

## **NOTE TO CEAN READERS:**

*This article pertains to the UK's National Health Service and its own model of Patient and Public Involvement (PPI). We hope you find this of interest. Please bear in mind that the context is slightly different for CEAN members in VCH, because PPI is not mandated by legislation in BC, as it is in the UK; patient advisors in the UK have different responsibilities. However, we hope that CEAN members who are asked to take part in VCH committees will find much to illuminate and inspire in this thoughtful article.*

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### **15            A change of heart** *David Gilbert*

#### **“So, David, what do patients think?” Origins of a dilemma**

After recovering from mental health problems, I wanted to improve things for others – to campaign for change, and support people through similar hardship. I joined my Community Health Council and local chapter of Mind and found myself on various local NHS committees, faced by a dozen powerful, well-paid, suited, professionals. They'd ignore me, or inquire at odd moments: “so, David, what do patients think?”

“What, *all* of them?” I thought. Since I was there to ‘provide the user perspective’, I told them about my experiences - both good and bad. Some thought: ‘Great - here’s someone telling it like it is at the coal face.’ Others smiled benignly... or fell asleep. They wanted me to be ‘representative’ and go beyond my personal experience, but nobody could tell me what that meant.

So I forged relationships with service users, carers, members of the community and local groups. When I reported back their views, those who had previously seen me as credible, because I talked from experience, switched off. Those who had wanted me to be more representative had moved on to ‘more important’ matters: quality, risk and budgets.

In effect, I was used as free labour, marginalised as a quasi-operational lead for patient and public involvement, and exhausted myself (and other victims of consultation fatigue) in the process... and guess what ? My reports sat on the shelf and nothing changed. At the beginning I had been marginalised as ‘not knowing enough’ to contribute but now I knew ‘too much’.

So, what was my role? This chapter is about what I know now that I wish I had known then. Hopefully it will be useful for those who find themselves as ‘lay representatives’ that

is, people who find themselves in the ‘professional’ arena representing those who have experience of services but are not ‘professional’ health care workers.

### **The Outsider-Inside – The effective patient and community representative**

‘Experts’ complain that not many people get engaged with public services and assert that this is due to apathy and disillusionment with the political process<sup>1</sup>. Others see public services being reformed and cry out for people’s involvement in decision making<sup>2</sup>. What seems to escape both is that there are about 50,000 health-related voluntary sector organizations and half a million people involved in formal governing bodies<sup>3</sup>. Millions of people volunteer their time, take part in focus groups, fill in questionnaires, get consulted on local service changes, sit on interminable committees on cold February nights, and really care about health and health services.

One problem is the *numbers* of people coming through the ranks and the need to create further opportunities for those who give one off views in surveys so they are able to sit at the decision making tables and talk with the people in power. The other problem is competency - how to make sure that these people have the resources (money, skills, support, etc) to take part.

In Shrek 2, the talkative donkey and Shrek are in a dungeon. Donkey rants that he has “the right to remain silent ...”. Shrek replies wearily: “Donkey, you have the right, but do you have the *capacity*?” Likewise with Patient and Public Involvement (PPI) there is now a statutory duty for all NHS bodies to involve people in decision making<sup>4</sup> but few have the capacity to make it real and those who wish to make it real may also lack capacity.

What I always needed but never got, was the support and training to make me an effective patient and community representative, clear in my role and confident in my abilities to change things.

What I have learnt is that patient or community (lay) representatives are ‘**outsiders-inside**’ and must simultaneously play two roles:

- **Community link** – externally facing, keeping in touch with local communities and bringing in wider perspectives.
- **Critical friend** – internally facing, flying the patient flag and offering strategic advice from a non-institutional perspective.

