



Editorial

Are the epilepsy representative groups truly representative?

This is a timely piece of work given the emphasis being placed on the patient in the process of health policy formulation and service design and commissioning. Duncan et al. therefore ask a very relevant and important question about the validation of patient and service user involvement and in particular the qualification of representative groups that purport to voice the views of people with a particular condition such as epilepsy.

In trying to put some sort of representative measure on patient groups, one should not over emphasise the importance and significance of the number of members such groups have. Membership is a relevant indicator, but now that groups and their supporters interact in so many different ways, membership is just one indicator. People have the choice whether or not to join one or more of the epilepsy groups. But they do not have to join. The groups, usually registered charities, are not there solely as membership or representative organisations. Of course they want as many people to join as possible, but it is more important to them that they are of service to people first regardless of them being a member or not.

For example, Epilepsy Action had 14,751 members at the end of 2012.¹ At only 2.45 percent of the estimated UK population of 600,000 with a diagnosis of epilepsy² this alone does not make the charity representative. However, adding in the 24,300 personal donors; the 23,000 social media followers; and an online community of 5800 people, not to mention the thousands of volunteers, then the scale and range of interest in the charity can be seen differently. This diversity of interest allows Epilepsy Action to draw on a broad base of experience of epilepsy, not just people with the condition. It connects with parents and other family members and includes 500 medical and non-medical professional members.

It would be misleading to simply aggregate all these numbers to produce a total level of support because some people engage with the charity in more than one way. But this highlights another critical measure of representativeness. Having a large number of members and other supporters is not enough. To take advantage of this the group must ensure that it collects, interprets and accurately reflects the views of all those it claims to represent.

Developments in information and communication technology have made a huge difference in this area. Now groups can establish and sustain bilateral contact with their supporters and service users personally and collectively. Online polling and sampling can deliver immediate responses on topical issues. Epilepsy Action's website was visited 1.18 million times during 2012. This included 877,000 visits to its advice and information section. The website is now the most important communication channel between the charity and all those it seeks to represent. So another marker for an

effective representative organisation should be evidence of appropriate communications with its stakeholders.

Representative groups are responding to the changes in the National Health Service as policy decision-making and service development decisions are devolved further and further downwards to local level. Influencing national policy is still essential – as long as national policy exists. Arguably, more important in the future will be the capacity to influence locally with the Clinical Commissioning Groups.

This offers a new opportunity to groups. Local commissioners want to know what local people want and need. They want to hear from the people directly. They are less interested in what a large or national representative body has to say. The role of the representative group is consequently beginning to change. The time when one group spoke for a whole condition may be passing. Instead of articulating the collective views of its members and others, groups are increasingly working to facilitate people with a condition to speak for themselves. Part of this support is to help them understand how the NHS works, how policy is decided and the part that they can play in this. Epilepsy Action is not alone in providing training for people who want to do this.

It is therefore notable that Duncan et al. report that an overwhelming number of people in their research preferred to try and influence their health care service personally and individually with their doctors and nurses and saw this as the best way to improve their service.

Epilepsy affects people in diverse ways. That is why the collective representation of people with the condition is extremely complicated and always prone to challenges of being based on skewed opinion or experience. However, the same weakness can be identified when only individual views are relied upon. How representative might these be?

Consequently, it's hard to see a time when collective representation will have no part to play at all in influencing services. What it must do is emphasise the spectrum nature of the condition; that epilepsy is personal. It's also why it's important to have groups that can offer an overview of a condition's experience. Lobbying for an epilepsy health service is to ensure that the range of services that might be needed are available to those who need them when they need them acknowledging that different people will need different things at different times.

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¹ British Epilepsy Association trustees' annual report, 2012.

² Joint Epilepsy Council of the UK and Ireland.