



## **NHS Alliance “Three at the Top” Conference**

### **WORKSHOP ON INVOLVING THE PUBLIC: “CAN IT WORK? DOES IT WORK?”**

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**Notes:** about a dozen people attended this workshop: chairs and chief executives of PCTs and chairs of PECs. Dr David Jenner, a GP whose practice is in Cullompton, Devon, chaired the workshop.

Non-attributable notes of the discussion were taken by MAC colleague Valerie Moore and used in the annotations (pp. 6-13) which follow the handout slides (pp 1-5) .

## **Involving the public: ethics + aspiration + statute**

**ethical dimension** - moral axiom *“nothing about us without us”*

**aspirational dimension** - user involvement, patient experience and “patient focus” are pillars of Clinical Governance and (draft) *Health Care Standards under the NHS* - eg “Patient Focus” developmental standards D6-D7 state users must receive information when they need and want it and be actively encouraged to become experts in managing their conditions and daily lives

**legal dimension** - Section 11, Health and Social Care Act 2001  
duty to involve and consult patients, carers and public *“...directly or through representatives...”*



## **Involving the public: user wants and needs evidence**

### What the public wants from its NHS (CHI, *Getting Better?* 2003)

- treatment that is effective and delivers good outcomes
- services that are quick and easy to use
- services that are well organised
- to be treated with dignity and respect
- to be treated in places that are safe, clean and comfortable

### What the ideal patient experience means (DH, *Patient Experience*, 2004)

- Taking pride in good service treating me well and being involved in decision making

### What choice means to patients (MORI/DH, *Choice Consultation*, 2004)

- not more choice of hospital and doctor so much as being involved in deciding what is going on wherever it is happening



## **Involving the public: reality checking the evidence in 2004**

**ethical** - NCC Policy Commission on Public Services found

*“...**choice** and **voice** should be extended in order to rebalance services away from provider interests and towards the interests of users.”*

**aspirational** - Strategic Leadership of Clinical Governance in PCTs found

*“most had not yet developed the systems and processes to secure an effective local representative voice in all aspects of the planning, delivering and monitoring of their provided or commissioned services.”*

**legal** - Learning on PPI from CHI's work found involvement is not yet *“part of the corporate bloodstream ... there is a brick wall between activities going on and changes on the ground that happen as a result.”*



**Involving the public:  
Challenges for the NHS and its public**

**patients, carers, users, public, consumers,  
citizens .....**

All of them?  
Some of them?  
None of them?  
Beyond them all?



## Discussion Notes and Annotations

### **Involving the public: what do you think about the two big questions?**

#### **▪ CAN INVOLVEMENT WORK?**

Workshop participants general view was “yes, public involvement can work”, but not automatically. The right policies had to be facilitated and supported (people and resources) to achieve anything.

#### **▪ DOES INVOLVEMENT WORK?**

The workshop’s view was a (qualified) “no, what we were doing wasn’t working (or at least not generating much evidence of success) as it was currently being done in most PCTs.”

The reasons were: most PPI activity was seen as too policy-heavy, DH led and performance driven; too concerned with structures. Most seriously, it ducked the power sharing issues in health care that had to be addressed. PPI was fundamentally about identifying and sharing power. There was too much reluctance to use the “P words” together: Public+patients=power. Anxieties and opposition from managers and clinicians had to be identified and addressed about this.

The traditionally passive “patient culture” also had to change if users and carers were going to handle shared power in a positive way.

### **Do we believe in it?**

The view was that throughout the NHS some do and some don’t believe in public and user involvement for a complex of reasons. There was a consensus that some professionals (clinical and managerial), often for mixed reasons, did not want to share power with “lay people”. But it was not good demonising “the professionals”. We had to understand their negative motivation and address their positives through persuasion about PPI.

Patients and carers should always have been at the front of health service providers’ minds. It shouldn’t need to be stated and restated as policy that this should happen. The more the policy on involving users has to be stressed, the less it is likely to be happening in practice “on the ground” where it really matters.

