Putting People at the Heart of Public Services: Can We Make it a Reality this Time?

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Patient and Public Involvement Solutions

Abstract
Exploring a brief history of patient and public involvement as a pathway to the present, the article considers whether we are close to achieving a system of public engagement in health and social care that can be truly held to account as enabling people to influence the decisions that affect their lives. Considering the most recent legislation and in particular local involvement networks the article looks more closely at ‘quality’ in public involvement and focuses on how we can work together through personal responsibility to achieve it.

Key words
public services; people; patient and public involvement; ‘quality’; personal responsibility

Introduction

The merry-go-round of patient and public involvement is turning once again. Despite continuous change and the often spoken mantras of empowerment, choice and voice, the question we must continue to ask of ourselves regardless of policy fashion is: are we working together to make sure that people can influence the decisions that affect their lives?

The context in which we find the latest legislation to ensure the involvement of patients and the public in health and social care decision making goes back at least some 35 years. It is worth a brief trip down memory lane in order to be able to take into account how history has influenced the present, leading us to the question of: will the next step on the patient and public involvement continuum help or hinder the progress towards public services that are truly accountable? The late 60s through to the late 70s have been described as the ‘golden age of community work’ (Popple, 1995: 15). A time when there was support for community based initiatives in the statutory sector and a growth in voluntary and community based organisations (Mayo, 1994: 133). Due to a level of international political unrest with the high profile assassinations of Robert Kennedy and Martin Luther King, increasing demonstrations from the international student movement and uncertainty in the air concerning the economy in the UK, the government began to recognise the need to involve communities in addressing social, political and economic problems, with the implementation of, amongst other initiatives, Community Development Projects and as part of the health remit, the inception of Community Health Councils (CHCs). A simultaneous uprising of community initiated and led groups aimed at influencing decision makers indicated a desire from both sides to move ‘away
from centralism and towards a belief in ordinary people’ (Mayo, 1994: 134).

It is on this tide of belief in community participation that we can trace a journey that has led to an ever-evolving rhetoric of patient and public involvement in health and more recently, social care.

Community health councils

1974 saw the birth of Community Health Councils (CHCs); these were set up as a committee of lay people to safeguard patients through more public involvement and scrutiny (Hogg, 1999: 87). First proposals came from the conservatives and were accepted and modified by the incoming Labour government. They were established to provide a visible level of public scrutiny and accountability to healthcare decision making. In 1978 the World Health Organisation (WHO) launched the Declaration of Alma Ata (Health for All by the year 2000) which had as its fourth recommendation:

‘The people have the right and duty to participate individually and collectively in the planning and implementation of their health care’ (WHO, 1978: 3).

The WHO’s recommendations were not taken forward by the incoming Conservative government of 1979, however this important declaration was reflected nearly 20 years later as a key strand of policy development for New Labour, and was visible in the Health and Social Care Act 2001 within the legislation that facilitated the abolition of CHCs.

The response to the announcement (in 2000) to abolish the CHCs was not altogether positive. As many as 5,000 people at any time had invested time and commitment freely to the work of CHCs (Health Committee Report, 2003: 4) and many felt that the abolition was an excuse on the part of New Labour to water down a powerful vehicle for collective public opinion. Dr Liam Fox, then Shadow Health Secretary was quoted by the BBC as saying: ‘Doing away with the CHCs is designed to protect the government from any critical comment in the future’. From the announcement of the intention to get rid of CHCs through to their final abolition took three years, with repeated readings in the House of Commons and the Lords. Despite much contention the CHCs finally fell to their resting place at the end of 2003.

Patient and public involvement

From the publication of the NHS Plan in 2000, with its promises to patients of information, choice, protection, advocacy, redress, views, scrutiny and patient representation followed the establishment of the Modernisation Agency in 2001 with a remit to ‘shift the balance of power in the NHS to empower staff and local communities’ (DH 2001: 9). Later that year the Bristol Royal Infirmary Inquiry was published. The Inquiry recommended that patients should expect inclusion and involvement in the NHS both as patients and members of the public. The significance of the Inquiry with its high levels of media coverage and its strong emotional content raised the profile of the important role of patients and the public in decision making even further.

The Health and Social Care Act 2001 set out what was seen as a fairly complex and fragmented system to achieve the aspirations outlined in the NHS Plan. It placed a legal duty through section 11 of the act on PCTs and NHS Trusts to involve and consult patients and the public; involvement that included not just major change but ongoing planning, not just considering proposals but developing them and in decisions that might affect how services are run. In addition, to address public accountability and external scrutiny a role was identified for the new Health Overview and Scrutiny
Committees within local authorities. A programme of implementation ensued including the establishment of an independent system to enable complaints redress (ICAS – Independent Complaints and Advocacy Service). Procured through third-party hosts it is still in existence today, although with a relatively low profile publicly and an uncertain future with radical change to the complaints system on its way. Alongside and to fill another gap previously filled by the Community Health Council system, Patient Advice and Liaison Services (PALS) were set up internally within NHS organisations to support the journey of patients through the system. PALS have been a relative success and are still in place. However, in the early days emphasis was placed on their seniority within organisations and their important role in influencing the most senior levels of decision making. Guidance advised that:

‘lead PALS staff should have direct access to the chief executive and have sufficient status and influence within the organisation to negotiate with clinicians and managers as part of responding to the concerns raised by patients, their carers and families.’ (DH, 2002: 7).

