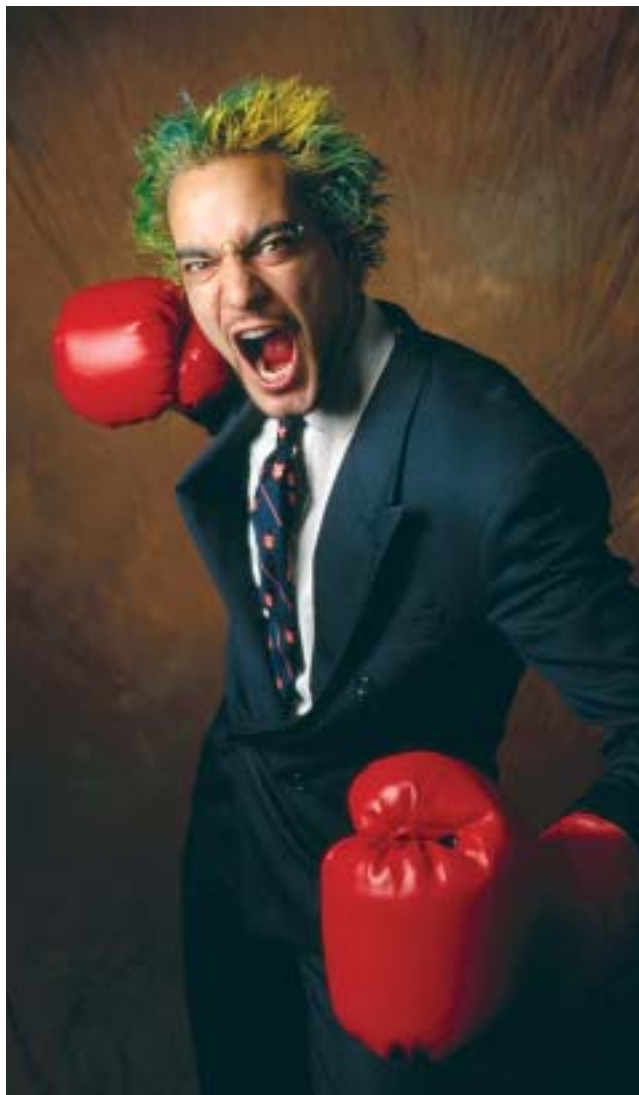


Fighting for survival

User involvement should not just be about getting better treatment. It should be about bringing about long-term change to society's attitudes, says Dr Michelle Cave of the Alliance.



What is user involvement, with whom are we involved and to do what?

This question has become more relevant to me over the past few years, as I have been involved in setting up groups. Some have flourished, while others have either limped on for a while in name only, or simply withered away. Those that have endured are committed to making desperately needed changes in their area, as a result of consistently poor services. Obviously this type of involvement is essential and must continue, as the only way change has come about is because the group members have persevered in difficult circumstances.

Clearly then, local groups are important, but in spite of this user involvement must entail more than just local treatment changes. If things are to improve, involvement has to be more than sitting in a room sponsored by a government organisation and talking. Talking in circumstances like these is only useful if there is someone taking it seriously. After all, you can talk until you are blue in the face, but if no-one is listening, all you end up with is a sore throat and a blue face. We must look beyond the local and immediate.

One way user involvement has strengthened its influence is by forming an association with other interested groups such as medics and academics. This alliance with like-minded professionals who are in positions of power has allowed us to implement some of our wishes – without them we are, in reality, powerless. Users have no formal or legal structures through which our opinions and beliefs can directly influence policy, so we literally depend on this support. While their co-operation is highly valued, it is not enough. Ultimately, it means that users still depend on powerful intermediaries.

As a result, it is almost impossible for us to influence the way we are perceived in society. If users are to ever find a place of legal acceptance, if we are ever going to see the right of someone to use quality drugs safely, we have to make major changes ourselves. We must be recognised without prejudice, as equal members of this society; to achieve this, users need to be part of the design and outcome of policy. Participation in the decision-making process is essential.

There are two prominent groups in our society who took the fight to the law makers and won. These are the gay and the women's

'Some flourish, some limp for a while, some wither away...'

Wiltshire Service User Group was featured in our 'Fact File' last autumn (DDN, 5 October, page 13) when the group was off to an optimistic good start. DDN talked to Ben Holtom about the group's unwilling demise.

'After such a good start in September last year and high optimism at the time of our Fact File article, our numbers dwindled rapidly and by Christmas we were

down to a hard core of five people,' says Ben Holtom, who set up the group.

'I assumed the authorities would continue to support the

initiative, but there has been an alternative process under-way to involve users and carers in the development of services,' he says.

Holtom is disappointed that the value of his group does not seem to have been recognised.

'People don't always like going one to one – they're not always ready to pour their heart out,' he says of local initiatives to involve service providers in user groups. 'It can be much easier for service users in a group situation.'

The group also felt its niche was to share members' skills with each other. Someone with counselling skills would listen to others; another member would teach others to cook.

It was important to the group to create its own dynamic, says Holtom. 'The group was empowering people – and people who were recovering wanted to help others. One woman who regained control after 15 years now wants to do some fundraising for the user group.'

