for major changes to health services are reasonable. This power of health scrutiny is matched by a duty on NHS bodies to provide information to OSCs and on NHS officers to attend OSC meetings to answer questions. They are also required to respond to recommendations from OSCs and must consult relevant OSCs about proposals for 'substantial' service changes. If OSCs consider that proposed changes are not in the interests of local people they can refer them to the Secretary of State or to Monitor, the independent regulator of Foundation Trusts.

The Centre for Public Scrutiny (CfPS), established in 2003 to support and promote public scrutiny in modern and effective government, has worked closely with local authority health OSCs to support the new function, offer advice and guidance and evaluate practice nationwide. This has included facilitation of a health scrutiny champions network, action learning projects and briefings on policy and practice.

The new power of health scrutiny is a particularly interesting development since it gives local councillors the right to hold to account all those responsible for the provision of healthcare services in their area. Many of these services are not provided by the council itself (with the important exception of social care services). This has led to the term 'external' scrutiny to describe scrutiny by councillors of organisations and service providers external to the local authority. This is much more than a symbolic shift. The reason for this is not only because local councillors have the democratic legitimacy of public election to reinforce their credibility to hold to account on behalf of local people, but also because they bring a public health focus to their activity. This is a perspective which naturally leads to recommendations for improved services for health prevention as much as health cure. It raises public awareness about ways in which individuals, families and communities can increasingly take responsibility for their own good health.

There were high expectations for the impact of the new model of health scrutiny. The aim was to provide effective public accountability to local people in relation to their health and well-being, through a coherent programme of scrutiny focused on outcomes to improve the health of local people and resulting in local improvements in local service delivery. A second, but equally important, aim was to use health scrutiny to take account of and seek to address health inequalities, not least by reflecting the complex solutions required for cross-cutting issues of public health. Thirdly, it was anticipated that health scrutiny would help to promote health and well-being in response to local circumstances and the needs of local people.

In terms of the process of health scrutiny, the message was very much to constructively inform and shape proposed changes to local health service provision, whilst reflecting a proper balance between 'mainstream' scrutiny of public health issues and scrutiny of specialist areas of health. It was clear from the

outset that the most constructive approach was an informed joint enterprise between OSCs, their partners in the local health economy and local people.

Progress so far

The University of Manchester Centre for Public Policy and Management is currently undertaking a three year evaluation of health scrutiny for CfPS. During the first phase of the project, the team gathered information from health OSCs and NHS bodies about their perceptions and experiences of health scrutiny. The findings from the surveys, in a report called 'Process Progress and Making it Work' in September 2005, show that:

— Health scrutiny has developed tremendously in its first two years, with structures and processes in place to facilitate health scrutiny, with the numbers of dedicated health OSCs increasing. In some county (two tier) areas, district councils are leading local health OSCs (often based on PCT boundaries).

— Health OSCs are increasing their knowledge base and expertise by co-opting representatives from external agencies. Patient and Public Involvement Forum members, district councillors and Directors of Public Health are the most common co-optees.

— Health scrutiny reviews are increasingly themed around cross-cutting public health issues, disproving an early fear that health scrutiny would become focused on institutions and organisations.

— Relationships between local government and the NHS are improving, contrary to an early fear that partnership working would be damaged by health scrutiny.

— Two thirds of NHS bodies surveyed have consulted health OSCs about 'substantial' services changes, but less than a third have an agreement with OSCs about what is regarded as 'substantial'.

— Over a third of NHS bodies surveyed have changed policies, procedures or services as a result of health scrutiny.

— NHS bodies perceive health scrutiny to be less onerous than inspection, but it has yet to develop the same impact.

Overall, these early findings are encouraging. However, some issues need to be tackled if health OSCs are to fulfil their potential to increase public involvement, bring greater accountability to the NHS and improve services. Some health OSCs perceive the financial resources supporting them to be inadequate, although this is being reported to a lesser extent than two years ago. Also, in some cases,

consultations from the NHS, together with the need for joint scrutiny, can restrict the capacity of some health OSCs to manage their work programmes without careful co-ordination. Lastly, there are still training issues for health OSCs. These persist in terms of consistency of membership and for the NHS in terms of building understanding and appreciation of the health scrutiny function.

Health scrutiny in practice
The Centre for Public Scrutiny has supported a number of health scrutiny reviews, a small number of which are outlined below. The range and extent of these reviews indicate how health scrutiny can be a vehicle for reviewing and influencing policy and practice. Each one is focused on a different aspect of public health and facilitates partnership working and public consultation.

Derbyshire County Council: sexual health
Informing a health needs assessment for North East Derbyshire Primary Care Trust, the health OSC engaged 'hard to reach', marginalised, stigmatised groups and communities suffering disadvantage.

Coventry City Council: breastfeeding
This review tackled social and cultural attitudes to breastfeeding. It developed local peer support and outreach services and looked at low rates of breast–feeding amongst babies born by caesarean section. The health OSC worked with Coventry University and Warwickshire County Council.

Cornwall County Council: patient pathways for older people
Informing a joint commissioning strategy for older people across social care, health and housing agencies, the health OSC is hosting a 'planning for real' exercise, bringing together professional partners, patients and carers.

Norfolk County Council: death and dying
This project tested perceptions that people do not wish to die in hospital. It considered whether palliative care tends to be dominated by the needs of elderly people dying from cancer and explored cultural attitudes to death. The outcomes of this review informed 'Better Care for Norfolk', a rethinking of methods of health delivery.

Cumbria County Council: teenage health

A review that explored health promotion, physical and mental well-being and corporate parenting. Teenagers helped to frame questions for service providers and met separately with providers, 'comparing notes' with the OSC. Its conclusions were tested with teenagers before publication.

Kent County Council: preventing disease through physical activity

This project aimed to encourage physical activity as a way of preventing disease. The County Council and three District Councils undertook simultaneous reviews in their areas, informing the development of strategies to combat obesity being prepared by Primary Care Trusts.

Conclusion: the future

It seems that the model of health scrutiny has much to offer. The examples above suggest that local authorities are well placed to take the lead in reviewing the commissioning and provision of healthcare services in the locality. Facilitating a sustainable new local accountability relationship between healthcare providers and the public depends on the role played by locally elected representatives as champions, advocates and mediators of local views and concerns. This is a question of reconciling issues-based politics with collective well-being. Local authority health scrutiny reviews provide new opportunities for local people, as individuals or members of communities of interest, to become involved in policy-making and key decisions regarding the provision and commissioning of healthcare in their local area which concern them personally. In this mode the prime role of the elected representative will be as the advocate of interested individuals and groups. But this role will inevitably have to be balanced against the role of the elected representative as mediator of a range of local voices. This will be important during local consultation on a major service reconfiguration, for example, or, as is envisaged in future, consultation on the commissioning priorities for local healthcare services where priorities and choices will need to be made in the local common public interest. Assimilating and representing the many and varied interests in these circumstances is, moreover, likely to cut across traditional party political boundaries and may more closely align with the needs of a particular geographical place or locality. Questions about the future role of the local hospital, for example, starkly make this point.

The key issue here is access for local people to their representatives and to the scrutiny process. In order that local accountability and responsiveness of health and social care can be promoted and sustained, there is a need for simplicity and clarity of structure and process, as well as adequate resourcing and support for public involvement. The local authority scrutiny function goes a long way along this route. Most local authorities have professional support staff for the scrutiny process who advise and guide elected members and create opportunities for public engagement. Local authorities conduct scrutiny reviews in public and publicise both reviews and recommendations.

But this of itself will not be enough to promote effective engagement. It has therefore been proposed that Local Involvement Networks (LINks) be established as the local focus for public involvement in health. If LINks become effective and inclusive local networks of all patient and public groups in each local authority, they could become flexible and responsive partners with which health OSCs engage to ensure they are picking up the views and concerns of the widest and most appropriate public constituency. As part of this landscape, health OSCs should be seen as 'first amongst equals', given their democratic legitimacy to speak on behalf of local people and their mandate to represent local needs and concerns. The relationship between health OSCs and LINks will therefore be an important one for ensuring the best possible representation of local voices. As the responsible and accountable body for ensuring adequate hosting of the LINks, local authorities are well placed to draw on and develop their expertise in democratic services and community development to support effective networking.

The scrutiny review process is providing an important and unique function which focuses on cross-cutting public health issues. But does it amount to robust local democratic accountability? NHS bodies are required to submit themselves for scrutiny but to what extent do changes in design or delivery result? The requirement for NHS bodies to consult with OSCs on 'substantial reconfiguration' of services is an important step in the right direction. The formal integration of the local public voice, through OSCs, into the Healthcare Commission inspection process may prove to be a very effective way forward, particularly in assessing NHS bodies' response to its section 11 duties. The challenge now is to develop scrutiny such that elected representatives become local leaders for the process and increasingly gain credibility for enabling the public voice to challenge and improve local services.

Beyond the NHS
7. The role of the voluntary sector within involvement in health

By Belinda Pratten

The voluntary and community sector has an important contribution to make to health involvement, not least in the proposed LINks. Belinda Pratten argues that public bodies need to recognise and support the sector's advocacy role to ensure that a wide range of voices can be heard.

Introduction

In recent years there has been much interest in the role of the voluntary and community sector (VCS) in public service reform. This has focused primarily on how it can play an increasing role in delivering services. Less attention has been given to the sector's role in promoting voice and facilitating public participation in decision making. This article provides an overview of the sector and the range of contributions that voluntary and community organisations (VCOs) make to health and health care. In particular it highlights the sector's role as a catalyst for community engagement, working alongside democratic institutions to give voice to people's concerns and ensure that a wider range of voices are heard.

The voluntary and community sector

Key characteristics of the voluntary and community sector are its independence and its diversity: it consists of a wide range of organisations each established in response to a particular need or to further a cause. The common factor that unites VCOs is their motivation. They exist for public benefit, not private gain. They are driven by their mission or purpose and the values that sustain this. They are run by voluntary management committees or trustee boards who are

accountable for ensuring that resources and activities further their mission and provide maximum benefit to their users and members. And they will typically undertake a wide range of activities to achieve this, including campaigning and advocacy; community development work; giving advice and information; and direct service provision, either independently or on behalf of government.

VCOs have their roots in civil society, in citizens coming together to make a difference to their lives, their community or to the lives of others, independently of both the state and the market. As independent organisations, VCOs have fewer constraints and more flexibility than public sector bodies. This means that they are able to take a holistic approach to people's needs, working across organisational and administrative boundaries. It also gives them greater flexibility to develop and pilot innovative ways of working. And because they do not have to generate shareholder value they can undertake activities that the market is unable or unwilling to engage in. Their bottom line is how effectively they maximise the benefits to their users within the resources available. This is no less a driver of efficiency than demonstrating a return on capital is for private sector companies. Moreover, as independent organisations working for public benefit, they are often able to command higher levels of trust and confidence than other sectors.

The contribution to health and healthcare

There is a long history of voluntary action in health and welfare. For example, the UK's oldest and most renowned teaching hospitals were originally established as voluntary hospitals funded by subscriptions from wealthy patrons. Clearly the nature of such activity has changed and adapted over the years in response to changes to the environment they work in. With the creation of the NHS, for example, these hospitals and some other services were transferred to the state sector. However new forms of voluntary activity continued to flourish alongside this, providing services that were complementary or ancillary to statutory provision and pioneering new ways of delivering services, especially to those not well-served by the mainstream. At the same time there has been significant activity from a wide range of organisations campaigning, lobbying and advocating on behalf of their users and members for greater involvement in decision making as well as for better quality health care.