## Do we know what it's for?

The group acknowledged that there was lots of muddy thinking on this point. Was involvement an end in itself, or was it a means to achieve something else? If so, what was that “something else” and was the NHS being straight with the public about it? For example, with shared decision making came shared responsibility for the decisions taken. This could involve prioritising scarce resources, which would not be to everyone's liking. Was shifting some of the responsibility for the NHS on to users ethical? Access to power and capacity questions came in here and we needed to be honest with ourselves about this.

Health is understood by most people to be good in itself for themselves, their families and their communities, but they intuitively understand “health” as far wider than the NHS or “health services”. Statutory bodies like the NHS and local authorities have to take risks with the wider “real health” issues in which people want to have a say and not confine opportunities to input user views just to “services”. Both the NHS and local government have to do this jointly because that is the way local people see things, not in neat bureaucratic or funding boxes. If this joint approach doesn't happen, no one will make the time to get or stay involved for very long.

The tenants' movement in the social housing sector was put forward as a good example of people getting involved because they have a real stake in the process and the outcome. The NHS could learn from some examples outside health and social care. The impetus behind Foundation Hospitals as public benefit corporations should be followed for what it might, or might not, be able to teach us in primary care. It was a pity that the “foundation idea” was not tried first in PCTs anyway.

At any one time an individual can be: a patient, a member of the public, a tax payer, a carer and have different views and perspectives on health issues by virtue of their multiple roles. PPI in the NHS has to be flexible enough to take account of this ; there is no such thing as a single or simple “patient's view”.

## Do we know how to do it?

Not enough people know how and not enough people do it well. It is not “someone else's job”, but everyone's.

The NHS must hear the voices from a wider range than just current “patients”. Many younger and more affluent NHS users don't see themselves as patients anyway and they may be using services for reasons of health not illness, for example women with a normal pregnancy or people wanting travel immunisations.

Formal business meetings during the day in NHS premises are off-putting to most people, even if they have the time to attend. Committee processes are de-powering by their very nature.

AGMs can be the epitome of dullness, but there are ways to enliven them and get the formal work done too. Turning the AGM into a “health fair” or some similar participative event that is visual, interactive and interesting can pull in an audience. Having “talking tables” around the room staffed by enthusiastic and well-informed NHS staff who can give attendees information and offer opportunities to get involved has worked for some PCTs and Trusts.

Always going to the “usual suspects” -- who are often other types of professionals anyway -- cuts off opportunities (though they are harder to switch on and sustain) to reach out to more and different kinds of people. People involved in PPI know this, but short time scales and pressure to get something done often override efforts to look further afield.

“Participation fatigue” is a real factor; people switch off when they get involved around a big consultation and then they get no feedback about their views. They get the message that it didn’t mean anything and they won’t make the same mistake twice.

Jargon really puts people down by sealing them off from understanding and influence. It is one of the strongest and often unintentional signals the NHS sends to lay people that they are on the outside not on the inside. Many health professionals don’t understand all of the jargon either, of course, but they will never admit it because that would show weakness. Never assume that people even know what the letters “PCT” stand for or what a Primary Care Trust does!

## Do we have the power and the right tools?

In theory yes, but in practice more can probably be achieved by not using the power overtly but relying instead on persuasion backed by the sanctions of power. Section 11 of the 2001 Health and Social Care Act and the copious guidance linked to it should be more than enough, though it could have more about local participation at GP practice level. GPs and primary care staff in practices should be more central to public and user involvement. Do they feel they have the right tools and attitudes to do it? Is anyone taking the time to ask them? Just giving them copies of Section 11 guidance isn’t sufficient.

There are many sources of information and examples of good practice on the web, eg the NatPact site.

We cannot wait for legislation to make us healthy (said in reference to the Wanless Report and the forthcoming public health White Paper and what might flow from it), though legislation could be used to curb unsocial activities like smoking and alcohol misuse which have significant health consequences.

Getting people involved around behavioural issues that affect health could be a way to increase engagement, but would need careful handling.

## Does it make a difference?

The general view of the group can be summed up as “agnostic, but aspirational and living in hope”.

## Do we know what success looks like?

It isn't about putting lay people on every PCT committee for the sake of appearances. Being present does not automatically equate with being supported to make a contribution. If users are on committees and groups, they must be enabled to contribute to the full range of the work not just bits and pieces of it.