Sharing practical skills was

movements; there was a time when both these groups were persecuted and gaoled. Forty years ago, predicting that a gay couple could freely marry in the twenty-first century would have seemed absurd. This group were medicalised and criminalised – just as drug users are today. Similarly, it was not long ago that women were considered incapable of rational thought; therefore exclusion from politics, education and anything else too demanding was routine. Unfortunately, many women were themselves convinced of this, so it meant the fight was even tougher than it needed to be.

It is from these two influential groups that user involvement could take models for action, ways to influence the organisations that govern our lives. We must strive to be involved in the argument ourselves – allowing others to do it for us means that important issues may be diluted or avoided completely, as they are not politically expedient.

This brings me back to the nature of user involvement. I would suggest that user involvement must result in more than improved drug treatment: life is much more than treatment, just as it is for anyone who attends some sort of clinic as a patient; we need to be making changes that affect the entirety of our way of life.

How do we aim to make these changes? Can we become a movement as the Gay population did?

I believe that we need to address the most important question of all – prohibition – important because of the massive impact it has on our lives. Everything related to drug use, the quality, cost and availability are all affected by the illicit status prohibition bestows upon it. While there is no quality-control of drugs, and people cannot be legally educated to use drugs safely, there will always be problems. Users need to put prohibition at the centre of the debate, if we are ever going to make a real difference to the way we are viewed in society. Treatment, while important, is not enough.

After all, what exactly are we being treated for? Are many of us in fact being medically treated for an opted lifestyle?

If we really want a different way of life, if we want to be able to choose freely, then we have to fight for it as the woman's movement and the gays did.

As Christabel Pankhurst said: 'We are not ashamed of what we have done, because, when you have a great cause to fight for, the moment of greatest humiliation is the moment when the spirit is proudest.'

a way of bringing chaotic users back to normality, he says. He knows of members who are still struggling, and who miss the group. He knows of someone who is drinking again, and another who's 'having a bad time'.

Holtom felt that Wiltshire SUG played the fundamental role of a user group – 'filling the black hole for users who are isolated and lonely after detox, with nowhere to turn to'. He's worried that individuals are not being accessed, particularly as

service users are spread over a rural area, and there is no money for transport.

'We should be supported as one of a number of vehicles that offer help,' he says. 'A user group shouldn't be fitted to what the service provider wants.'

'We can't make any progress because we're in a cloud of bureaucracy – pre-meetings, meetings, debriefing meetings. Politics shouldn't get in the way. It should be about the service users, not the service providers.' **DDN**

Post-its from Practice

Hepatitis C

Treating Hepatitis C patients is a stark reminder of the shocking state of Hep C treatment in this country, say Dr Chris Ford and Dr Janet Gillespie.

John had come back to get the results of his recent blood tests. Registered with us for the past six years, his drug use is very stable on 90mg of methadone but his major problem has always been alcohol, which he finds more problematic to control. He is also positive for Hepatitis C and because he was feeling more unwell, we had repeated his blood tests. A couple of years ago, he had attended our local hepatology clinic but had been told that he was not eligible for treatment due to his continuing use of drink and drugs. Sadly, his liver functions tests were worse and for the first time his alpha-fetoprotein was elevated, raising the possibility that he was developing liver cancer.

John's situation is not unusual. The prevalence of Hepatitis C is between 0.7 to 1 per cent of the UK population, equating to about 470,000 sufferers. Injecting drug users account for over 92 per cent of cases. Shockingly, Britain is the worst country in Europe at treating Hepatitis C infection, risking many lives because of inadequate screening and treatment for the illness. Less than 10 per cent of potential cases of infection have even been diagnosed.

The treatment situation is also appalling with only a tiny fraction of infected patients entering treatment. It is estimated that this lack of foresight will cost the NHS up to £8 billion over the next 30 years. Hepatitis C treatment now cures between 40 and 80 per cent of those infected. Early treatment may have prevented John's recent deterioration, but only 1-2 per cent of infected people in the UK receive NICE approved treatments, compared

with patients in France who are 6 to 12 times more likely to enter treatment programmes.

In our practice, (list size 14,000) we have 93 known patients who are positive for Hepatitis C. (Statistically, there should be 98 to 140 patients.) We have referred 38 of them, but only 4 (8.3 per cent) have commenced treatment. The other 34 have not been offered treated for a number of reasons, the commonest ones being because they continue to smoke or inject drugs or drink or have declined a liver biopsy. None of these are evidence-based reasons for refusing treatment, but seem to reflect opinion based medicine – perhaps something to do with the patient group who suffer this condition?

And why haven't the other 55 accepted our gentle persuasion for referral? Their reasons are varied: judgmental attitudes of hospital staff, out-of-date information about treatment, fear of the liver biopsy and feeling that they are not worth it. Many of them said they would accept treatment in general practice. This is now being done in a few areas and, for us, seems to be a practical way forward.

At 39 years old, John should not have to die from a preventable disease. With the necessary resources, support and funding, Hepatitis C treatment can and should be developed in general practice – it's our choice... and their lives!

Dr Chris Ford GP Lonsdale and Clinical Lead for SMMGP, and Dr Janet Gillespie GP Lonsdale Medical Centre