In recent years VCOs have taken increasing responsibility for service delivery. A significant proportion of social care services is now provided by the voluntary and community sector. Current policy contains a strong commitment to create a similarly mixed economy in health care, by encouraging a wider range of providers, including VCOs, to deliver services on behalf of the NHS. The Department of Health has made an express commitment to removing the barriers that prevent VCOs from taking on an expanded service delivery role.[1]

However, there are also many VCOs for whom health and access to health care are key concerns, yet who have no interest in delivering services directly. Rather, they want to ensure that the services available are delivered in ways that are accessible, acceptable and appropriate to the needs of their users and members. This is a concern for many organisations working with individuals or communities that are disadvantaged or vulnerable and therefore have little economic or social power.

There are also many organisations engaged in preventative activities. These might include a women's group working to prevent cases of domestic violence, a community centre providing opportunities for older people to take exercise or eat well, or an organisation providing support and information to enable people to manage long term conditions. These activities might also include work directed at addressing the wider social and economic determinants of health. Such organisations can and do make a direct contribution to the NHS, although it is not easily quantifiable and not always recognised.

Therefore, the voluntary and community sector has a significant role to play in achieving the priorities set out in the white paper, Our Health, Our Care, Our Say, by promoting greater choice in the range of services available, giving people a louder voice to influence decisions, enabling them to make informed choices, providing early support for intervention; and working to address inequalities. The Government has shown that it is committed to reducing the barriers that prevent VCOs from taking on a greater role in delivering health and social care and many are well-placed to take on this role. However, the sector's wider role also needs to be valued and supported. Simply facilitating the transfer of public services to the voluntary and community sector will not, by itself, secure the transformation of those services that everyone wants to see.

The role of the VCS

One way in which VCOs can contribute to debates about local needs and priorities is by feeding in their own knowledge, derived from their experience of working with their users and members and understanding 'what works' for them. As mission-focused organisations, VCOs tend to have a strong user-orientation: only by having a good knowledge and understanding of the needs, preferences and concerns of those they work with can they achieve their goals. As a consequence VCOs are often a vital source of 'intelligence' on local needs that decision makers can tap into.

VCOs can also facilitate community engagement in decision making processes. They can be a means of ensuring that a diversity of voices is listened to, not just those who find it easiest to make their voices heard. Many have developed expertise in reaching out to marginalised groups, such as refugees or people with mental health problems, and doing so in non-stigmatising ways. As such, they provide a link between commissioners and local communities, enabling people to participate directly and giving them the skills, confidence and support to enable them to do so appropriately and effectively. And they can build links within and between communities, bringing people together to identify their common concerns and priorities and the values that they believe should drive NHS reform.

VCOs' knowledge and experience can also be an important resource for local authority Overview and Scrutiny Committees. One committee, for example, invited a local carer's organisation to give evidence on their experience of older people's discharge from hospital. The committee were able to listen to the views of individual carers, and those of the organisation, and discuss the issues with them. This example shows how elected representatives and voluntary organisations can work together to enhance the democratic process: VCOs can be a catalyst for local engagement, reinforcing representative democracy and increasing the reach of democratic institutions.

However, voluntary sector involvement is not a free resource. Funding is needed to enable VCOs to attend meetings and to reach out to those they work with. That requires investment. At present, many are finding it difficult to effectively represent the views of those they work with, or to link people into decision making structures, because they are not funded to take on this role. This is the case

even in those areas where the government has made a clear commitment to involving them. For example, disability organisations have strongly welcomed new equality legislation that requires public bodies to consult with them with regard to implementation. Nevertheless, some have expressed a concern at their capacity to manage and respond to requests for consultation and involve a wide range of disabled people in doing so.

There is a need to build the capacity of these organisations by investing in campaigning, advocacy and community development work, to enable them to make a full contribution to patient and public involvement. There is a particular need to engage with smaller organisations. For many of them work with the most vulnerable or disadvantaged individuals and communities, yet have the least resources and therefore are most limited in their capacity to take on additional roles.

Campaigning and advocacy are also likely to be core activities for VCOs that deliver services: they are complementary ways of working, ensuring that the type and quality of service an organisation offers is informed by their knowledge of user needs. Equally, their campaigning and advocacy work may be strengthened and has legitimacy because they also have direct experience of providing services. Where organisations do take on both roles, they should be able to show how this enhances their ability to deliver, for example through evaluation and impact assessment. They must also make it clear when they are speaking on behalf of their users, and when they are speaking for their organisation.

Local Involvement Networks
The creation of Local Involvement Networks (LINks) will provide new opportunities for voluntary and community organisations to play a greater role in facilitating patient and public involvement in the NHS and ensuring that a diversity of voices are heard. It is a welcome recognition of the sector's wider contribution to NHS reform and their links to and support of individual service users and local communities.

LINks should not reinvent the wheel. They should build on the interest in, and activity around local health issues that already exists, both within the VCS and through Patient Forums and their support organisations. They must also be able to reach out to the diversity of organisations, networks and interests in an

area. Local infrastructure organisations, such as councils for voluntary service, already play a key role in facilitating local involvement. This is achieved through local strategic partnerships and by supporting voluntary and community organisations. They may be well placed to support LINks in their areas.

LINks will need to be outward-looking, involving patients, carers and voluntary and organisations in all aspects of their work, both in their governance arrangements and the way they work. This can by done by undertaking outreach work, by providing additional support to those who find it harder to make their voices heard, for whatever reason, and by communicating widely and in a range of media. To do this effectively, it will need to be appropriately resourced.

In coming months, much attention will be focused on these networks and on the role, capacity and governance structures of the organisations funded to support them. However, the capacity of those responsible for commissioning services to engage effectively and to respond to local needs, concerns and preferences must also be taken into account. The value of patient and public involvement, and the contribution that voluntary and community organisations can make to this, must be understood by commissioners and integral to the decision making process. It must not be a marginal add-on. Again, this must be reflected in the way the commissioners work. It must be part of their commitment to entering into a dialogue with their local LINk and using it to reach the communities they serve.

Conclusion
To achieve a positive transformation in the delivery of health care, it is vital that people are involved in designing services, as citizens and as members of the communities, not just as consumers. VCOs can play a vital role in strengthening the public's voice in the NHS and providing a bridge between the statutory sector and local communities. But this role is not always recognised: the sector's role in promoting voice has not been given the same emphasis as its role in promoting choice. NHS bodies need to have a better understanding of how VCOs work and how they can facilitate people's involvement in commissioning health care. This is particularly important in relation to the involvement of hard to reach groups. (Although, as one organisation once said, from a community perspective no-one is as hard to reach as NHS managers!).

The proposed Local Involvement Networks will enable VCOs to play a greater role in relation to patient and public involvement. There is a real opportunity here to bring together the expertise developed by Patients Forums and the knowledge and reach of the VCS. However, their ability to be an effective voice will depend in part on whether anybody is willing to listen and to engage with them on the issues that matter to local people.

1   Department of Health Third Sector Commissioning Task Force, No Excuses. Embrace partnership now. Step towards change! (2006).

Beyond the NHS
8. Partners in Participation? involving people who use Social Care services

Frances Hasler

Health care and social care providers are increasingly working in partnership. Frances Hasler reflects on the experience of involving service users in social care, contrasting this with the experience of PPI. She shows that institutional culture can still make concrete user influence hard to achieve.

Introduction: Social Care and User Involvement

Not so many years ago, disabled people and our organisations were involved in campaigning activity with the slogan 'Nothing about us without us'. Our aim was simply to ensure that when services for disabled people were being talked about, some of the people who actually used the services should be part of the discussion. Today, the notion that people who use services should have a say in shaping them and that services should be accountable to their users has mainstream acceptance.[1]

This article examines and compares user involvement in health and social care. Both social care and health care have policies and structures to support user involvement. These currently operate in different ways. As further moves to bring social care and health care together take shape, the need to create a shared understanding of how user involvement should be achieved is growing.

Recent White Papers build on previous policy drives to plan and run health and social care services more closely, signalling an increase in the commitment to 'personalised' services and to making sure that people have real choice over the

sorts of service offered to them.[2] It is planned that the Healthcare Commission and the Commission for Social Care Inspection will merge in 2008, becoming smaller as they do so. The task of regulation will change, too. There will be explicit requirements to assess how commissioners and providers are involving their users, but there will be fewer centrally set targets to assess this. In this changing environment, how possible is it to produce viable models for involvement that work across both health and social care?

Social Care	Healthcare
Rationed (based on 'eligible' need)	Universal (based on clinical need)
Means tested	Free at point of use
Social model (changing the environment around the person)	Curative/Rehabilitative (changing the person)
Mainly long term	Mainly short term
Cash available in lieu of services (direct payments)	Cash in lieu of services not allowed
Main adult user groups relate to disability and age	Main user groups include those relating to disability and age but also many others e.g. maternity, accident and emergency

Commonalities and differences
There are some obvious links between health and social care, not least in the overlap in the population of regular users (older people, disabled people). It is clear that some functions are provided equally easily by either route. This might include day services in mental health. Working together makes sense – good social care reduces need for acute health care and good health care maintains social function.

However, there are some important differences. Social care is not a universal service: it is rationed and charged for. There are contested areas of responsibility, specifically 'continuing care'. This affects joint working and affects the relationship people have with their services.

Social care increasingly reflects the social model of disability, focusing on removing the barriers to people's social and economic participation. This approach does not always translate well under a health care model, which is about making the individual better or rehabilitated.

Within social care there is experience of user-designed, user-managed services, which can provide a model for devolving power to users. There is also more experience of user designed and user managed research than is the case in health care.[3] Current initiatives are giving individuals the capacity to purchase their own care and design their own structures of support outside the health and social care professions, a different but significant form of 'involvement'.

Traditions within patient and public involvement (PPI) differ, not least because health is a universal service, so public engagement is a stronger feature of the work. Thinking about working together on user involvement means some honest appraisal of what has been effective in the different approaches.

PPI in health is a formalised system, with specific duties and resources attached to it. In contrast, within social care, the principle of local autonomy has meant that involvement is more varied. The drivers for involvement have always included a mix of the 'top-down' and 'bottom-up'. Top-down influences include national economic concerns around healthy communities and a desire to hold the bureaucracy to account. Bottom-up influence has come from people who use services themselves and from sympathetic workers who are looking to improve the system. But there is still a long way to go before the aspirations of people who use services are matched by the actions of people who commission and provide them (see box on next page).

Some of these findings could equally well apply in health services, where most involvement is also at the lowest rungs of the involvement 'ladder'. Nor do health care users necessarily want involvement to be the price they pay for choice. And involvement can lead to better investment in health care too.

As all public services are encouraged to move to greater use of the 'third' sector (voluntary and community groups) as providers, the lessons about the potential disempowering effect of the contracting process need to be learned. And

if health and social care are working more closely, it is vital that knowledge on involving disabled and older people is widely shared.

