Policy Task Force - Having My Say

Final Report

Chair: Ed Mayo, Chief Executive, National Consumer Council

Our taskforce met in October / November 2005 to find ways to promote people’s ‘say’ in health and social care so that services develop in ways that are genuinely responsive to their needs and choices.

Having My Say Matters

Health and social care play a vital role in many people’s lives. But services are also dependent for their success on those same people, and their carers. And they rest on public confidence. It was enough in the old days to make assumptions about this. But many of the changes we are likely to see in health and social care make it all the more urgent that people are able to have their say.

In future, there will be more personal choice. Some might claim that this will make ‘voice’ redundant. But the introduction of choice makes the public voice more, not less important. The embryonic market should not just respond to the articulate and confident consumers. Choice needs voice for the vulnerable and for those who suffer health inequalities. Voice can also shape and extend the choices on offer. This is particularly the case in community care, compared with the acute sector, and for people with disabilities and chronic illnesses, where there may be fewer opportunities for service users to choose.

In future, there will be a more dynamic market, in which providers and commissioners need to move quickly, with the discontinuities of choice and direct payment for care. Some might claim that user involvement will get in the way. But the need to adapt services also makes the public voice more, not less important. Giving people the chance to have their say, as service users and as members of the public, can minimise conflict and avoid damaging public backlash as services are reconfigured.

In future, there will be more integration across health and social care. And it is clear that service users can be a force for integration across health and social care, because their lives are not separated into silos.

There are two fundamental objectives that underpin these future changes: first, how to make services more patient centred and, second, how to create a joined up health and social care service rather than a fragmented sickness service. Developing effective ways for patients and citizens to have their say will help make both of these ambitions a reality.
Enthusiasm for having my say:

The people who contributed to the Listening Exercise strongly supported public involvement in decisions about health and social care. As one said “We use and pay for these services - we should have a say”. Around 70% of participants at the National Event in Birmingham said that it is very important to consult people locally about:

- Making changes to existing services;
- Giving views on the design of new services;
- Deciding the future priorities for health and social care.

Just as importantly, the public want this to be done well. They are concerned about whether decision-makers respond - “will it make a difference?” - and whether involvement is inclusive - “not the same old faces”. They also stressed the need to inform people so that they can be engaged, and to inform people as to how services responded.

Having My Say Principles

This tells us that there is far more appetite for involvement from the public than the minority currently engaged, for example to serve on Patient and Public Involvement Forums in health, and we need to tap into this.

At present, there are examples of world-class practice in engaging service users, particularly in social care. But, despite the commitment to put a user and citizen focus at the heart of services, they are sporadic. At their worst, processes around involvement have been stop-start and labyrinthine and these need to be thoroughly overhauled. A strong framework is required, based on a shared understanding of why it is important to engage people in decisions, and how this can be done effectively.

To guide us in spreading best practice, we identified four core principles, set out in full in Annex B, which are:

1. The ability of people to have a say is essential to ensure that high quality health and social care services are available to meet their future needs.

2. The right kind of involvement is needed at every stage of the design, delivery and evaluation of services.

3. The quality of involvement matters but can be achieved in different ways.

4. There needs to be a systematic way of encouraging decision-makers to listen and to respond to what they hear.
**Having My Say Action**

### Proposals

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### A. A Partnership Approach to Individual Care

A responsive system starts from episodes of care that listen to and act on the views of individuals and those that support them. Initiatives such as personal health plans, owned and held by service users, direct payments for care and the expert patient programme adapt services to be more like a partnership between people and professionals. Aggregating knowledge from individual experience can then systematically inform service management, commissioning and inspection.

Even so, people can be vulnerable and reluctant to criticise the services they are receiving. So positive new ways to support a partnership approach range from comment cards, interactive kiosks and bi-lingual advocacy through to community development approaches and the involvement of users and carers in staff training.

Such approaches must work ‘with the grain’ of health inequalities by seeking out and offering involvement methods which work best for users who suffer such inequalities.