The Patient and Community Engagement (PACE) Team at the former NHSU (which was to have been the ‘corporate university for the NHS’) found that lay representatives:

- wanted clarity about their role, even though there was little consensus on what the role entailed or what was expected from them in terms of gathering views;
- had to balance what they did outside the organisation (linking with communities) and what they did inside (as ‘critical friends’);

- needed to establish legitimacy to gain influence which depended on flexibility to respond to specific situations;
- were motivated by personal experience, but needed to move beyond this and avoid doing work that paid staff were responsible for;
- did different things to get patients' perspectives integrated into decision-making;
- had to strike a tricky balance between being supportive of decision-makers and being independent and challenging, with little support or guidance on how to achieve this.

### **What matters to patients, carers and the public – the dimensions of the ‘patient’s experience’.**

Ask any user of services what matters to them and they will have an opinion. Most people involved in trying to improve things for patients are motivated by experience; some grateful who want to give something back, others damaged who want to demand change. Without this passion and commitment the decision-making tables would be even more sterile places.

The downside is not that people ‘have an axe to grind’ but that their sight is partial. If my problem as a patient was not getting access to services, then it would be hard for me to fully understand that this is not the only thing that matters to patients and carers. If I have had poor treatment, how would I know that dissatisfaction is not the norm?

But you don’t *have* to know everything! You only need to know broadly what the research evidence says matters to patients, and become conscious of your own experience and how these two aspects – experience and evidence – relate to each other.

On the whole, the things that matter to patients and carers are:

1. Getting better, feeling better (outcomes of care);
2. Getting the right care from the right people (clinical quality);
3. Being treated as a human being (humanity of care). Including respect, dignity, etc;
4. Information, communication, having a say (involvement) –including receiving information, clear explanations and being able to participate actively in decisions about treatment options;
5. Being supported – practical and emotional support including access to statutory and voluntary sector services;
6. Support for carers and relatives;

7. A safe, clean, comfortable place to be (environment of care) –including privacy, hygiene, food;
8. Right treatment at the right *time* (access 1) –including prompt response to an emergency; timely access to car, short waits, etc.
9. Right treatment in the right *place* (access 2) – convenient locations; transport; parking, etc.
10. Not being passed from pillar to post (continuity) – a smooth ‘journey’ through primary to/from secondary care, etc.
11. Continuous care – ‘after care’, support in the community, etc.

Numbers 2 – 7 should be there at each stage of our care. Numbers 8 – 11 are about receiving *continuous* care. These things are important for all of us, regardless of circumstance or health problem. On top of this, there are particular needs for specific groups or particular barriers that people from different parts of society face when trying to get the things they need. Therefore, diversity and equality issues are central to all 11 dimensions.

### **Reframing my own experience**

So how do these dimensions relate to my own experience? And how should I bring both personal experience and what matters to others, to the table?

The temptation has been to exaggerate the drama of aspects of my own poor clinical care or to think I have nothing to say. One of my blind spots is a legacy of feeling vulnerable because of my illness and imagining that doctors must be heroes who know everything and should cure me. When I was ill I did not want choice, only for the pain to go away. I was a child wanting daddy or mummy doctor to magic me better. I think the paternalistic medical model survives in a modern uncertain world mostly because of a primitive desire to be looked after.

So I took my pills compliantly and prayed they would work. The collusion was complete – doctors and nurses did not need to give me information and were absolved of the need to chart the difficult waters of shared decisions. I complied with my own need to stay ignorant. I did not dare to challenge this conspiracy of power and dependence.

It is all too easy to concentrate on the non-clinical aspects of care that I ‘know about’, the environment of care and patient information. However, the 11 patient experience dimensions help us to take a broader view.

Maybe I should gag myself and not tell my personal story at the decision making table? Not at all, the *judicious* use of story telling – the use of narrative – can be very powerful. Health professionals deride the ‘anecdote’ but actually use them more frequently than lay representatives! Story-tellers and poets know that they can illustrate a wider truth and reframe issues in useful ways. The secret is in when and how to use them.