User involvement is now common currency in social care and well understood. It rests on a long history of activism. Getting users directly involved in local service has come in and out of fashion. During the 1980s many local authorities involved disabled people very directly by co-opting seats on Social Services committees and special sub committees, funding user-led services and so on. Small

The evidence (on user involvement in social care)[4]

— Tradition of user involvement – consultation built in to 1986 Disabled Person's Act, and 1990 NHS & Community Care Act (building on long tradition of self help among disabled people).
— Majority of involvement is at lowest levels of 'ladder', information and consultation
— Work towards partnership is hampered by institutional tendency to status quo; fragile state of many user organisations; short-term investments.
— Examples of delegated power exist in independent living movement but are at constant risk (from drag back to status quo).
— Contract culture does not lead to good support for user organisations.
— Groups that feel disempowered are often tempted to fight for territory rather than co-operate for influence.
— Benefits of user involvement include far more effective investment, e.g. savings in direct payments and individualised funding models
— Users do not want involvement to be the price they have to pay for choice – it should be an option, not the only way to achieve a responsive service.
— People who are social care users are often marginalised in more general community involvement work (for example people with learning difficulties or very frail older people are often left out of general consultations and deliberative events). But good, tested models for their involvement exist.

local initiatives led to some big changes, for example a Dial a Ride scheme was started in one London borough, led by a handful of local service users. Within a few years Dial a Ride was being set up across the whole of London, with the backing of the (then) GLC.

The most obvious and far-reaching response by social care to a user-led campaign is the development of direct payments. Direct payments were developed in the UK the early 1980s by a small group of disabled people. They were championed by a small group of enlightened social services managers. The work to convince government to legislate to legalise direct payments was carried out in the early and mid 1990s by disabled people in coalition with enlightened managers and some sympathetic politicians. Within ten years, direct payments had moved from a small scale idea, used by a couple of hundred people to a government-backed policy, serving as one of the key performance indicators for social services and used by over 20,000 people.

But, as the Social Care Institute for Excellence (SCIE) research review found, this strong tradition of user involvement has not led to the far-reaching culture changes in established provider organisations. In fact, one of the things that the development of direct payments demonstrates is how little formal involvement mechanisms helped the process. Direct payments came about through a process of informal networking and relationship building. Formal involvement at the time was almost wholly focused on improving the existing service, not with transforming it. Once direct payments had become part of community care law, formal involvement processes on their implementation started to happen. Even at this stage, it was clear that there was resistance to an initiative that had come from a non-professional, grassroots background.

Equal voices
One of the repeated findings of research is how certain groups remain marginalised in wider involvement activity. There is a need to pay particular attention to people with minority communication requirements, such as British Sign Language or people with non-standard communication requirements, such as people with multiple impairments who do not communicate in words. 'Not everyone is equipped to speak up. Everyone wants to know their views are taken into account' as one user told the Commission for Social Care Implementation (CSCI) recently.[5] There are examples of successful work with such groups.[6] A

challenge is to spread knowledge of these initiatives and to start to mainstream their findings.

What this means for the future

Most people want involvement at a local or even personal level. In the new landscape of 'personalised' services, user involvement needs to include user control of the services closest to them. The experience of the disability movement is that individual choice and control has been best achieved through collective advocacy. So support for self-advocacy organisations is important. There are numerous local examples of self-advocacy organisations playing a leading role in developing new service approaches that enable the broader participation of disabled people.[7]

Example

Action Disability Kensington & Chelsea is a local organisation run by and for disabled people. They have published 'Inclusive Kensington and Chelsea' which explores the experience of disabled people in all areas of life and lifestyle choice. It is already being used in the borough as a guide for people planning services.[8]

In many such examples, the local authority has provided some of the funding for the work, and is to a greater or lesser degree a partner in it. But such partnerships are often fragile. Innovative and valued services are often lost due to lack of ongoing funds once the development money (typically from a charity or from a specific government initiative) runs out.

For those who want to influence services more widely, a number of routes to participation are needed. This includes the governance level, working on policy forums, working in inspection, training staff and getting involved in practical aspects of delivery of services.

When local services are unable or unwilling to make the changes that users want to see national policy provides a route to get things done. This is often the point at which involvement turns to campaigning. For user-led groups it is also

often the point at which their voice gets supplanted by the louder voice of large national charities, which tend to have established routes to national policy makers. Making it easier for people to link their local concerns and national policy making would help to strengthen the user movement.

Collaboration and partnership

Jane Campbell (former chair of SCIE) advocates developing the idea popularised by Demos, of user involvement as 'an exchange of equals ... where people come together bringing with them something of value, be that resources, skills, experience or ideas, and after exchange and interaction leave with something of benefit.'[9] In other words, user involvement must go beyond notions about the trade of ideas and know-how, to considerations of joint ownership and collaboration.

A fundamental starting point is working with user-led organisations – there needs to be a developmental model, enabling individuals to gain as well as share knowledge, enabling organisations to be sustainable. User-led organisations need a lot of support and investment to enable them to play an equal role in partnerships with commissioners and providers.

Example

DAD (Darlington Association on Disability) has been working with CSCI and looking at user involvement as part of the inspection process 'it was a positive experience to work with a national organisation who respected us for what we did – we had a lot of autonomy and were able to cost it fully from the start. CSCI had prepared the ground first and people and inspectors knew what was going to happen and were enthusiastic about it.'[10]

Ideally, user involvement should be supported by a framework that guarantees that local health and social care authorities will support (fund) local 'voice' as well as local user provision. This framework should also ensure that the place of user governance in user voice is recognised. That means it should, for example, support organisations that directly represent people who use services, being controlled by them, as well as organisations that represent the interests of people who use services.

One disabled activist wrote:

The … top-down approach to 'involving users' … totally ignores the one driving current within organisations in the voluntary sector that makes it distinctive and indispensable … Our organisations identify needs where they arise. Nearly always, they are needs for change in relationships, and they arise from experience of exclusion, disempowerment, or oppression. Solutions, therefore, cannot only be in terms of 'service'; they also must be in terms of rights.[11]

Challenges and opportunities

1 Developing mechanisms for culture shift

This can be achieved, for example, by ensuring user involvement in leadership positions. While this on its own will not secure change, it is an important building block. Research on service users in governance positions in arms-length bodies showed that there needed to be a critical mass of user representation in order for culture change to take place. One or two users cannot exert sufficient influence, but three or four could start to have a real impact.

Once involvement moves beyond the token, it starts to make demands on organisations. Senior managers need to be willing to champion the user viewpoint, so that demands can be responded to positively.

2 Mainstreaming interests of social care users (such as older people, disabled people, looked after children) in health service involvement

This means doing public involvement differently and planning for inclusion from the outset. As one civil servant has observed: *User participation is not another task to do: this is the task we should be doing.*[12]

The Department of Health has had success using deliberative events to involve members of the public in thinking about NHS plans. (This includes the recent consultation on 'Our health our care our say'). Yet the people for whom social care is most important are almost always excluded from this sort of consultation. People with learning difficulties or older people living in residential care are unlikely to be able to take part in large scale public events, even if the contact methods used manage to reach them in the first place. However, by not designing their participation in to the process at the beginning, they are relegated to

the status of 'special' or 'other', not counted as part of the general public. It is essential that engagement methods develop in fully inclusive ways.

3 Facing forwards

Turning the opportunities offered in the current policy framework into tangible benefits for people who use services is possible but challenging.

4 Sustaining and developing the user movement

Involvement will not achieve its aims unless some space is created for the work of imagining a different future and new ways of delivering services. Organisations run by and for people who use services are vital resources in this. Funding their infrastructure is important, but not enough. Service commissioners and policy makers must also start to work collaboratively, providing opportunities for user-led organisations to develop their own knowledge and increase their skills.

5 Working inclusively

Organisations need positive policies on outreach and communication. Inclusion is about removing physical barriers. Making sure meeting spaces have induction loops or are near bus routes is a good example of this. It is also about removing attitudinal barriers: we must stop seeing people who are not like us as 'hard to reach' or assuming that older people will not want to try new things. It is, crucially, about removing institutional barriers, because formal processes can block involvement very effectively.

Example

SCIE set up a body called Partners Council a few years ago, consisting of a group of about 45 people from all sort of organisations. At first, the expectation was that it would be the service users who would have difficulty taking part in discussions, but in fact the people who had difficulty were the representatives from managerial and official bodies who weren't used to talking on equal terms with people using services.[13]

6 Multiple methods of engagement

People who use services may want to engage in different ways at different times, sometimes via a survey, sometimes via a seat on the board. Some people can only engage if their particular access needs are met. Multi-media facilitation at meetings is a good example of this.

7 Commitment

Work on service change and improvement must be collaborative. The involvement of users must start from the belief that they have as much expertise to contribute as any other participant in the process. Their involvement needs to be supported in ways that let them demonstrate this expertise. In practical terms, this means things like providing planning information in accessible ways. In process terms, it means involving people who use services at a sufficiently early stage that their input can make a real difference, including whole scale redesign if required.

Conclusion

This article has outlined some lessons and experiences from the social care field which are useful for developing involvement in healthcare more widely. The knowledge on how to involve people is there. People who use services have knowledge and problem solving ability. Modest investments in enabling them to apply that knowledge could pay dividends for services. What is needed is the will to make it a reality.

1   David Miliband, from a speech given at the Guardian annual public services summit.

2   Department of Health, Our Health, Our care, Our Say (2006); Department for Communities and
    Local Government, Strong and Prosperous Communities (2006).

3   The Joseph Rowntree Foundation has supported a wide range of user-managed research, see
    www.jrf.org.uk

4   Sarah Carr, Has service user participation made a difference to social care services? (SCIE, 2004).

5   CSCI, Real Voices, Real Choices (2006).

6   Joseph Rowntree Foundation, From Outset to Outcomes (2002).

7   See the work of adkc and wecil.

8   www.adkc.org.uk, (Accessed 28.10.06).

9   P. Miller, S. Parker & S. Gillinson, Disablism: how to tackle the last prejudice (London: Demos, 2004)

10 JPSG Partnerships for Participation in Miller, Parker & Gillinson (2004)

11   www.dcil.org.uk (Accessed 28.10.06).

12   Quoted in F. Hasler, Users at the Heart: User participation in the governance and operations of social care regulatory bodies (London:

13   Social Care Institute for Excellence, 2003).

14   JPSG Partnerships for Participation.

Involvement in Primary Care
9. Patient and Public Involvement and Practice-Based Commissioning

Brian Fisher

In the past many of the most important decisions in the NHS have not been informed by opportunities for patient and public involvement. This has been a particular problem with how resources are spent. Brian Fisher argues that new reforms offer a real opportunity for communities to shape their local health services.

Introduction: the NHS and accountability

At present the NHS is not accountable to its users or to the public. Evidence suggests that recommendations by local people can improve the style and quality of health services.[1] And most NHS organisations have developed mechanisms for hearing the views of local people in specific aspects of care. But these mechanisms are not systematised and often they are not very effective.[2] The process of commissioning, where much of the real power in the NHS lies, has been largely untouched by public involvement.

Section 11 of the Health and Social Care Act 2001 ensures that NHS organisations seek out local views, with no guarantee that those views will be acted on.[3] Although Foundation Trusts offer an approach to accountability through their members, there are no similar structures in primary care or in non-Foundation trusts. However, this may be about to change. The current reorganisation of the NHS offers significant opportunities for locality-based Patient and Public Involvement (PPI).[4]

The old system

Commissioning is a process which underpins how the NHS develops services. If local users and the public were to influence commissioning it would make a significant difference to care. Commissioning involves a number of steps, which seem deceptively simple on paper:

— Identifying the needs of the local community across a range of criteria. This might include understanding the prevalence of disease, such as a high rate of sickle cell disease.
— Identifying what interventions are needed to make good deficiencies, or improve services.
— Identifying the resources needed. These might include people, money or machines.
— Contracting is the process whereby resources are put in place. This is distinct from commissioning.
— Monitoring and evaluation ensuring that decisions are acted upon.

This is rarely the logical and straightforward process it appears to be, because Interpersonal, political and financial issues frequently interfere.