### B. Intelligent Commissioning

Improving planning and commissioning, at all levels, so that it is based on the priorities of the local population and a thorough insight into how users experience and value services is the single most important action to build responsive health and care services. If you know how service users experience services, and how the public might set priorities where resources are scarce, you can commission and develop market capacity to deliver the right services and better deal with controversies. Engagement with the community, involving both formal and informal qualitative approaches is the key to good commissioning.ii
We propose a core definition of intelligent commissioning, which is “to identify the diverse health and social care needs and preferences of the population, with particular regard to health and care inequalities, to monitor these systematically and to procure high quality and accessible services to meet those needs efficiently and to the satisfaction of service users and citizens.”

Intelligent commissioning for health and social care should:

- Start from an understanding of service users and carers’ circumstances, needs, and how they can contribute – in order to support informal care, independent living, healthy choices, and community well-being.

- Meet national standards while adapting them to local circumstances and open up questions of commissioning priorities to wider public deliberation – creating a framework for more flexible change and addressing issues such as concerns that current services are delivered within a framework that is experienced as discriminatory, particularly around ageism.

- Ensure that giving priority for user focus is led from the top in every commissioning organisation, and provide operational support by appointing a senior member of staff as ‘consumer advocate’, bringing professional commissioning skills to bear upon the design of commissioning in order to check, challenge, and improve services for users. Their sole purpose is to champion user interests and to ensure adequate and appropriate consultation.

- Draw on processes that personalise and integrate services for users, such as data from the single assessment process for older people and joint performance indicators on prevention with other service providers through Local Area Agreements.

- Apply, through contracting a) an appropriate element of revenue and risk that will vary in relation to customer/user satisfaction and b) a consistent framework for all service providers, including new market entrants, for compliance with NHS standards and behaviours, human rights legislation and arrangements for service user involvement and responsiveness.

- Introduce, with care, user dissatisfaction triggers for review of commissioning and delivery. This could include, above a certain threshold, scope for petitions to act as triggers for service review or inspection.

- Monitor service provision, including a reporting framework of user satisfaction, complemented by the selective use of ‘mystery shopping’.

- Operate, with inclusive models of governance.
C. Responsive Services

There are 25,000 separate employers managing and providing services in the social care market, and there may be many new entrants in future healthcare. It should be core to the service they offer that they have ways to hear and to respond to the views of users and carers. While allowing for different ways of achieving this, this should be specified as a requirement in contracts.

Those running responsive services will look more to self (or third party, which could be user led) inspection and quality assurance rather than waiting for statutory inspection. There is a strong case for a ‘Participation Standard’ in health and social care building on current good practice, to be developed as a voluntary quality standard for providers around user involvement. By integrating this with the methodology for statutory regulation, assessment and inspection (where compliance with the standard is sufficient evidence of user involvement), it will be possible to build incentives for take-up and improvement. A standard would also allow for organisations to ‘quality score’ how well they are doing on user involvement.

Those running responsive services will also make an over-arching commitment to developing services from an ‘independent living’ perspective – an approach that was backed by members of the public in the Listening Exercise and by responses to Independence Well-being and Choice.

To support a plurality of providers, we recommend consideration by local authorities and Primary Care Trusts of an integrated “Health and Care Social Enterprise Strategy”, combining contracting and business support programmes to encourage the emergence of user-led initiatives.

D. Integrated Complaints

The current state of redress across health and social care is not fit for purpose. It is essential that users and carers can complain in relation to a package of care and do so easily through a single gateway. In this way, complaints can be a force for the integration of health and social care and an important source of strategic feedback on the quality of service.

A quality framework for ‘first tier’ complaints, with defined service standards, needs to be part of all provider contracts so that the complaints mechanism is consistent across the health and social care market. We recommend that the approach to second tier complaints now exists in Scotland and Wales across public services should be investigated. The complaints system should work in ways that fit the context and needs of different groups such as young people and people with disabilities with support and advocacy available for the vulnerable whose complain may not be heard.
E. Better Regulation and Inspection

Legislation for an integrated approach for regulation and inspection is a critical opportunity to embed a patient and service user focus in the new structure (learning from recent experience in other sectors on how to achieve this) and in its statutory objectives. This would include recognition of the:

- value of carers,
- role of public and user involvement,\textsuperscript{iv}
- requirement for public safety, and
- benefit of engaged citizens in relation to public health.

