

THE SOUND OF ONE HAND CLAPPING? THE EXPERIENCES OF STAFF IN INVOLVEMENT AND PARTICIPATION

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The Missing Perspective

Discussions about Patient and Public Involvement (PPI) tend to concentrate on service users so that what it means for staff is rarely discussed, but no sound of clapping comes from one hand. This article emphasises the importance of understanding staff perspectives in developing sustainable involvement.

4Ps is a specialist agency that prepares staff to work in partnership with patients and the public. The London Specialised Commissioning Group (LSCG) commissioned 4Ps to develop the 'Expert Staff' part of their tripartite Living Well programme. A series of workshops were run with staff from six London HIV services. The workshops gave staff time to reflect on changes, to explore how macro policies were impacting on them, to identify how and what they could

Below: The 4Ps group



influence and in particular how they could lead a renewed PPI agenda. The issues that emerged and actions that followed are described below.

Then and Now

Involvement and participation have been on the health agenda for a long time but it reached a high point in the development of HIV services.

“In the early days of the epidemic, staff were attracted to a new area of work and often shared the social characteristics of their patients and a commitment to civil rights.”

They campaigned together for appropriate services as well as lobbying for gay rights. The nature of the disease meant intense involvement as patients and staff struggled to find a 'cure', to identify the best ways of caring for those with HIV and to cope with the inevitable deaths. Together they succeeded in getting resources, user-led services were established and gay rights legislation enacted. HIV services are the only NHS services jointly developed by patients and service providers. This has left its legacy in that HIV services are still perhaps the most patient sensitive of all NHS services.

The changing social characteristics of HIV patients and staff, funding arrangements and developing technology have all had implications for involvement practices. The biggest change concerned the socio-economic

characteristics of the user population. While the impact among gay men remains, the majority of new infections originate in Africa amongst heterosexuals.¹²

“New patients are now both men and women with a high proportion from African communities. They occupy a different place in the socio-economic hierarchy and this is reflected in their influence on the political and service agenda.”

Race and immigration are now the political issues of relevance.

Staff, too, have changed. People now come to work in HIV services because of job opportunities, often for experience before going back to work in their home countries, not necessarily because they share social characteristics of the users or are committed campaigners. So, we have different groups of staff and patients with differing expectations.

The welcome introduction of anti-retrovirals changed HIV care from acute and palliative to chronic, leading to concomitant changes in relationships. This meant that early care models were neither sustainable nor desirable. While staff could see that older models of care induced dependency rather than the independence they tried to create, the changes made them anxious about diminished intensity and quality of service. However, they also recognised that involvement-free, consumerist-style contact was

what some patients wanted. As well as these unique issues, there were some concerns that were reflected more widely within the NHS. How could they get more people involved in policy? Why weren't all staff, particularly medical staff, more fully engaged?

Engaging with the Patient and Public Agenda

The workshops for staff began by exploring the 'building bricks' of PPI: why develop PPI, how to engage with patients and advocates, how decision-making is shared and the need for feedback and dialogue. These were examined against current issues, practices and policies.

As 'homework', participants asked their colleagues to define what PPI meant. This quickly brought home the extent to which PPI has become a mantra without meaning (readers can test this for themselves).

“For one group the 'eureka moment' came when they realised that they as staff did not feel involved in decision making and that they were not even very good at talking to one another. Their first action was to take very practical steps to keep one another informed; necessary underpinning for coordinated care and PPI.”

The changes the participants made were small but profound. They thought they knew how good they were at providing information but had not usually tested their perceptions with patients. The challenge was how they could make information in their services specific and relevant to their patients, not something the NHS is good at. In one example, reception staff wrote the 'script' for telling patients about a walk-in clinic that recognised that even

the name 'walk-in' is jargon and liable to misinterpretation. Another group drew up an implementation plan for sharing records and correspondence with patients. However, setting up involvement groups and including other than the 'usual suspects' remained a problem until the numerous ways that people can be involved was appreciated. When the function of groups is clear and time is invested in preparation the outcomes are more satisfactory. Trust PPI leads and Volunteer Coordinators can be useful advisors.

Maintaining the Momentum

Groups of HIV staff are continuing to meet and there is cross-stimulation and challenge. Portfolios have been constructed of actions towards PPI that are shared with the group. These serve as a record of progress and as an incentive for further initiatives. Some participants have put PPI initiatives as a regular item on departmental meetings and others have set up special groups that involve all staff to allocate tasks and monitor progress against their action plan. One clinic piloted the Patient Friendly Recognition scheme¹³ and, with their help, this will be rolled out in other HIV clinics in South London.

The LSCG has agreed that Patient Friendly Recognition will be an audit tool for PPI.

Overall, the PPI development programme helped staff to:

- Acknowledge the magnitude of change in their service.
- Recognise that small things make a difference.
- Take responsibility for their sphere of influence.
- Build on what they were already doing.

Their experience demonstrated that it is the small things that matter to patients and that good patient engagement is built step-by-step.

Ultimately, participants took back to their services the understanding that patient involvement is about everything that health care professionals do and that it is different but related to public involvement. They became champions for PPI amongst colleagues and this was a necessary step on which to build the foundation for a meaningful partnership between staff and service users.

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Expert patients are informed, trained, and supported to be more involved in their health care i.e. to 'live well'.

Expert communities are expert patients supported to develop their skills, including how they can feedback into planning and run support groups.

Expert staff are skilled to engage with expert patients and communities. The aim is to enable them to work more effectively with patients and communities to influence how services are commissioned, developed and delivered.

¹² Health Protection Agency (2005) Mapping the Issues. HIV and Other Sexually Transmitted Infections in the United Kingdom, 2005. London: Health Protection Agency Centre for Infections.

¹³ See www.patientfriendly.org.uk