Until April 2006 money would arrive at the Primary Care Trust (PCT) from the Department of Health (DH). The PCTs would commission services from their local hospitals, as well as providing community services such as district nurses and health visitors. PCTs tended to buy blocks of work from hospitals, for instance, 1000 hip replacements a year. This helped planning but was inflexible and unresponsive to short term changes in patient need. The PCTs' priorities were largely determined by central targets, most of which were clinically relevant and evidence based. However, the main target, a reduction in waiting times, was a response to very clear national user dissatisfaction, based on many surveys.

Changes driven by the PCTs have yielded examples of excellent work across primary and secondary care. These include reductions in waiting times, open-access investigations and better pathways of care.[5] But these changes are sometimes resisted by hospitals. PCTs have often struggled to deal with the power of the hospitals to continue diverting resources from primary care and their unwillingness to work differently. The system of commissioning has been deemed by the DH to be underperforming due to limited radical change in hospital services, inefficiencies in the system and little responsiveness to patient flows.

Involvement was exercised through PPI Forums, small groups of lay people in each PCT and hospital, supported by a national organisation.[6] However, they were not seen as effective either, although there have been excellent examples of involvement.[7] The best initiatives have been proactive, reaching out to local people in innovative ways and engaging many levels of the PCT.

The new commissioning system
New commissioning arrangements aim to create a constant drive to efficiency, without a reliance on central targets. The two key drivers are:

1 Payment by Results (PbR)
Since April 2006, every hospital gets paid a nationally agreed sum or tariff for each procedure it performs. Examples of this might be a hip replacement or outpatient appointments, emergency appointments and operations. Because the tariff is the same for each procedure across every hospital, it is not possible for hospitals to compete on price. The system encourages competition on efficiency and quality. There is thus an incentive for hospitals to do as much as possible. If this activity costs the hospital less than the tariff the hospital will make a profit.

2 Practice-based Commissioning (PBC)
From April 2006, each individual practice, or groups of practices has been given a budget with which to buy care for their patients. The budget is based on historical spend on hospital referrals. If practices generate savings by either doing fewer referrals, or by referring patients to cheaper services, often in a community setting, those savings can be used for improved patient care. For instance, if patients with osteoarthritis of the hips are referred to exercise classes rather than operations, the savings could be used to buy more physios based in the community (see box on next page).

The new process offers a number of advantages. Pathways of care will be designed by clinicians who know their patients and the local clinicians in primary and secondary care rather than by commissioners at the PCT level. With the current restructuring and enlarging of PCTs this local knowledge is very important. While PbR encourages hospitals to lure as many patients through their doors as possible, PBC supports GPs in keeping people out of hospital. This tension may be productive, or it may undermine planning and good relationships. The future will tell.
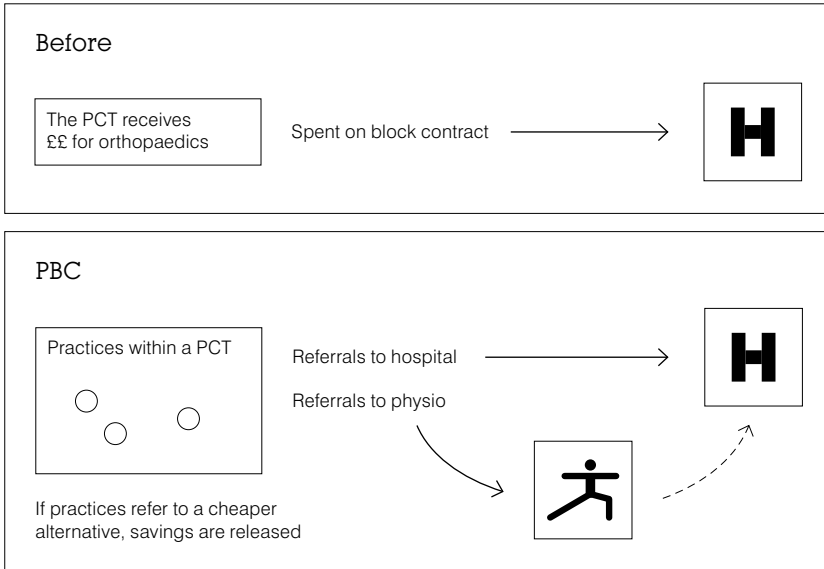
3 Patient choice

The third element that makes the system work is patient choice. Choice is currently exercised at the point of referral, when patients can choose their hospital. They can be given information to help them make the choice, including comparative data such as parking, star ratings or MRSA rates. In reality, there may be few choices in rural areas. Patients are more likely to choose hospitals with good outcomes and good patient-centred services. In this way market forces are introduced into the system.

4 Patient and Public Involvement

Currently, there is no formal mechanism for patient or public influence over the general development of services in PBC. Commissioning practices may decide that most diabetics should be cared for outside hospitals. Although this may be a sound decision, there may have been no discussion with local people at all. The same is true of non-Foundation Trust hospitals – they can make investment (or dis-investment) decisions with little recourse to local people. While PBC and PPI are often mentioned together they are distinct.

Foundation Hospitals have a mechanism by which patients and staff can influence decisions. There is debate over its effectiveness, but it is an important and interesting model which could be exported, with improvements, to PCTs.

5 The difference between PPI and Choice

As they are currently construed, Choice and PPI are different. The Department of Health perceives Choice as an individual's ability to get what he or she wants from the system. At present this mainly consists of referral, but will involve management of care in future. PPI is a more holistic and collective approach: the local population as well as individuals and the public as well as patients offer recommendations for good practice that affect and influence the delivery of care for all. Choice is subsumed within PPI. It is, however, still urgent to ensure that PPI is integrated into decision making within the new NHS in such a way that local recommendations are heard, debated and responded to.

It should be added that the notion of failure in the current system is not universally recognised by NHS workers. Many consider that more time would have allowed the system to realise more benefits. To some, the new system is ideologically driven and does not offer a practical solution to the need for continuous improvement.

Practice Based Commissioning and PPI

PBC offers an opportunity for GP practices, Primary Care Trusts and local people to work together to develop more appropriate pathway-based care and more efficient services. However, despite a general feeling that users should be involved, views of local communities are rarely taken on board with PBC.

Surveys of PCTs suggest that some practices are experiencing barriers to involving patients in the early phases of PBC, despite adequate mechanisms. In March 2006, 299 responses were received to a survey of PCTs. Of these, 172 reported active PBC. Seven out of ten PCTs said that PPI can have a positive impact on PBC and that they have good mechanisms for engagement. Yet just 29% of those who already have active PBC in their areas said they have moderately or well functioning PPI in PBC. [8]

The same survey of health professionals and the public demonstrates that, although there is an increasing amount of involvement and a positive approach by professionals, the actual experience of patients seems to be poor:

— Most (93%) health professionals say that ordinary people should have a say in how their local health service is run and feel that involving patients would improve services.
— 74% of the public want to have a say in how their surgery is run. However,
— 50% think that ordinary people can't influence their local health service.
— 76% have never been asked for their views.
— 68% of people do not know how to feed in their views.

Tensions in commissioning and PPI: Can LINks help?

This section tries to describe the tensions within the concept and practice of PPI, both in general and in relation to PBC. It then examines whether the new system of LINks addresses these difficulties.

General tensions:
— The NHS has become much better at listening to local people but remains poor at responding to their views.[9] The main task for PPI structures and processes is now to ensure that the NHS seeks out and responds to local need as it is defined by professionals and local people.
— NHS management and clinicians are frightened of PPI. One common fear is that 'the floodgates will open'. In other words, it is feared that once local people's opinion is sought, there will be a torrent of expensive demands, impossible to fulfil. Yet experience shows the opposite: most requests are modest and usually focus on change of attitude rather than increasing costly services or facilities.
— There is a fear that local people will demand ineffective and inappropriate things. There can be a clash of different cultures of evidence.
— PPI and the new structures shift the risk towards the NHS, away from the patient. Payment by Results, Choice and PBC mean that NHS organisations feel a whiff of market forces. A rebalance here is long overdue.
— The NHS has relatively inflexible management with little experience or inclination for the shifts in focus and approach demanded by effective PPI.
— In essence, however, no-one wants to share power. So, to make PPI work, policy has inclined towards formal structures and processes that often act as a brake on developments. These can include scrutiny functions held by

Community Health Councils, Overview and Scrutiny Committees and Patient and Public Involvement Forums, all of which need to be consulted about significant changes in the system.

Tensions at practice level:
— Clinicians in general and GPs in particular have not had a culture of involving patients in non-clinical decisions. In some respects, PPI is analogous to involving patients in consultations, but writ larger. Practices, like the rest of the NHS, are learning fast, but there is still a long way to go.
— GP practices which are small profit-making concerns have become more engaged with Choice and feedback from patients in the last couple of years. Practices earn money for carrying out standard surveys of their patients and responding to the results. Referrals are increasingly made through Choose and Book, where Choice is a key aspect.

New plans for PPI involve Local Involvement Networks (LINks). These are existing voluntary agencies that will be funded to offer proactive involvement across health and social care organisations, gathering information, and passing it to PCTs and Overview and Scrutiny Committees. There will be a new duty placed on commissioners to respond to patients and the public.[10]

What structures and processes could support PPI in the work with PBC?
The key challenge is to provide engagement without exhaustion, developing effective PPI without interfering excessively in the daily life of practices who continue functioning under an increasingly workload. This section of the article offers suggestions that build on kind of current PCT experience demonstrated in the NHS Alliance Acorn awards.[11]

1 Working with community development workers (CDWs)
One approach is to work with existing community development workers or Health Trainers to gather local views on behalf of cluster or practice. The PCT and the local authority may already have funded such workers. Community development workers perform outreach work, identifying the key health issues perceived by local people. They work with health organisations to discuss implementing their recommendations.[12]

In one arrangement, a community development worker is attached to each GP commissioning cluster, brokering a dialogue between local people, community groups and practices (see box below). The community development workers, with voluntary agencies, are represented on PBC groups as advisors and participants, helping to draw users into relevant sub-groups where needed. An excellent example of such a community development in action can be seen in the Lewisham Community Development Partnership.[13]

CD workers in each locality

A community development presence in each locality

4 PBC localities
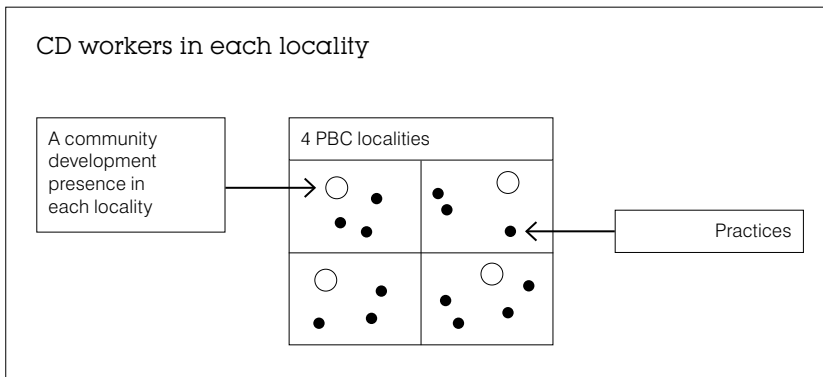
Practices

Such arrangements can foster improvements in provision of care without exhausting either practices or the public.

2 Patient participation groups / Critical Friends
Patient participation or patient critical friends groups can be attached to each practice.[14] For clusters, there would be a democratic forum composed of representatives from all the individual practice groups.