Alongside what is required in terms of less, better and more risk-based regulation, there is a key role for the regulatory bodies to signal the importance of integrating the say of service users. This can be advanced by accelerating current work at CSCI and the Healthcare Commission, in order to develop an integrated approach to assessment of public and user involvement across health and social care.\textsuperscript{v}

For the new merged body, inspection should, as a headline rather than sideline component, test the effectiveness of the way that organisations involve people.

Better regulation will understand what service users expect from inspection, including the assurance of baseline quality / outcomes and information that can assist their choices. Equally, service users can act as ‘experts by experience’ to assist the regulator at the point of assessment and inspection. In terms of economic regulation, there is a need to integrate elements of quality into payment by results but these should represent quality as experienced by service users and carers - by integrating, for example, metrics of user satisfaction.\textsuperscript{vi}

F. Positive Accountability

There is a benefit to accountability mechanisms that champion the interests of more vulnerable users and promote service improvements that benefit service users more widely. For example, commissioners should be accountable to their local population for their decisions and how they reached them. Some of the headline policy is already in place for this, including the Section 11 duty to involve and consult and similar provisions for local authorities in relation to social care. Overview and scrutiny is becoming well established. However, we need a more effective input of service users in terms of accountability.

We believe that we should not invent new institutions, but build robust processes for ensuring that service users and the public are effectively engaged in decisions.
Overview and scrutiny

Overview and scrutiny needs to be nimble enough to cope with change and challenge decisions where needed, including dealing with ‘failing’ organisations. Local authorities have a community leadership role and there are ways to support Overview and Scrutiny Committees (OSC) to achieve this:

- join up planning cycles;
- promote the wider use of ‘forward plans’ by the NHS bodies relating to substantial service changes (similar to local authority executive forward plans of key decisions) to enable the OSC to scrutinise consultation plans;
- clarify what counts as ‘substantial’ service changes at different levels of the region, sub-region and locality;
- give flexible powers to the Independent Reconfiguration Panel to ‘mediate’ disagreements;
- explore an option of reduced scrutiny to bodies such as Foundation Trusts with significant membership, if they have already widely canvassed proposals for change;
- select key patient pathways to review, such as the needs of elderly people that are housebound.

Forums

There are a number of individual members of Patient and Public Involvement (PPI) Forums (health), user groups such as older peoples’ forums (social care) and members of Foundation Trusts that can engage with commissioners / providers in new ways. Thirty two current Foundation Trusts, for example, have a membership of 475,000 people. There are options for consideration and further consultation that could advance these, including action to:

- allow for a more flexible, less bureaucratic approach than has been the case for PPI Forums;
- focus their work on the core goal of accountability rather than ongoing monitoring of services;
- enable user groups, such as PPI Forums, to merge so that they benefit from being co-terminous with local authorities and new PCTs;
- give a choice to PPI Forums for them to select their preferred organisation to support and perhaps host them;
- ensure that user involvement is adequately resourced, with core support to co-ordinate its activities and promote involvement;
- strengthen the participation of user and community organisations to broaden the base of involvement;
- decentralise financial support to make the most of what PPI Forums receive;
- explore close working relationship with OSC with agreed joint activity and linked support through pooled budgets;
- explore integrated approaches to look at the needs of the same users across health and social care.
Voluntary and Community Sector

User groups and wider voluntary and community organisations tend to have strong independence and typically, a good connection with the constituencies they are advocates for. There are positive ways to support these groups to get much greater input to involvement.

In other public service sectors, such as regeneration and volunteering, government has been far more active in support of networks and infrastructures that can allow voluntary organisations to thrive. There is therefore sense in exploring how to support the voice and advocacy of the voluntary sector in improving services, through

- a separate designation for user representation in the Section 64 General Scheme of Grants run by the Department of Health, and

- an expression of interest for funding a national network for patient, carers and user-focused organisations, to assist organisations to develop and to allow them to engage in strategic policy change.xvii

- enabling the new learning centre on patient and public involvement to engage and benefit a wide range of user-led and community-based groups.
Having My Say Conclusion

If we get the systems right, we can use people’s voice to create a virtuous cycle of improving the patient experience. Some of the infrastructure is in place for public and user involvement, such as duties on consultation, but it is not being done properly and there are more creative ways of engaging people than are deployed. Such involvement will improve services if it is integrated into every level that decisions are taken in health and social care – but it is not effective as an add-on.

