

Goodbye community health councils – Hello patient forums

Malcolm Alexander, director of the Association of Community Health Councils for England and Wales, assesses the work of community health councils and offers advice to the new patient forums.

THE establishment of community health councils (CHCs) in 1974 was a bold and innovative experiment in user and public involvement. For the first time in the history of the NHS lay people had the responsibility of scrutinising their local health service, informing the public of their rights in health and representing the views of their communities.

For that first generation of volunteers the task ahead of them must have been extremely daunting. They faced a health service with little experience of listening to patients, a professional culture inclined to close ranks in the face of criticism and, perhaps most difficult of all, they faced a challenge that lay people had never faced before.

Looking back now it is clear that the experiment was a success. CHCs and their members rose to the challenge. Despite lack of resources and even outright hostility from some governments, CHCs have made a real impact on the delivery of UK health care.

WHAT COMMUNITY HEALTH COUNCILS ACHIEVED

Every CHC across England & Wales can point to a long list of achievements for patients. These accomplishments range from the small but vital changes such as improved signage and extended surgery hours, to successful and possibly life-saving campaigns such as the

saving of an accident and emergency department or removal from the General Medical Council register of an incompetent consultant. CHCs have also been involved in the development and building of new hospitals and primary care services.

At a national level many initiatives first developed by CHCs have now become accepted as an essential part of the health service. CHCs have been at the forefront of opening up the NHS to voice of the public and voluntary organisations. They have undertaken innovative and original work, spreading good practice across the NHS.

The CHCs have kept health service managers in touch with their local communities. They have helped and supported hundreds of thousands of people with complaints. Above all, CHCs have helped to give users confidence to challenge and question the people who provide their health service.

We now stand at the brink of a new period of patient and public involvement. CHCs are making way for whole new system of patient and public involvement with the patient forums. So what advice would CHCs have for the new bodies and the people who will make them up?

DON'T REINVENT THE WHEEL

Firstly, it's important to say that although the task ahead of building the

new structures may be daunting, the new patient forums have the great advantage of being able to draw on the enormous experience of CHCs.

If the transition to the new structures is handled well, there should be no need to reinvent the wheel. The experience of CHC staff and members will be crucial to the new system and it is to be hoped that every effort will be made to ensure that as many CHC members and staff as possible will transfer over to the new system.

It is clear then that CHCs will be a tough act to follow, but let me offer a few general words of advice to their successors.

Get your hands dirty. Being an effective patient representative, means being able to distinguish between the rhetoric and the reality. Yes, you will see glossy annual reviews from the trusts, you may even see statistics that show excellent performance by the trust; but what is the reality?

ADVICE TO PATIENT FORUMS

To get the true picture you will need to do some digging: you will need to visit the wards and speak to the patients and staff; you will need to draw on anonymised data from the complaints service; and you will also need to keep your ear to the ground, via public meetings and consultation exercises, to get the views of the local community.

Try and reflect good practice in your own organisation. If you want to be credible to the groups you represent, you will need to spend some time and energy on finding ways to engage with them. Ensure that your meetings are advertised widely and be sensitive to the languages spoken by different local communities.

Try to hold meetings on different nights and in different parts of the area you cover. Be conscious of all the different groups and communities, particularly those who are 'hard to reach'. Remember to be sensitive to very different understanding that different cultural groups will have of public involvement and participation and find out how best to communicate with and involve all the different communities in your area.

Don't forget children and young people who are not often represented. Some CHCs have established shadow CHCs in schools, both to elicit the views of children and to encourage them to engage in local issues.

Also, patient forums will need to use experts. You can't be expected to know everything and many issues of concern to patients touch on complicated legal and legislative questions, such as patient consent, or confidentiality and data protection. Experts are also useful if you wish to conduct a survey of patients and need help with methodology or with hard to understand acronym or jargon used by health managers and health professionals.

Lay people involved in patient representation will need the assistance of professional staff, if they are going to

perform their role effectively and staff need to be encouraged to communicate more effectively with the community.

SHARING INFORMATION

Patient forums will also need to share information. Sometimes you might feel that you are the only group dealing with a particular problem. In fact the problem may be much more widespread and sometimes patterns only begin to emerge when local groups share information. Meanwhile, perhaps colleagues in patient forums in other trusts may be able to suggest ways of dealing with the problem, or perhaps it is an issue that needs to be raised and tackled at a regional or even national level.

Nothing is set in stone. Patients and the public need effective representation; if you feel that your ability to deliver that representation is being hampered by a lack of independence, under-resourcing or inadequate statutory powers – make a fuss about it and if necessary use the local press or radio.

CHCs have a very proud record. For more than a quarter of a century, the network of over 200 CHCs in England and Wales have been a democratic and accountable part of the NHS, acting as a highly effective 'thorn in the

side' of both local and national health service policy makers and managers. The CHCs have had a massive effect on the standards of NHS care and have empowered patients and communities across the country. It is too soon to tell how the bodies that make up the new system will bed down, but if they learn from the past and have the courage to make their own mistakes, there is every reason to believe that they will prove a fitting successor.