3 Citizens' juries
When specific questions need answering, such as establishing a policy on classified drug use, a Citizens' Jury can be employed. Here, a small group of people are picked to represent, so far as possible, the local community. They are given background information about the topic and then call witnesses to discuss the issue with them. Their conclusions are frequently accepted by the organisation that paid the considerable cost of organising the process.[15]

4 A not-for-profit organisation

Practices can band together in a formal structure similar to a company with a Board that includes patient representatives. This would have an outer shell of members who offer a more representative approach, along the lines of a hospital Foundation Trust.

The issue of representativeness

It is often objected that those involved in a PPI initiative are not representative, and therefore their views can be ignored. This has been a key argument in the debates leading up to the abolishment of first the Community Health Centres (CHCs) and now the Commission for Patient and Public Involvement in Health (CPPIH).

However, this argument however rings: finding a cross section of local representatives is well nigh impossible. There is a similar problem with the representativeness of professionals involved. Clinicians are often represented by the same people who are frequently unrepresentative of the wider clinical body.

A study of users involved in social services work showed different approaches to the issue of representation. Most said they did not see themselves as representative. All said they brought a user perspective to the role. Some stressed that they were more than a user.[16] And yet, despite the intractability of this problem, there are ways of mitigating it. We could:

— Consider users not as representatives but as 'patient involvement advisors', asking key questions and ensuring appropriate responses to local people.
— Work with an existing local voluntary group and encouraging them to consult with a wider population.
— Look at the literature on the field in question.
— Harness PCTs' existing mechanisms for engagement.

Issues for consultation

Here are some key issues that commissioning practices or clusters should discuss with their populations:

— The pathways or issues to be prioritised by the PBC group.
— How patients perceive the relative convenience or problems of existing services.
— Whether local people can provide comment on the design of new

approaches and developing new approaches that the group has not thought of before.
— How to spend the savings. If there are net savings these will be owned by the practice/practices However, a decision will be needed as to where the funds are applied, essentially an ethical choice underpinned by data on effectiveness and equity.
— How to guarantee and measure quality. Patients can be involved in developing standards for practices and others.[17]

Conclusion

Commissioning is central to the way in which the NHS operates. Commissioning decisions lead to real change in services and health outcomes. In the past PPI has tended to shy away from this area, which is seen as complicated and too specialised for public involvement. However, the new system of PBC provides a real opportunity to open up the commissioning process to wider influence and create better health outcomes. It can build patient centred care pathways, empower local communities and create a more efficient health service. These are high stakes.

There is an opportunity here for real double-devolution, one that will shift power from the centre to local practices and share this with local people. And yet there is still a real risk that NHS shrinkage driven by financial stringencies will over-ride any proactive PPI developments. The use of PPI within PBC won't necessarily happen on its own and there are many challenges involved, but there are already good examples out there as inspiration.

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Involvement in Primary Care
10. Public and Patient Participation in Primary Care: A Golden Age?

By Graham Box

Graham Box reflects on 30 years of patient participation groups and argues that, while they are sometimes overlooked, recent reforms make practice level groups more relevant than ever.

Introduction: The 'Golden Age' conviction

In May 2006, the Nuffield Trust hosted a seminar in which one speaker concluded that we are now entering a 'golden age' for patient participation in primary care. He argued that professionals and policy-makers have never been more open to the idea that patients should have a greater say in their treatment and in how services are provided. But others voiced concerns about continuing paternalism, poor communication and a culture that resists fundamental sharing of power and influence with patients.

This article explores the 'golden age' conviction, offering historical context and providing insights into current policy and best practice. But rather than addressing the statutory structures that are typically the centre of debate, its focus is on primary care and on the role that can be played by patient participation groups (PPGs) in GP surgeries. These PPGs are based upon relationship building, engagement and goodwill rather than formal powers to monitor, inspect and hold to account.

PPGs are far from new. Indeed they have been around for four decades now. They have had to adjust to numerous structural changes within the NHS and there are good reasons to believe that they can also dovetail effectively with con-

temporary structures and policies. In particular, PPGs can make an important contribution to practice based commissioning, health promotion initiatives and the proposed new structures for patient and public involvement in health.

A short history of patient participation[1]
The very first practice-based patient participation group was established by Dr Peter Pritchard in his Berinsfield practice, south of Oxford, in 1972. He believed that he could improve the quality of service provided by inviting some patients, who were also involved in local community groups, to offer their ideas and suggestions. Shortly afterwards, a groups was formed in Aberdare, based on the perception that patients have a 'right to a say' in the way that their GP practice is run. Another was formed in Bristol, inspired by the observation that well-run organisations depend upon regular feedback from their clients.

The National Association for Patient Participation grew out of these groups and by 1988 had established itself as a registered charity with 90 members and regional structures. The profession largely greeted these developments with suspicion and scepticism. In 1981, World Medicine claimed that 'PPGs by definition are likely to attract the more volatile and extrovert…complainers and neurotics'. A Lancet editorial from the same year remarked that 'to many practitioners, few innovations [PPGs] can ever have seemed so threatening.' In 1983, the British Medical Association stated that 'in most parts of the country the relationship between practitioner and patient is extremely good. In these cases there is little or nothing that this type of activity can add.'

Current activities
The early PPGs were formed for a number of different reasons, as mentioned above, and these varying motivations continue today. As a result, every PPG is different, evolving to meet local needs.

All of them, however, should involve a partnership between the practice and its patients, overcoming the feelings of 'them and us' that sometimes characterise the life of a GP surgery. And they should be set up in a way that can make a real difference to the patient experience and to the health of the local community. In other words, the PPG should be at the heart, rather than the periphery, of the practice.

The services provided by PPGs take many forms:
— Some PPGs play a role similar to that of the Board of Governors of a school, ensuring that the views of the local community are conveyed to the practice, participating in away days, helping to recruit staff and generally offering strategic input. However, final decision making powers still remain with the practice.
— Health promotion events organised by PPGs convey key messages to large numbers of patients that enable them to understand and manage their condition more successfully. They are often extremely well attended and can be targeted to suit the needs of particular communities, particularly those with long-term conditions.
— PPGs often provide information through newsletters, websites and information resource centres. These resource centres allow patients to visit a volunteer immediately after seeing a clinician and take away materials that will enable them to learn more about their condition.
— Other roles for PPGs include providing volunteer transport, carers groups, bereavement support, citizens' advice, prescription delivery and other services. The benefits include an improved patient experience and a reduction in unnecessary visits to see the GP.

A Golden Age?
There is no doubt that PPGs are slowly becoming more mainstream. In November 2006, the National Association for Patient Participation had 270 affiliated patient participation groups and we estimate that roughly one in five practices now has a group of some sort. Their value has been recognised by their inclusion within the new GP contract which rewards practices who discuss the findings of their patient survey with a patient group. Although in some cases this is not much of an incentive, since the same financial gains can be secured by putting up posters in the waiting area!

Yet the reservations, even hostility, expressed in the 1980's have not altogether disappeared. A survey of 1800 practices by the National Association for Patient Participation (N.A.P.P.) generated nearly 500 responses. From this, N.A.P.P. learnt that 46% of practices without a PPG 'mainly or strongly agree' with the proposition that patient groups are a forum for moaners. The comparable figure for practices with a PPG was just 13% (using sample sizes of 351 and 131 respectively).

Apart from the fear of attracting the 'wrong kind' of patients, practices that took part in the survey were also deterred from setting up a group by concerns about the time that it would take (a kind of 'change fatigue') and a belief that they are already very close to their patients. It is important to note that practices were also pretty sceptical about the public involvement activities of their Primary Care Trusts (PCTs). 60% of responding practices considered the public involvement work of their PCT to be either a waste of time and money or to have had very limited impact. Interestingly, the figure for those without a PPG was 67%, while it was just 39% for practices with a PPG.

A model for the future
Primary care should be the most fertile setting for patient participation, since it generates strong links between patients and their practices, based upon a relationship that often spans decades and generations. Although now under threat from changing ownership and other structures, continuity of care has created strong feelings of loyalty towards the local GP surgery. Moreover, 15% of the entire population sees a GP in any two-week period and 90% of patients with chronic conditions will never be referred by a GP to hospital.[2]

So, there is a familiarity between patients and their practices that makes the partnership model of patient participation groups achievable. With strong links to existing community organisations, these groups can provide valuable channels of communication to and from the practice. They can also deliver the services and undertake the health promotion work described earlier. This role becomes increasingly important given the shift of emphasis from hospital to community care.

The value and relevance of patient participation groups is further enhanced by the introduction of practice-based commissioning. This will see practices, often working on a locality basis, taking decisions about how services should be provided to their patients. Inevitably, this will require some prioritisation and, as a result, will lead to some groups of patients winning and some losing out. Equally, the process should generate some savings to be reinvested in services.

Although professionals are well placed to undertake the technical analysis (with public health input an essential component), they should not assume that they

know what matters most to patients. Patients need to be a central part of the decision making structures and PPGs have a clear role to play, whether operating at practice level or nominating representatives to sit on locality-based commissioning committees. As a result, decisions should be more balanced and should also have greater legitimacy.

Patients will need targeted education to play their full part in this process. Regrettably, training on practice-based commissioning has to date been aimed almost exclusively at professionals and this needs to change. Equally, PPGs need to be supported so that they can take soundings from the wider community when necessary. This may be as simple as talking to patients as they wait for their appointments or it could require more complex techniques such as establishing virtual networks of consultees or helping to design specific surveys.

This structure, with a well-informed PPG in every practice, would also be a valuable asset for other organisations. In particular, the Government is proposing that Local Involvement Networks (LINks) should be created to provide a flexible way for local communities to engage with health and social care organisations.[3] By forging relationships with existing PPGs, the LINks will have ready access to a source of intelligence and a mechanism for communication with (depending on the prevalence of PPGs in the area) a significant number of local people.

PPGs sit particularly well with the LINk model since the best PPGs already have very strong links into their communities, with some of them recruiting by inviting representatives from key local organisations. The LINks will be able to encourage networking across PPGs (an area in which N.A.P.P. is already active) and will be in a stronger position to influence health and social care services as a result of the partnerships that they establish with PPGs.

PCTs could also bring the PPGs together in a network (or series of networks) to help address the worry that PCTs will become more remote as they become larger. This will help PCTs to gain a clearer picture of the patient experience within primary care that is far richer than the current focus on national priorities. It also allows the Trusts to communicate with their community and be closer to them. This was, after all, one of the driving motivations behind the decision to establish PCTs in the first place.

Some challenges

The patient experience component within the Quality Outcomes Framework of the General Medical Services contract for general practice is now in its third year. It provides substantial rewards to practices, largely for carrying out an annual survey and developing an action plan to deliver improvements. It also provides financial incentives for practices to discuss their action plans with patient participation groups. This is welcome and there is every indication that it is leading to the formation of more groups. But more is not necessarily better. There is a real concern that patient participation groups formed on this basis are largely tokenistic. It is feared that their role is tightly limited around commenting on the findings of the patient survey.

To be fully effective, PPGs should meet the following conditions:

— They require a genuine commitment from the practice to engage with their patients in a different way. The practice needs to be open to the views of patients, willing to countenance doing things differently, and interested in what patients have to offer.

— The objectives of the PPG need to be clear and regularly reviewed. These should be agreed between the practice and the patients, and should make a real impact on the health and well being of the community that is served by the practice.

— The PPG needs to be appropriately constituted for the role that it plays. Like so many organisations, PPGs find it difficult to attract members that reflect the diversity of their population. Strategic input requires that the group is representative of the practice population, or at least that it has mechanisms by which it can tap into wider views. A broad membership base is less important if the focus of the PPG is in other areas such as health promotion or service delivery.