Drawing on the work of the taskforce, the key recommendations I make to the Secretary of State are therefore to:

1. Set a priority for action on improving involvement around commissioning. An example is for commissioning bodies to nominate consumer advocates at senior level, to ensure that they understand the needs and expectations of service users and carers.

2. Use the opportunity of new legislation to introduce a clear and strong user focus into the statutory objectives for the new regulatory framework for health and social care.

3. Promote voluntary action by health and social care providers of a better quality of engagement through a new Participation Standard.

4. Set compliance with involvement and consultation as a high priority within the new inspection and assessment regime.

5. Introduce an easy-to-use complaints approach covering health and social care, probably based upon a single gateway and process, to manage complaints across different providers, and ensure that these form part of all contract agreements.

6. Promote a more focused role for Patient and Public Involvement forums, with greater flexibility to connect up to support and host organisations and to operate in new ways.

7. Promote an active role for the voluntary, community and social enterprise sector, including through an expression of interest for funding a national network for patient, carers and user-focused organisations to assist them to develop and to improve services on the ground.

In summary, policy action to enable people to have their say, by putting strong systems in place to capture their views, will assist providers and commissioners to keep abreast of changing expectations and ensure that services meet the needs of the many rather than the few.
Annex A: Having My Say Taskforce Membership

Chair: Ed Mayo - National Consumer Council

Sharon Grant (CPPIH)
Anne Roberts (Crossroads)
Anna Coote (Healthcare Commission)
Elizabeth Manero (Health Link)
Jonathan Ellis (Patient Forum)
Jane Martin (Centre for Public Scrutiny)
Jo Lenaghan (Birmingham and the Black Country SHA)
Dr Bryan Fisher (NHS Alliance)
Jabeer Butt (REU)
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Sue Slipman (NHS Foundation Trust Network)
Emma Jenkins (LGA)
David Pink (LMCA)
Henry Tam (Home Office)
Philip Hurst (Age Concern)
Stephen Lowe (Age Concern)
Frances Hasler (CSIC)
Jeff Jerome (ADSS)
Gary Fereday (NHS Confederation)
Annex B

Having My Say Principles

1. The ability of people to have a say is essential to ensure that high quality health and social care services are available to meet their future needs.

- People, as active or potential service users and as members of the public, want to be able to have a better say in relation to health and social care services. Those services are better all round when the views and experiences of people using them are systematically taken into account. Without such a say, they are significantly less effective.
- Service users should have a say through the individual choices they make and encounters they have with professionals. But they also need a say in shared ways, to shape what choices are on offer and to ensure that more vulnerable users do not lose out.

2. The right kind of involvement is needed at every stage of the design, delivery and evaluation of services.

- There should be an involvement with service users and the public at every level at which decisions are taken in health and social care.
- The responsibility for giving service users a say should rest with the decision makers responsible for commissioning and providing services.

3. The quality of involvement matters but can be achieved in different ways.

- Arrangements to engage people need to be simple, visible and consistent across local services. And they need to include the voices of more vulnerable service users, who may not always be heard.
- An effective way to promote a culture of involvement is to build more inclusive governance into programmes of health and care.

4. There needs to be a systematic way of encouraging decision-makers to listen and to respond to what they hear.

- There should be a less prescription on the structures decision-makers use to engage, to allow for more creative approaches, but an increased focus on their accountability, through scrutiny, inspection and regulation, for the quality of engagement and their responsiveness to it.
- There is a need to recognise and support the independent voice of voluntary organisations in shaping services for users.
This report is the Chair’s attempt to identify summary themes from wide ranging discussion within the taskforce at three meetings, and work by individuals between meetings. Although the timing was tight to achieve this, the taskforce saw its role as developing policy proposals that were rooted in the aspirations and ideas that emerged from the Listening Exercise. We benefited from the opportunity to engage in this way, and indeed used some of the ideas that emerged, such as Health MOTs, where the positive public view runs counter to a more negative health professional perspective, to test the robustness of our emerging recommendations.