In practice it is questionable as to how many PALS managers now have a direct line to the chief executive and real influence at board level relies on effective reporting mechanisms and organisations that genuinely value the feedback and learning gathered through this service.

The final piece of the jigsaw was to provide an independent mechanism to engage and involve patients and the public. Through the work of a Transition Advisory Board (TAB) set up by the Department of Health, the new vision for patient and public involvement began to emerge. The chair of the TAB, then chief executive of Diabetes UK said:

‘Patient and public involvement is easy to say, hard to do. If we get it wrong we could end up with an expensive, fragmented and adversarially driven system, which makes little real difference to patients, carers, the public or health care providers. If we get it right we can play our part in transforming the way the health service looks and feels to those who use it and those who deliver it. The stakes are high but the potential rewards are enormous.’ (Transition Advisory Board 2002)

A new Arms Length Body was set up and in January 2003 the Commission for Patient and Public Involvement in Health became a legal entity and was tasked with establishing a system of volunteer networks known as Patient and Public Involvement (PPI) Forums. The task to create an organisational structure to support effective patient and public involvement began. However, with the organisation in such an immature developmental stage there was no clear mechanism for independent public scrutiny of health service decision making. This lack of public accountability created a strong pressure point with force from both policy makers and activists alike to get a system operational. As a result, the deadline to have Patient and Public Involvement Forums operational was brought forward. In practice this meant that a target of 5,000 recruited volunteers was to be achieved within a very short timescale by December 2003.

Amid heightened expectation and under close scrutiny the many challenges of forming a new organisation and recruiting a publicly accountable workforce of volunteers were achieved. Steadily the PPI Forums began to find their way in influencing their local health services. However, in June 2004 a government report: The Reconfiguration of the
Department of Health’s Arms Length Bodies (DH, 2004) described key reasons why the overall number and total investment in arms length bodies needed to be reduced, including:

- devolution to the frontline
- appropriate impact for minimal burden
- the Gershon Efficiency Review
- the Lyons Review of public sector relocation.

As part of the report the abolition of the new Commission for Patient and Public Involvement was controversially announced just nine months after the Forums it supported became operational. Harry Cayton, then Director of PPI for the Government was quoted in the British Medical Journal as saying:

‘I look forward to seeing the savings and the reduction in bureaucracy arising from the changes being translated into benefits for patients and frontline staff’: (BMJ, 2004).

Throughout the following two years, the future of patient and public involvement as an independent mechanism to provide public accountability in health decision making looked uncertain. A range of solutions were explored, initially relying on the PPI Forums remaining in place but with the central support provided from another existing arms length body. With no satisfactory resolution or solution identified the Forums and their Commission remained operational despite ongoing uncertainty and debate. In January 2006 following a high profile consultation, Our Health, Our Care, Our Say – a new direction for community services, was published by the Department of Health. It represented a policy commitment to shifting services closer to home.

PPI Forums had not provided the panacea to meet the policy rhetoric for effective grass-roots engagement of a broad and diverse range of people and groups, enduring in their short and difficult life a perhaps unjust level of criticism. But perhaps more importantly, and in relation to a cross-government trend of decentralisation, they represented a model for engagement of people that was outdated and not fit for the vision of the NHS of the future.

‘The arrangements for involving patients and the public need to be updated to support the significant changes being made to the health and social care systems.’ (DH, 2006a: 7)

It was to be a further two years before PPI Forums and the Commission for Patient and Public Involvement finally and simultaneously came to the end of their tenure.

LINks
In response to the white paper in the summer of 2006 the government produced A Stronger Local Voice, the policy document that introduced an altogether new mechanism for patient and public involvement, the Local Involvement Network (LINk). The concept of LINks heralded a new aspiration for patient and public involvement. The aspiration was for a network that would grow out of the infrastructure of the community and be shaped and organised by the local community, for the local community:

‘We recommend a more flexible framework for supporting public and service user voices in health and social care at the local level’ (DH, 2006b: 5).

The establishment of LINks heralds a move towards a system of patient and public involvement that is about engaging with people in their ways, in their time and on their issues. The findings by Skidmore et al, (2006: XI) are helpful here in citing that people
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are more likely to participate if structures for engagement are embedded in the everyday spaces of community life and the informal social networks through which people live their lives:

‘Community participation tends to be dominated by a small group of insiders who are disproportionately involved in a large number of governance activities’.

The aspiration for LINks therefore has been described as a network of networks, creating a system for ongoing conversation within all parts of local communities.