— There needs to be good leadership both from within the practice and of the patient participation group itself. This may require a greater investment in training and development of both professional staff and patients.

We should also acknowledge that many PPGs fail to realise their true potential. Some patients remain too deferential for the PPG to make any significant contribution and some PPGs never really take off because of insufficient commitment from the practice or patients. There are no guarantees at the outset that a new PPG will succeed and it has to be worked at, like any relationship.

Conclusions

It is critical that patients and the public generally are more involved in health and social care. The Wanless report, for example, argued that an annual saving of £30 billion could be achieved by 2022 if we could move to a scenario in which patients are 'fully engaged'.[4] This will require that individuals engage in their health in a far more meaningful way than at present, with more self-care, better health promotion and major improvements in the availability of health information. Yet patient and public involvement remains on the margins at many organisations, seen as the responsibility of an individual or department, rather than as a shared commitment.

In primary care specifically, there remain tensions with respect to patient and public involvement. GPs who see themselves as running small businesses are not always willing to work openly with their patients. Managers may resent what they come to see as just another requirement and yet more work. And patients are losing faith that they can make a difference when the outcomes of major consultations, such as the recent restructuring of PCTs, seem to be driven from the centre.

Nonetheless, with the growth in PPGs and other initiatives such as the expert patient programme and the recognition of carers within the new GP contract, the age of public and patient involvement in primary care is more golden than bronze. With the help of PPGs, general practice needs to continue to move in the direction of empowering patients to care for their own health as well as the health of their communities by building on its traditions as the patients' advocate. Success in this area will then provide a strong foundation from which other patient and public involvement activities can flourish.

— See, Sir Denis Pereira Gray, A Dozen Facts About General Practice (unpublished, 2004).
— Department of Health, A Stronger Local Voice (2006).
— Derek Wanless, Securing our future health: taking a long-term view, (HM Treasury, 2002) 11. Foundation Trust and Public and Patient Involvement

New Innovations
11. Foundation Trusts and Patient and Public Involvement

By Sue Slipman

Foundation Trusts represent one of the most dramatic NHS innovations of recent times. Sue Slipman considers whether the new arrangements have helped NHS Trusts become closer and more responsive to their local communities.

Introduction: What are Foundation Trusts?

Foundation Trusts are a new model for health care organisations in the UK. They are public benefit corporations, which place public, patient and stakeholder involvement at the heart of their governance. Foundation trusts are independent organisations operating within the NHS to improve health outcomes for patients and local communities. Once an aspiring foundation trust passes the very demanding authorisation process, proving that it can govern itself and manage its finances, it ceases to be under the command of the Secretary of State for Health. It is no longer performance managed by NHS authorities.

Foundation trusts continue to provide services within the NHS and agree legally binding contracts with service commissioners. And they are still regulated: the regulator intervenes in proportion to the risks the foundation trust faces in all aspects of its governance, including clinical risk and to its finances. Foundation trusts have greater freedoms to borrow than other NHS Trusts and can make surpluses from operations. But, unlike private sector bodies, any surplus is not distributed to shareholders, but reinvested in health improvements for public benefit.

The structure of Foundation Trusts

The majority of foundation trusts are acute hospitals in England, but they are rapidly being joined by mental health trusts. The government now plans to extend the Foundation Trust model to enable other kinds of providers to participate. This includes the third sector and social entrepreneurs that are capable of meeting the rigorous financial and governance criteria to become foundation trusts.

But foundation trusts are about more than just financial and administrative independence. They do not simply perform as fully independent organisations, with all the financial and risk liabilities this implies: foundation trusts are also mutual organisations, with a membership base that elects governors to bodies that operate alongside and inter-act with the boards to ensure true dialogue between the separate parts of its overall governance structures. There are now 35 foundation trusts, with more in the pipeline. These already authorised trusts have over half a million members between them. Their members are recruited from different constituencies, including patients, public and staff. Each of these constituencies elects a number of governors. In addition, there are a number of appointed governors who may be from local government, from commissioners in the health service or from other vital stakeholders in the local community, such as the voluntary sector. This local accountability replaces the previous command of central government. Some of the tasks of community representation that used to be fulfilled by non-executive representation on the board of NHS Trusts, now devolve to the boards of governors.

This new model of governance is a huge challenge but it has the potential to help foundation trusts to be locally-owned organisations driven by local priorities, responsive to local needs. As a result, it aims to deliver better patient care, involving patients, the public and their own staff. Foundation trusts have a duty to consult and involve the board of governors in their strategic planning. In addition the governors appoint the Chair of the foundation trust (who also chairs the board of governors) and the non-executive governors and approve their remuneration. This gives the governors a significant role in the governance of the organisation as a whole.

When the legislation to create foundation trusts was making its way through the parliamentary process, there were severe worries that their advent was about

privatisation and heralded the death of the NHS. Two years on most of these concerns have faded. It is clear that most foundation trusts are enthusiastically embracing their wider governance structures and view their members and governors as a great asset in improving their services and making themselves more accountable to the communities that they serve. This is not exactly what their critics envisaged. This commitment is being strengthened by the authorisation of mental health trusts who have a strong tradition of user engagement in their services.

According to Monitor, 500,000 people are now members of their local foundation trust. In the first set of elections for the first 32 foundation trusts, the overall turnout of members voting to elect their representatives to the board of governors was 36%, which represents patient and public involvement on a massive scale.[1] The fact that this percentage of 36% is comfortably higher than the number of people who typically vote in local council elections was clearly an encouraging early sign of the enthusiasm of members have to feel involved in their foundation trust.

Foundation Trusts and opportunities for increased involvement

There are numerous examples of foundation trusts that are using their new governance model to ensure that the new opportunities for patient, public and staff involvement are fully exploited.[2]

The increase in hospital-acquired infections such as MRSA is a cause of concern to patients and the wider public and one issue for debate has been the possible impact of visitors coming into clinical areas. Chesterfield Royal Hospital NHS Foundation Trust chose to consult its entire membership of 10,000 people for their views on establishing shorter visiting hours and restricting the number of visitors per patient. An impressive 4,000 members responded to the consultation and 94% agreed that visiting hours should be reduced, so the Trust will use these results to implement revised visiting hours. This is clearly a big issue that would have been highly controversial had any hospital imposed this upon patients and their families without a major public debate taking place in which the clinical reasons for a change of direction could be properly understood. Since then, other foundation trusts have undertaken similar exercises in asking the members what they want on critical issues of hospital policy.

Equally, foundation trusts must demonstrate that their governors, elected by patient, public and staff members to bring their interests and views into the very heart of the organisation's governance, have the opportunity to do just that. Again, at Chesterfield Royal Hospital NHS Foundation Trust, public governors are fully involved in how the Trust spends more than £9 million of capital investment. They are helping to shape developments from the drawing board – and it's not just lip service. An outpatient project is now being re-evaluated after governors raised concerns over a potential location for the new facility.

Homerton University Hospital NHS Foundation Trust in east London manages its own membership database and can map that membership against both ethnic groups and illness patterns in Hackney. In addition, Homerton has set up members' forums, led by governors, on issues like hospital hygiene so that governors hear the views of their members in a structured and meaningful way. This has now been adopted by a large number of foundation trusts.

Models for Foundation Trusts
The foundation trust network runs seminar and conferences to help foundation trust learn from emerging good practice and to help aspirant trusts learn from the experience of those who went before so that the pace of change and public and patient involvement can be quickened

There is, however, no single, standard model. There are many different types, shapes and sizes of foundation trusts, from the big teaching hospitals to the small district general hospital; from the highly specialist tertiary centre dealing with the most complex of treatments to the mental health trusts running services throughout the community in partnership with other agencies. One model would not be fit for purpose across such diversity. But it is inevitable that members of the boards of governors will share some functions right across the foundation trust model.

Enabling patient, public and staff governors to play a representative function inside the foundation trust requires a lot of support and development. Many of the issues with which the organisations are dealing are complex and require knowledge of the healthcare system. Some organisations are the size of FTSE 250 companies with turnovers that run to several hundred million pounds. All of them are now operating in a completely new environment. There have been

problems for governors in understanding their roles. Whilst they have the formal powers described above, a key task for governors is to feed into the board discussions, so that corporate boards are able to listen carefully to stakeholder view when making strategic decisions. There has been some confusion over the differences between the governor and the corporate board role. However, those foundation trusts which have been authorised for some time report that this settles down over time. All foundation trusts have invested funds into governor training and enabling governors to feed into technical discussions on business planning and key investment decisions.

The board of governors in each foundation trust is new and needs to grow into its role. However, the board is also making a huge transition from acting as a sounding board in the old NHS model, to executing a real corporate strategic function in the foundation trust model. The board needs to hear clearly and understand what the governors think and the governors need to be clear about what can realistically change as a result of their contribution. Much of the success in making these relationships work rests on the shoulders of the chairs.

Membership of Foundation Trusts

Finally, the members and governors of foundation trusts are people who have a general interest in and have chosen to become involved in health matters. They have joined the foundation trust because they have an emotional commitment to their hospital and because they also have a lot to contribute to wider discussions of health and care in local communities.

It has been argued that such a membership and governance structure should have been attached to the strategic centres of decision making about health in local communities, the Primary Care Trusts (PCTs). But the problem is that few people have enough emotional attachment to the PCT to become a member. It will, however, be important that PCTs hear the public and patient voice in framing commissioning strategies. The Local Involvement Networks (LINks) organisations should make a big contribution to this. They need to be built strongly upon existing organisations that understand health and care needs in local communities. This seems like a more viable strategy than extending the foundation trust model to PCTs.

The membership base and governors' and members' councils of foundation trusts must become a key part of the resource that the LINks represent for improving health and care. The Foundation Trust Network believes that the people mobilised through their membership of foundation trusts should be encouraged to participate in the LINks to influence the way in which health and care is commissioned and delivered so that it meets their needs.

Conclusion

The fears voiced when foundation trusts were set up have been shown to be unfounded. The foundation trust model is an innovative and successful way of bringing NHS trusts closer to their communities. It should play a key role in the involvement infrastructure of the future.

1   Monitor is the non-departmental public body which authorises and regulates NHS
     foundation trusts.
2   The Foundation Trust Network New Voices, New Accountabilities (2005).

New Innovations
12. Creating Reputations: involvement beyond exit and louder than voice

Paul Hodgkin

The Internet has revolutionised the way we relate to music, shopping and the media. Paul Hodgkin argues that it is high time that it also changed and improved the flow of communication between the NHS and its users.

Introduction: The eBay Example

In 2003 10 million trades were made on ebay.uk. At that time fewer than 100 were fraudulent.[1] What was it that kept the other 9,999,900 honest? The answer lies almost entirely in the reputation system employed by eBay where each buyer rates each seller on a three-point scale of +1, zero or -1. The history of all previous trades made by an individual constitutes their on-line reputation. Get any significant number of minus scores and you're dead meat so far as other traders on eBay are concerned.

This is a surprising phenomenon as mainstream theory suggests that most services are policed by two processes:
— Exit: where people choose to leave a provider and this in turn creates pressure for improvement.
— Voice: where people suggest, complain or campaign for improvements directly with the provider.[2]

Although eBay does have 'voice' procedures in the form of complaints and appeals, voice plays little part overall in keeping the system efficient or honest. Equally there seems to be little demand for 'exit': eBay keeps on growing as its competitors drop by the wayside.