We see it as very positive that government is getting out and about to listen through the public consultation. Having said this, the taskforce was clear that we also need to build future processes that are not shoe-horned into short-run consultations. This was reflected in the weakness of some of the survey deadlines, which reflect policy needs to extract information for decision-making rather than slower dialogue designed to co-create the policy itself.

The policy proposals explored in this paper are not fully worked up, do not necessarily have a full evidence base, nor are they likely to be comprehensive. But they are creative, and, if implemented with care and attention to detail, would make a very significant contribution to the future health and well-being of people out of hospitals.

This is not the place to analyse the Listening Exercise in depth. But, in summary, what we have seen is:

- When asked, and asked in the right way, people are willing and happy to engage.
- People are most comfortable responding to practical issues and ideas that relate to the service they get.
- People want the assurance of a good service, but few want to play a formal role in helping make that happen.
- People want to dip in and out of engagement rather than join formal structures
- People are wary of involvement in governance of services they use themselves
- There was strong relative support for user involvement in the process of commissioning, in particular.
- Policy-makers welcome more active users, because they can drive up service quality by seeking out the best for themselves. But most people’s actual appetite for involvement, in their own service or for others, should not be exaggerated.

Of course, commissioning is also a complex process. Right across public services, there are real weaknesses in how this is done, and procurement is implemented in relation to user needs. Commissioning will take place at many levels, from pooled budgets for a selection of services for a population, through PBC, PCT and LA commissioning to regional or national commissioning for specialist services.

Health services have extensive service use epidemiological datasets, but across public health issues, where it is people’s behaviour that matters, they often don’t know what is going on in people’s heads. The development of social marketing in the NHS reflects this insight – that to change behaviour, you have to see it from the perspective of the person concerned.

Equally, public deliberation and user involvement must itself be inclusive. To achieve this, there needs to be: an ongoing engagement, rather than relying on a series of short term activities around policy decisions; an active outreach to seldom-heard voices; and capacity building for key groups to develop their ability to voice their perspective.

Drawing on a proposal by the CBI, these include: being accredited by an external body (the CBI suggests the National Consumer Council); trained; involved in decisions on – design, specification, procurement, reviews, service monitoring and review.
Excellent opportunities exist to connect health and social care with innovative policy ideas around user empowerment, citizen governance and community development, that are being taken forward under the auspices of the Home Office (Together we can) and ODPM.

A systematic way for measuring this is being developed at present by Cabinet Office for user across public services. Including integrating this within future updates to the QOF for primary healthcare.

At present, all PCTs have boards that comprise a chair, non executive members and executive members. The role of the board is to provide strategic oversight and verification to the work of the Professional Executive Committee. There is useful learning on inclusive governance from Foundation Trusts. This proposal could therefore be to widen the non-executive membership to include local authority and user representation. Strategic Health Authorities too would benefit from inclusive governance, with user representation.

Alongside other voluntary and community sector providers. This could be supported by commissioning targets set for achieving user-led and wider voluntary and community sector provision in health and social care.

Indeed, there is a case for a customer facing service akin to the Patient Advice and Liaison Services (PALS) across all service providers, beyond the NHS and into social care. A 2 year national evaluation of PALS, commissioned by the Department of Health and led by researchers from the Centre for Public Health Research, Faculty of Health and Social Care, University of the West of England, began in January 2005. This will provide an opportunity to assess future developments in this service.

First tier complaints are typically directed, through an appropriate gateway, to service providers for resolution. Second tier complaints involve alternative dispute resolution mechanisms such as Ombudsmen.

This would include an objective to "embed a consistent approach to engaging service users and the public in decisions about health, well-being and social care."

This includes important work to see how to involve users in designing inspection approaches, gathering evidence and acting as members of inspection team or ‘experts by experience’. Also relevant is Monitor’s plan to produce a governance framework for Foundation Trusts that will encourage governors to develop their role, fulfil their statutory duties and increase the likelihood that corporate boards will listen carefully to them.

It is noticeable in the private sector, for example, that senior executive compensation has shifted over the last ten years from sales figures, which are easier to manipulate and talk only to today, to measures of customer satisfaction, which are more robust and talk also to future performance.

These could be linked to health inequalities, so that public funding helps to support the voice of those users that are likely to be relatively disadvantaged or vulnerable in the emerging new mixed economy of health and social care.