It is hoped that a LINk will be successful at finding out what people think, investigating specific issues, suggesting ideas to help and holding services to account. One crucial aspiration for LINks is their anticipated ability to influence organisational decisions at the point of purchase; ‘the information they [LINk] gather will help commissioners make informed decisions about what people in the area need, and assist them in their role as contract managers’ (DH, 2006b: 15).

But what of success, how will the conversations be heard, taken seriously and acted upon by the organisations and people charged with making the important decisions?

‘It is crucial that PCTs effectively involve patients and the public in their commissioning processes. A commissioning strategy without the input of the community is not worth the paper it is written on. But if they are to prioritise this, as they must, PCT staff need help: they need budgets, leadership, techniques and technology.’ (Chisolm et al, 2007: 2)

Ultimately success will be measured by outcomes at the local level and by local people seeing that their influence is important and that they can make a visible difference to the services that they use. At the core of LINks policy there is a strong desire to enable local creativity, through the development of bespoke systems and approaches that grow out of the needs of the community and its infrastructure.

In an attempt to achieve this, LINks’ policy has been developed in a loose way, with minimum restrictions and directives in how a LINk should develop and operate. The previous system with its detailed legislation and regulations indicated that to create a system that is bound by rules and regulations is to create a system that dates quickly and cannot effectively respond to change and meet the needs of the people it is established to serve.

However, there is a risk attached to the new strategy for LINks and in fact PPI more generally and that is the question of: how can public assurance be given that people are being engaged and involved appropriately to the highest standard possible?

The need for quality is not just born out of a need to do a good job. Involving patients and the public needs to be done with the highest level of respect for the people who give their time, experience, commitment and knowledge. A patient or member of the public who becomes involved usually does so as a result of a personal desire to make a difference, and often as a result of a personal experience that motivates them further. To protect the interests of those who become involved or engaged and to ensure genuine impact at the point of decision making we need to ensure there are mechanisms that encourage and reward quality, that are evidence based, accessible and visible to the population at large and that contribute towards a culture of learning, improvement and excellence.
Success for patient and public involvement both through its internal and independent mechanisms will be achieved by local people making an impact on local services measured by tangible change as a result of their involvement. Success will also be about creating a recognised and valued system of public accountability that local health economies and communities genuinely respect, value and listen to as being able to shape decision making.

The ability of patients and the public to influence in a meaningful and impactful way relies on a very personal commitment by all who participate in the dialogue.

In discourse with a group of patient educators at London South Bank University this year the group shared their experiences in being involved and involving others in health and social care decision making. The table below emerged.

While the table below is simple it is drawn from the very real and poignant experiences of those who involve patients and the public and those who are involved as patients and members of the public on a regular basis. It outlines a number of fundamental principles that if applied at the individual, collective, organisational and societal can start to underpin an essential lever of quality in all of our engagement strategies and plans for operational delivery.

Such words as ‘respect’, ‘dignity’ and ‘empowerment’ however, need to be applied cautiously and with great depth of thought about what they represent. Language in this context can be used as a pacifier and a convenient way to mask the very real challenges in truly achieving real outcomes that can be experienced by people as tangible changes and improvements.

‘The danger here is that their usage can become over-generalised, sometimes to the point that their meaning and impact become seriously watered down.’ (Thompson, 1998: 169).

**Conclusion**

If we are to achieve real and tangible quality and outcomes in patient and public experience we must not leave it to chance. We must not rely on the few committed individuals who happen to have ‘PPI’ or ‘community engagement’ in their job titles and a few more who fortuitously work from this values base. We must ensure that robust processes are in place that require all levels of our organisations to take responsibility for working in true partnership. Processes and policies should be whole systems with clear methods for reflection and review and must be led from the top.

**Table 1: Cross-cutting themes emerging from shared practice in patient and public involvement and engagement**

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<th>Individual</th>
<th>Collective</th>
<th>Organisational</th>
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<td>Accountability</td>
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<td>Empowerment</td>
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<td>Proactive citizens</td>
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<td>Information</td>
<td>Responsibility for own actions</td>
<td>Work with others</td>
<td>Influence and be influenced</td>
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<td>Respect</td>
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<td>Dignity</td>
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<td>Focus on people</td>
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‘Engagement is hard work, and it has to be learned. LINks have the potential to contribute to reform: from reducing health inequalities to achieving credible, efficacious services’ redesign.’ (Sang & Drinkwater, 2008)

But success will rely on the ability of all component parts committing fully and pulling together. We need to work hard on the continuum of policies, processes and people. Working through each with commitment and personal responsibility to ensure the best decisions are made, creating and delivering the best services possible to ensure the best possible chance of health and well-being for all.

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About the author
Having worked in many aspects of the evolving systems and mechanisms for Patient and Public Involvement over the last decade Jessie has gone on to set up Patient and Public Involvement Solutions, established to support organisations to maximise their ability to engage and involve patients and the public. She is currently working on several projects: the establishment of the Kent LINk, service improvement in commissioning in West Sussex, supporting community engagement through the network of Post Office branches, and learning and development strategies with a LINk Host.

References