So here is a massive new business in which neither exit nor voice – the classic vehicles by which citizens exert their influence on both state and commerce – play much part. The new kid on the block is a resurgent, automated and highly visible system of reputations.[3]

Reputation, exit and voice

Reputations have always mattered. In the early days of commerce both choice and exit were limited. If you lived anywhere but London you were lucky to have either option. Contracts and legal enforcement were weak and expensive, so it is not surprising that reputations were highly prized. You were only as good as your word because, by and large, the trustworthiness of your word was all there was.

Industrial production brought choice and competition. 'Exit' had arrived, and following shortly in its wake a growing body of contract law and consumer rights legislation which progressively clarified what purchasers could expect and hence what they could voice complaints about. As the twentieth century progressed, public services slowly became less paternalistic and realised that the voice of those whom they notionally served was not merely an irritant but that it served two vital functions: firstly, improving services by listening to what users want; and secondly, providing much needed legitimacy to tax-funded services through the involvement of users. Meanwhile, reputation fell into decline with the growth of anonymous cities and communities. Of course people still used judgements of others' previous behaviour but this came to be seen as a matter of personal judgement at best and gossip at worst.

The interplay between exit and voice has been reflected in health policy over the last 20 years. Firstly, government sought to clarify what patients could expect from their doctor and hospital. After all, it's hard to decide to leave or complain if you are unsure about what constitutes good care. National Service Frameworks, star ratings, Healthcare Standards and NICE were central to this process.[4] Secondly, exit was strengthened through the introduction of quasi-markets such as fund holding and, later, Choice and Payment by Results. Finally, new mechanisms to make voice more audible were introduced, although not all of them were coherent: at first, Community Health Councils were abolished and less effective Patient Forums introduced. Now, a further reorganisation into Local Information Networks (LINks) is under way.

Of these three trends – clarifying the offer, encouraging exit through competition and strengthening voice – it is the last that has been the weakest and most confused (though not necessarily the most controversial). The tensions inherent in strengthening voice have been fully explored in earlier chapters in this book. What is striking, however, is that these attempts to extend voice have largely ignored simultaneous developments on the web that were turning most other service industries upside down. Banking, retail, travel, telecoms and insurance might have been being convulsed; billion dollar industries such as eBay and open-source software grew from nothing to stardom in the twinkling of the eye, but the NHS sailed on serenely. It behaved like a twentieth-century dowager duchess largely uninterested in how up-starts such as Google, Web 2.0 or Wikipedia could improve patient feedback and involvement.

The power of these technologies to strengthen the patient voice flows from the on-going transition that is occurring in all developed nations as we move from an industrial information economy to a networked information economy.[5] To run a newspaper, make a film or produce a television show is a classic industrial process involving a cast of thousands, big machines and lots of capital. Capital intensive forms of publishing create products tuned to the mass audience. These mass markets create and manipulate reputations of products and services into multi-million pound brands, but ignore minority interests. In contrast, writing a blog or uploading a video clip to YouTube costs nothing. These differences lie at the heart of our current transition from the industrial information economy of the last century to the networked information economy of the present.[6]

The major implication of the new information economy is that it gives everyone the ability to have a public voice. For health this means that anyone can use the web to describe their experience of care publicly using either a blog or platforms like Patient Opinion (see box below). Anyone can use their mobile to take a photo of the filthy toilet on Ward 19 and post it to www.flickr.com, free and easy-to-use a site owned by Yahoo.com that allows anyone to upload, tag and share photos. Whilst Flickr is not yet used in this way, the potential is obvious.[7]

Of course, having your say is not the same as being heard. But, just as the networked information economy democratises the power to produce a public voice, so it also provides tools that enable selective listening. Search and, by

and large, you shall find the voices that are blogging about your hospital. Ten thousand voices may be a cacophony, but with Google you can find the three that are talking about Ward 19 and whether the toilet has been cleaned. Such tools dramatically expand the conversational space available to patients and tax payers and can be used to create conversations that potentially cover every micro-aspect of a service that a Trust provides. In The Long Tail, Chris Andersen describes how the net enables retailers to efficiently service tiny interest groups: 20% of Amazon's profits now come from books with under 100 sales per year.[8] Exactly the same mechanisms are beginning to create public micro-conversations between patients and providers. The state of services on Ward 19 will form one of the many public conversations in the long tail of such micro-conversations on the web. In time these could cover most aspects of most services and revolutionise how patients and public interact with service providers.

These conversations, photos, blogs and postings constitute a new and fine-grained form of reputation. By being public, transparent and locatable, these reputations become automatic quality drivers that in turn reinforce and reinvigorate both voice and exit. What was previously essentially private and subject to individual bias – what I think of my doctor – can now in principle be both public and by gathering many opinions together in one place, much less subject to bias. Dangers remain of course. Gaming, confidentiality and trust all need to be thought through. But, in principle, these mechanisms create powerful user-generated reputations. These will complement the more systematic data generated by the Healthcare Commission, National Patient Surveys and the like. Taken together, the combination of patient-generated reputations and system-wide representative data will be at least the equal of voice and exit in driving quality.

Reputation and the NHS

So how might the aggregated reputations that can be created in the networked information economy be used to improve health services? If we take an archetypal health interaction like referral it is possible to see three potential reputation systems that could drive quality improvements (see box on the right).

Of these only one, Patient Opinion is currently in existence and this is discussed in detail below.[9] The consultant-generated reputation of GP referral skills would be relatively easy to create since all referrals are now received electronically through the Choose and Book system. In technical terms it would be simple

to add a screen where consultants could grade incoming referrals on one or more dimensions. The last reputation, generated by GPs about the quality of the hospital intervention for a particular patient, is harder to construct because the particular information flow is more difficult to capture.
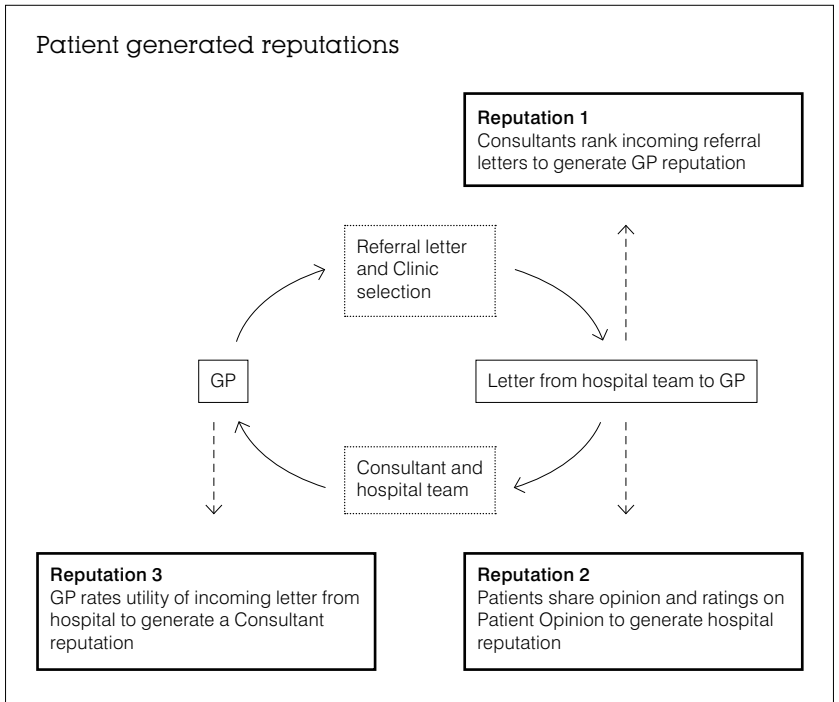
A reputational system in action in the NHS
Patient Opinion (see box on next page) is a website where patients can share the story of their care and rate various aspects of the service they have received. This results in visible, real time rankings of services down to departmental level. Reputations become concrete and measurable.

Patient Opinion makes use of the deep seated desire to tell one's story and be heard to collate thousands of stories about care. These can be moving human stories, touchingly personal suggestions or biting critiques of the service received.

Personal stories have long been known to have a power beyond their factual content and to exert more influence on what we think than data alone.[10] Such stories have an intrinsic appeal to citizens already used to using www.TripAdvisor.co.uk to plan their holiday. But how do NHS organisations react?

Both PCTs and Practice Based Commissioning consortia use Patient Opinion data to help inform commissioning discussions and service redesign. Trusts for their part, are beginning to change services as a direct result of comments and suggestions by responding to postings.

Patient Opinion
this is our NHS...
let's make it better

Home   Opinions   About   Help   Search   Login

Specialty: Heart Problems (Cardiology)
at Rotherham District General Hospital

Change text size
Language Support

Key to ratings

View hospital rating >>

What are others saying?

Latest   Thanks   Moans

How other people rated this Service	◆ ◆ ◆ ◆ ◇ (from 52 ratings)
Standard of medical care	◆◆◆◆◇
Standard of nursing care	◆◆◆◆◇
Cleanliness	◆◆◆◆◇
Parking	◆◆◇◇◇
Treated with respect and dignity	◆◆◆◆◇
Information and decision making shared appropriately	◆◆◆◆◇
Service punctuality/timeliness	◆◆◆◆◇

" I would like to be able to find out what I was being treated for, and repor ... "
MHFP006

" All the staff I encountered were excellent, shame there isn't a box for exc ... "
MHFP005

" The nurses were brilliant especially Sharon, Julie and Dawn. Also Mr Farag ... "
GFP002

More opinions>>

View opinions of : Rotherham District General Hospital , Heart Problems (Cardiology)
Return to previous page >>

Login to rate this Service >>

Patient Advice and Liaison Services (PALS)
tel:
email:

You can talk to PALS who provide confidential advice and support to patients, families and their carers, and can provide information on the NHS and health related matters.

Find out what Official NHS Sources say
NHS Star rating and other useful information

Like most web-based businesses, Patient Opinion has been designed to scale and we plan to be posting several thousand opinions per week by 2009. Subscribers are able to direct postings about a particular service to the relevant manager as a weekly email. So, for example, the orthopaedic business manager could set up a subscription to receive all comments about orthopaedics at her Trust. Subscribers can also reply to any posting about their own services and the patient is allowed a 100-word comment on what they think of the Trust's response. This creates a series of public conversations about micro-aspects of service at a Trust that helps Trusts understand how services could be improved and, at the same time, exerts pressure on the Trust to change.

Threats and opportunities

Reputational systems carry risks as well as new opportunities. These risks include the need for all players to trust the system: it is essential to avoid deliberate manipulation and gaming by those posting stories; we need to mitigate the distress associated with a poor public reputation, and we need to allay misapprehensions about how reputational systems relate to more traditional evaluations.

At Patient Opinion we have learnt that the business model used to finance and sustain the reputation system is a key variable in handling these risks. Our business model aims to create trust and ensure independence:
— Free to patients
— Carries no advertising
— All postings are previewed prior to posting and edited if appropriate
— Not-for-profit social enterprise[11]
— Financial independence secured through subscriptions from many organisations rather than a few large grants.
— Deliberately subjects itself to market signals (will Trusts subscribe?) in order to ensure that services represent value for money and to learn what customers want.
— Aims to support staff as well as patients by posting a paper copy of all Thank You's sent to the site regardless of whether Trust subscribes
— Trusts invited to respond to any posting that is particularly critical regardless of whether they subscribe or not.
— Site content freely available to anyone looking at the site in order to promote widest possible use by patients. Subscribers pay for added search and convenience services not data itself.