## The lay representative and PPI

When it comes to what patients think, health professionals often mistake a decision making forum for a focus group. One cause for this lies in terminology. The term ‘lay representative’ implies that such individuals should be a conduit for patient views or, more dangerously, the *only* conduit for them, or more dangerously still, the one who goes out to *get* those views. I believe the lay representatives should not be, or do any of these things. He or she should be a PPI *strategic advisor*, able to question and/or advise on ways that the organisation engages more widely.

The point here is not to outline what it takes to mainstream involvement – this is covered elsewhere but to think about a representative’s relationship to PPI. This can be done by charting the sort of journey a representative takes, looking at how their role shifts and what sort of support is needed on the way.

**1. From ‘doer’ to ‘advisor’** – In shifting the type of work they do, the representative will need to move from ‘doing’ engagement work to ‘advising’ others how to do it. Lay representatives may feel more comfortable going off and running discussion groups; it’s in their blood to find out ‘what the community wants’ and may keep them going after boring committee meetings (even though others may fall into the opposite trap - sitting on never-ending meetings and becoming divorced from the community reality). In this way they can maintain an ‘operational’ role which lets others off the hook. But this risks confusing their role with that of staff.

**2. From ‘PPI methods’ advisor to ‘organisational PPI’ advisor** – While shifting from doer to advisor, the representative should note that times have changed. The NHS is getting better at capturing the views of its patients, but still is not good at doing anything about them. The lay representative needs to shift from advising on the *techniques* of engagement (i.e. what sort of methods should be used to document peoples’ views) to advising on the *systems and processes* to ‘mainstream’ involvement and act upon findings from focus group discussions.

In the early stages, this may mean merely asking simple questions: ‘*we found out what patients thought but have we done anything about it?*’ Later it might be about identifying the way that reports from engagement feed into decision making: Who is accountable for this? How is PPI built into performance management and monitoring?

### Applying the learning

Earlier I tried to show how the response to the question, ‘so, David, what do patients think?’ should begin with framing the evidence of what matters to patients, reflected through the filter of personal experience. This can be supplemented with a question back to the others around the table: ‘*So, what has this group done to find out?*’. It becomes a shared responsibility and the lay representative should not have to find out everything themselves. They can offer pointers, but when they respond in this way, others are more likely to contribute. The lay representative may feel ‘less special’, but I have learned the hard way that this approach yields more action. And isn’t that what it’s all about?

## **The effective insider – keeping it real**

The central role of the effective insider is to keep discussions focused on what matters to patients. We have seen above that there are several ways in which a lay representative can avoid being seduced into wider operational matters. But when it comes to being at the decision-making table, more subtle skills are needed.

Asking the simple question ‘what does that mean for patients?’ is useful but overdoing it may make you seem naïve. Challenging the flow of a discussion in a similar vein can be valuable – “I’m not sure how much relevance this has to the patient-centred values we were talking about earlier?”.

But what sort of other skills help?

**1. Communication and presentation skills** – Many representatives say they want to listen and communicate better, to work on their own ‘attitudes’ or ‘confidence’. The overriding issue is a need to build self-reflection into learning activities. People need to relate to different audiences and this requires flexibility of styles. Presenting your case in a committee setting requires different skills to speaking at a public event, to patient groups or the media.

**2. Knowledge and understanding of healthcare** - Lay representatives need to know enough, but not become embroiled in the systems and processes of healthcare. Such learning needs to be relevant to the local circumstances and the role they are fulfilling. It is more important to know how to find the learning when you need it. A list of who to go to for different types of support and information at the beginning of a project or new role is invaluable.

**3. Analytical skills** – The representative is constantly faced with blizzards of facts, statistics and jargon. They need to understand information from the community (e.g. demographics, public health, analysing patient views) but also how to deal with data around healthcare providers. How do we critique information that comes from a different world? Again, the issue is not so much what sort of information should we be looking at, but “where do we go to find someone to help us”.