Consider the stalagmite and stalactite metaphor: rising up from the bottom, the stalagmite of local improvement through involvement is strong and well rooted. The stalactite of centralised policy coming down from the top is often brittle and doesn't have a firm anchor. The moral is “bottom up is better than top down” when it comes to success and user involvement.

We don't identify enough “paybacks” to people as tokens for their continued involvement (eg satisfaction, influence, knowledge, esteem)

Where there are measurable and describable successes, involvement has been linked to specific issues rather than generalities.

Real involvement can be one-off or ad hoc and lay people have the right to define how and when they engage. The professional objective for an ongoing system of involvement may not be achievable, but what can be there is a way to opt in when people want to.

## Do we have the evidence of improvement?

Evidence is hard to find. Where is the evidence that could be provided by participation in grassroots patients groups at surgery level? Why is this sort of direct involvement so hard to find around the country? This is ironic because surveys demonstrate repeatedly that GPs are the most “trusted” source of health information and advice, yet we know there are widespread dissatisfactions with primary care services through the surgery in some places, eg access and appointment times. Many GPs could do with some “patient friends” to help them do things differently, but there may not be the mutual trust and perception of time available to listen to each other.

Patients groups can provide the space and time for real discussions amongst “friends”. The new GMS/PMS contract may help people see this as a realistic possibility. But practices will need help and encouragement to understand how to bring it about and it will have to make sense in financial terms.

## Do we want to do things differently?

Yes. The workshop felt that what was missing in most areas (with a few honourable exceptions), was a way for users to engage at GP practice/clinic level. This would create a critical mass of participation at the grass roots reaching far beyond the "usual subjects". It would also provide the "legs" for other PPI initiatives and the recruits with the capacity to engage in a more structured way with the PCT.

## Flip chart key points from workshop discussion

- **Must hear voices of users – don't just put them on committees**
- **If users are on committees they must be enabled to contribute**
- **Patients and carers should always have been at forefront of health service providers – we did not need it to be announced as policy**
- **The “usual suspects” can be another sort of professional - need to involve more and different people**
- **Some interested patients and members of the public have given up having been “involved” many times before to no real effect**
- **Formal wide ranging business meetings put off ordinary people – they feel powerless**
- **Do the professionals really want to share power?**
- **(see Tenant movement as successful example of public and user involvement)**
- **Health is important to people but they have to feel they can make a difference or they will not give up time to become involved**
- **People “trust” their GPs but they are not satisfied overall with health services**
- **“Public” means wider than users**
- **Who is the consumer/user of health service – not just patients also DoH, SHAs, etc etc.**
- **Individual can be a patient, a member of the public, a tax payer, a carer, etc etc at different times or even simultaneously and have different views/perspective in each role**
- **Local Authority could/should be more accountable than health provider**
- **Where are the grassroots patient groups at surgery level? Why are there so few?**
- **Some places have widespread, thriving groups – is this because they are supported/funded?**
- **Is there evidence that PPI leads to improvement?**

- **Involvement in more attractive when related to specific issues**
- **The stalagmite of improvement is strong and well founded where as the stalactite is thin – ie grassroots up is better than top down**
- **Everyone wants a “payback” of some sort for their continued involvement (satisfaction, influence, knowledge, etc)**
- **Real involvement may be one off or ad hoc – a structure that requires permanent involvement may not be more stable**
- **Jargon shuts people out**
- **Board meetings and AGMs can be boring and put people off**
- **AGMs can be made more interesting – health fairs and similar imaginative information sharing participative events are more interesting and better attended than AGMs – make it fun – make it visual.**
- **People are (or should be!) interested in health more than health services**
- **Cannot wait for legislation to make us healthy (although where legislation exists it has been effective in changing unhealthy behaviour).**
- **Unhealthy behaviour may be shown to be anti social and that may stop people**
- **People soon spit when consultation is only a gesture – they want genuine engagement**
- **GPs could be more central to PPI but some GPs are reluctant about empowering/interacting with their patients**
- **How do we change the outlook of GPs who are overworked, part time, worried)**
- **Persuade GPs to listen to their patients because it will benefit their own practice**
- **Advantage of Patient Groups is that there is real discussion amongst “friends”**

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