— Content of site owned by Patient Opinion but held under Creative
  Commons copyright to enable widest possible sharing of data.[12]

Trusts can feel threatened by the new visibility and transparency of public repu-
tations. As one Director of Nursing said:

Why should we pay Patient Opinion to provide people with a site where they can
*publicly slag off our services?*

Such a response, whilst understandable, demonstrates how far Trusts are from
coping with the new world of reputation on the web. Commercial organisations
have found to their cost just how counterproductive it can be to try and silence
unfavourable comments about their services on the web. Equally, Trusts can-
not control the kind of comments posted about them on Patient Opinion (or
anywhere else on the web). Trusts also need to learn how to use the conversa-
tional idiom of the web in their responses. Otherwise, it does not matter how well
meaning they are, their replies will look like so much bureaucratic hokum when
they are posted amidst the easy-going rough and tumble of the web.

But organisational anxiety about the public nature of postings on Patient Opinion
is just the other side of the coin to the thing that gives the site its bite and it is that
with experience subscribing Trusts come to value. After six months working with
Patient Opinion, one Manager at a subscribing Trust observed:

The positive comments are nice to get. But it's the critical ones that are real-
ly useful because they are the ones that make staff sit up and take notice be-
cause they know that everyone can see them. That's how Patient Opinion drives
change for us and why it's more useful than most of the patient-derived data
that we hold already.

Patient Opinion is different from much evaluation in that it does not attempt to
be representative of users. It is not research, but rather real-time 'front of house'
data about how services could be improved. Typically around 50% of postings
are positive, 25% are critical and the rest are mixed. People clearly have to be
unusually pleased or disappointed in the care they have received in order to be
motivated enough to use the system. This motivation itself varies but can mainly
be ascribed to gratitude, anger and altruism (see box on the right).

Motivation for posting on Patient Opinion

Malice 2%   Anxiety 12%

Anger 26%

Gratitude 38%

Altruism 22%
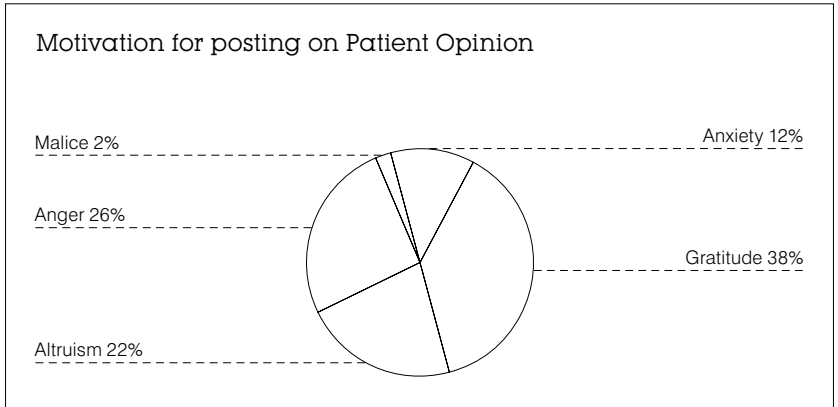
Conclusion

The networked information economy brings far-reaching changes in how the public relates to the public sector, commerce and politics. So far the NHS has not sought to harness these technologies much and has not explored their use to involve users in improving services. However, web-based reputations have great potential as a powerful, new way to extend user involvement across the NHS. Their ability to scale and to create many small, but public, conversations about micro-aspects of services holds great promise. The power of this approach derives from the independent and public nature of the postings and because the web drastically lowers the costs of creating a public dialogue between the people who feel passionately about a particular service and those responsible for running it.

Reputations have always lived in the space between people and organisations. They are qualitatively different from surveys and other evaluative methods in several important ways. Reputations include a much wider range of data which may or may not be representative of all users. Reputations do not have to be based on explicit criteria of what constitutes good care. In addition, web-based reputations are 'live': as aggregations of many opinions, they can reflect change in real-time. The technology also allows each posting to be automatically directed to just the right person, thus increasing the likelihood that feedback will be used. All this means that reputations are likely to be more cost-effective compared with traditional evaluation and feedback tools. In all these senses web-

based reputation systems are more akin to the invisible hand of the market than to other quality drivers.

Understanding how web-based reputations work and then building systems that realise their social potential will be important tasks for any health service in the 21st century. However such systems need to be built with care if we are to avoid their possible risks and capture their power for the public good.

At the very deepest level, web-based reputations are part of collection of new tools emerging from the web that allow us as a society to capture and distil our collective, distributed wisdom. These tools will become increasingly important as the social, technical and environmental challenges of this century become more acute.

1   See http://en.wikipedia.org/wiki/EBay for an analysis of the EBay feedback and reputation
     system plus its possible weaknesses. The rate of fraudulent trades on eBay has undoubtedly
     risen since 2003. However, the system remains extremely effective and a graphic demonstration
     of the simplicity and power of reputations as drivers of quality.
2   Albert Hirschman, Exit, Voice, and Loyalty: Responses to Decline in Firms, Organizations, and
     States (Harvard University Press, 1970).
3   Hassan Masum and Yi–Cheng Zhang, 'Manifesto for the Reputation Society' at http://www.first
     monday.dk/issues/issue9_7/masum/#m1
4   In many ways these standards and their related outcomes form part of the on-going
     infrastructure of reputations. See, for example, the recent data about out come of cardiac
     interventions on http://heartsurgery.healthcarecommission.org.uk. However, web-based
     reputation systems move beyond allowing users to simply make judgements about data by
     automatically aggregating multiple opinions together and providing new forms of dialogue that
     can draw users into helping to improve particular aspects of service that are of concern to them.
5   See Y. Benkler, The Wealth of Networks: How Social Production Transforms Markets and Freedom
     (Yale University Press, 2006) and M. Cassells, The Internet Galaxy (Oxford University Press, 2001).
6   Benkler (2006).
7   See http://en.wikipedia.org/wiki/Flickr for an explanation of Flickr. For an example of a
     photograph of a hospital toilet, see: http://www.flickr.com/search/?q=me%20steph%20hospital
     %20toilet&w=all.
8   Chris Anderson, The Long Tail: How Endless Choice Is Creating Unlimited Demand (Random
     House, 2006).

9   www.patientopinion.org.uk

10 T. Greenhalgh and B. Hurwitz, 'Narrative based medicine: Why study narrative?' BMJ 318
    (Jan 1999), 48–50.

11 A social enterprise is defined as one that primarily exists to fill a social need rather than to
    generate profits.

12 See http://creativecommons.org/about/licenses/meet-the-licenses for more about the Creative
    Commons system for protecting intellectual property.

Appendix A
Selected milestones
in Patient and Public
Involvement

This list is meant to provide readers with a brief overview of some key milestones in the development of patient and public involvement (PPI) in the NHS. It is not an attempt to write a definitive and complete history of PPI.

1972   First Patient Participation Group founded
1974   Community Health Councils set up
1989   Working for Patients set the agenda for consumer oriented services implying a degree of user control over service provision
1990   NHS & Community Care Act give district health authorities the responsibility to constantly evaluate the effectiveness of services from the user perspective.
        GP Contracts charge GP practices with providing information about their services and to produce annual reports incorporating user evaluations of services
1991   Patients' Charter sets out patients' rights in the NHS, including the right to information about treatments and the right to privacy and dignity.
1993   Achieving an Organisation Wide Approach to Quality lists 'the involvement of patients and carers in service planning and in providing feedback on services' as one of three essential elements of a quality service.
1996/7 Planning & Priorities Guidance (NHSE) states as a priority: 'Give greater voice and influence to users of NHS Services and their carers in their own care, the development and definition of standards set for NHS services locally and the development of NHS policy both locally and nationally.'

1999   National Institute for Clinical Excellence (NICE) set up
2001   Kennedy Inquiry report into the management of the care of children
       at the Bristol Royal Infirmary recommends increased openness about
       treatments and clinical performance and increased involvement of
       patients in decisions around their own care.
       Section 11 of Health and Social Care Act places a duty on all NHS
       organisations to involve and consult patients and the public in the
       planning of service provision, the development of proposals for change,
       and decisions about how services operate.
       Expert Patient Programme launched.
2002   Patient advice and liaison service (PALS) set up at all PCTs and NHS Trusts
2003   Commission for Patient and Public Involvement in Health (CPPIH) set up
       Community Health Councils in England abolished
       The Independent Complaints Advocacy Service (ICAS) set up
       First Health Overview and Scrutiny Committees set up
       Patient and Public Involvement Forums set up, one for each NHS Trusts
2004   First Foundation Trusts set up
       Decision to abolish CPPIH, following the Department of Health's Arm's
       Length Bodies Review
2005   Your Health, Your Care, Your Say consultation process involves
       thousands of members of the public and patient groups in developing
       the health white paper.
       GP practices taking
       Practice Based Commissioning (PBC) allows GP practices to manage
       indicative budgets and make purchasing decision about local
       health care.
2006   Our Health, Our Care, Our Say White Paper recommends that local
       people be given 'a stronger voice so that they are the major drivers of
       service improvement.'
       A Stronger Local Voice recommends that Local Involvement Networks
       (LINks), based around local authority boundaries, replace existing PPI
       forums. There is also a suggestion to set a network of large patient
       organisations to provide a 'national patient voice'
       PBC to be in place in all Primary Care Trusts in England
2007– CPPIH to be abolished
       LINks to be set up
       PPI Forums to lose statutory powers

Appendix B
A glossary of health acronyms

A&E	Accident & Emergency Department
COPD	Chronic Pulmonary Obstructive Disease (long term breathing problems)
CPPIH	Commission for Patient & Public Involvement in Health
CSCI	Commission for Social Care Inspection
GMC	General Medical Council
GP	General Practitioner
ICAS	Information Complaints Advocacy Services
LINk	Local Involvement Network
LMCA	Long term Medical Conditions Alliance
N.A.P.P	National Association for Patient Participation
NEDS	Non-Executive Directors
NHS	National Health Service
NICE	National Institute for Health & Clinical Excellence
OSC	Overview and Scrutiny Committee
PALS	Patient Advice and Liaison Services
PBC	Practice Based Commissioning
PCT	Primary Care Trust
PPG	Patient Participation Group
PPI	Patient and Public Involvement
PPIF	Patient and Public Involvement Forum
SCIE	Social Care Institute for Excellence
SHA	Strategic Health Authority
vCJD	Variant Creutzfeldt-Jakob disease, a degenerative brain disease (linked to CJD, 'mad cow disease')
VCO	Voluntary and Community Organisation

Healthy Democracy
The future of involvement in health and social care

From the extension of patient choice through to the proposed Local Involvement Networks, the Government is determined to give the public a greater direct role in deciding how services are run within the NHS. Yet experience on the ground shows there is a gap between the rhetoric of engagement and the practicalities of participation.

This book brings together a diverse group of practitioners and public policy makers from across the healthcare domain to critically evaluate existing and proposed engagement practises within the NHS. In identifying the challenges for service providers, patients and the public in securing engagement in service decision-making, these authors reveal why getting public participation right is critical to the future of the NHS as a whole.

This publication is a joint venture between Involve and the New NHS Centre for Involvement. The NHS Centre for Involvement is led by a consortium of the University of Warwick, the Centre for Public Scrutiny and LMCA and is committed to supporting the NHS as a whole, at local provider, regional and national levels to lead and sustain patient and public involvement. Involve is a not for profit organisation dedicated to understanding and promoting better civic participation, not just in the health sector but across all issue areas and encouraging the debate about what actually works.

involve   THE UNIVERSITY OF WARWICK   c*fps* the centre for public scrutiny — better scrutiny for better government   LMCA alliance for health