**4. ‘Critical friend’ skills** – The notion that patients and the public can be ‘critical friends’ is seductive. If I could have done this from the beginning perhaps I could have asked challenging questions in a more charming way. Lay representatives have to deal with professionals face to face, cope with feelings of vulnerability and know how to frame questions. Some will feel more comfortable with this than others. Being able to ask challenging questions in a non-threatening way is about more than just assertiveness training. But there will be times when asking the tough hard question is the right thing to do even if you are not appreciated for it, just as there will be times when it is the wrong thing to do.

**5. Influencing skills** – People also have to master some of the ‘darker’ arts of persuasion and behind the scenes influencing; all the things we learn by doing and the topics that are not valued in conventional learning programmes. People should learn how to use different influencing styles with different sorts of audiences, about negotiation skills and understanding where power lies.

## **Personal challenges**

The following list is derived from my own botched attempts at being a lay representative at various levels, local, national and international. They are the things I found and still find most difficult.

### **1. Being professional**

We have all heard professionals say that lay representatives should not become ‘too professional’. In fact lay representatives say it just as much. But those purporting to articulate the interests of patients and the public should be *more* professional. They should understand their role, be clear about what they are doing and how, be supported to do a good job, have clear shared agreements with others about how they conduct their business, take responsibility, feedback their views to the communities they serve and to the organisation, and behave responsibly. This is the essence of being professional.

We should not however, conflate ‘being professional’ with ‘going native’ – that is to confuse two meanings of ‘professional’ i.e. to do the job that should be done by health professionals and the need to ‘behave professionally’.

Some might argue that patients and the public should not be expected to take on this onerous role. But this argument is usually invoked by clinicians who are used to dealing with individual patients and not lay representatives. However, I have sometimes heard ineffective lay representatives argue in the same vein, unwittingly colluding with the very people they want to challenge.

What brings most people to be involved are personal values. The danger in too much experience of involvement is the loss of passion, but this danger is over-stated. It is not about ‘leaving personal baggage behind’, but being able to pack it in a smarter bag.

If people really care and are still linked to the world of patients through their own networks, the passion never goes away but is continually reframed in the light of experience. Good lay representatives are always seeking to sharpen their arguments and focus, always seeking the right point at which to make a crucial intervention. The second thing that happens is that professionals start to share the enthusiasm and passion of the lay representatives; the language spoken around the table becomes more animated. In fact, lay representatives can give permission to others to break free of their own restrictive debates, sterile and self-serving language. Not surprisingly, health professionals have their own tales of suffering to relate. We become more human by engaging in debate about what matters to patients.

### **2. Being representative**

So, how can one person possibly ‘represent’ the views of an entire community? I have tackled that by proposing that the lay representative focuses broadly on what matters to patients and forges a link between the health care organisation and the community rather than does it all themselves. I suggest that lay representatives never have been, never will be able to be, never should be seen as, truly representative. It is an impossible dream.

I am not a political theorist but I am pretty sure even a cursory glance at the role of the MP will put the lie to the possibility of someone being able to represent the total community's perspectives. Instead, what a good MP does to best serve the 'interests' of his or her community is to know what matters to them, know how to link with them, and understand the priorities.

How can I argue that lay representatives go beyond the personal and do not need to run focus groups or link extensively with all communities in their patch as part of their role? Without these mechanisms surely they may become decoupled from their roots? How can I propose that lay representatives are not the sole conduit for patient views but instead become some sort of catalyst or roving strategic PPI advisor? Perhaps anyone could do the job and lay representatives must be prevented from being representative, or that 'real' patients are not needed to do the job. No, being a patient or having had an experience of healthcare is necessary, *but not sufficient*.

In fact, I want to ban the phrase 'lay representative' despite having littered this chapter with it. First because the word 'lay' derives from the word 'laity' and refers to when the priesthood held sway. Secondly, because my argument is that the role should be 'advisory'. People should instead start thinking of themselves as patient and public advisors.

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