



## Short communication

# Epilepsy health consumer groups and charities; How representative of patients are they? The results of a pilot study

M. Grinton, Y. Leavy, D. Ahern, F. Hughes, S. Duncan \*

Edinburgh and South East Scotland Epilepsy Service, Department of Clinical Neurosciences, Western General Hospital, Edinburgh EH4 2XU, United Kingdom

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## ABSTRACT

**Purpose:** In the United Kingdom all health care providers are encouraged to consult with user groups. The submissions of charities and patient advocacy groups to NICE and SIGN are considered reflective of the patient groups they purport to represent, yet little is known about how representative they are. This pilot study was designed to ascertain how many patients attending a hospital based epilepsy clinic were members of such advocacy groups.

**Methods:** Patients were asked to complete a brief 9-question questionnaire before they left the clinic. **Results:** One hundred and twenty-five questionnaires were distributed, of which 101 were returned. Seventeen percent of patients were members of advocacy groups, with several being members of more than one charity/group. Only seven percent of the respondents had ever been contacted by an advocacy group to canvass their opinions. Seventy percent of patients questioned stated they thought a frank discussion with their physician, or specialist nurse was more likely to influence patient services. Patients with long duration of disease and taking multiple anti-epileptic drugs were more likely to be members of charity/advocacy groups.

**Conclusions:** As patient charities in the UK are often in receipt of public funds, and actively seek to influence public policy this raises the question of whether they should be required to consult more widely with the people they claim to represent.

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## 1. Introduction

Health consumer groups (HCG) are a diverse group of voluntary organisations promoting the interests of patients and carers through a variety of means. They have proliferated rapidly in the last 30 years.<sup>1</sup> Although often small their impact on the organisation of health care is increasing, with the UK government strongly encouraging the National Institute for Clinical Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) to incorporate the views of patient representatives into their discussions and recommendations. Both NICE and SIGN issue guidelines that determine practice in the United Kingdom, and are influential around the world. Professional members of these bodies are recruited because of their qualifications, experience and demonstrable expertise in their chosen field. Patient representatives who sit on these bodies, however, do not have to provide any

evidence of how representative they are of the generality of patients suffering from the condition under scrutiny. The authors are unaware of any systematic examination of how many of our patients with epilepsy are members of patient representative groups, or how many of our patients have been consulted by such groups. Such an examination is timely as SIGN is about to revisit its guidelines on epilepsy, and NICE published new guidelines for epilepsy in 2012.

## 2. Methods

The study was undertaken between March and August 2010 in the Epilepsy Clinic in the Department of Clinical Neurosciences at the Western General Hospital Edinburgh. A total of 125 questionnaires were distributed and 101 were returned completed before the patient left the department. In the case of people with learning disabilities their carer/support worker was asked to help them complete the questionnaire.

The questionnaire comprised 7 questions which could be answered with a tick. The eighth question required the patient to state an order of preference. A free text box was included at the end

\* Corresponding author. Tel.: +44 7970904732.

E-mail addresses: [Susan.Duncan@ed.ac.uk](mailto:Susan.Duncan@ed.ac.uk), [susanxduncan@gmail.com](mailto:susanxduncan@gmail.com) (S. Duncan).

Table 1

A		B	
Self reported employment status	Membership of HRG	Median years duration of epilepsy (interquartile range)	Membership of HRG
59 unemployed	11 members of HRG	12 (10–23)	Member (N = 17)
23 full time employed	1		
14 part time employed	5	16 (6–22)	Not a member (N = 84)
5 students	0		
Chisquare $P=0.06$		Mann–Whitney $P=0.28$	
C		D	
Self reported disability status*	Membership of HCG	Number of AEDs	Membership of HCG
Disabled N = 59	N = 12	No more than 2 N = 64	N = 5
Not disabled N = 30	N = 2	Three or more N = 37	N = 11
Chisquare $P=0.8$		Chisquare 0.003	

\* 12 people did not reply to disability question.

of the questionnaire for comments. The study was sanctioned by the Lothian Research Ethics Scientific Office.

### 3. Results

A total of 101 patients completed and returned the questionnaire. Seventeen (17%) were members of an epilepsy charity or patient self help group dedicated to people with epilepsy. These were Epilepsy Scotland, Epilepsy Action, The Epilepsy Society, Fife Epilepsy Network, Epilepsy West Lothian and Scottish Paediatric Epilepsy Network. Of the 17, 2 were members of three separate epilepsy associations. Seven of the sixteen (44%) had been contacted by the group of which they were members to ask for their opinion on services for people with epilepsy. Some of the topics included: nocturnal seizures, their opinion on an information leaflet, and views on medication. Two of the 101 patients had used services offered by these HCG's/self help groups. Fifty-nine of our respondents were unemployed, 23 were in full time employment, 14 were part time employed and 5 were students. Employment status did not appear to influence membership of an HCG (Table 1A).

There were no significant differences in duration of epilepsy between those who were members of patient groups (Table 1B), but there was a trend for those who had suffered from the condition for many years to be members.

Thirty-four (34%) of the respondents took one anti-epileptic drug (AED) only, 30 (30%) took two AEDs and 37 (37%) took three or more AEDs. We divided the respondents arbitrarily into those

taking no more than two AEDs, and those taking three or more, on the assumption that the latter group was much more likely to be intractable. Significantly more people who took three or more AEDs were members of patient advocacy groups than those taking one or two AEDs (chi-square 0.003) (Table 1D).

There was no significant difference in HCG membership between those who considered themselves disabled as opposed to those who did not (see Table 1C).

Respondents were asked to rank in order of preference how they thought they could best influence services for epilepsy. Seventy percent replied that a discussion with their general practitioner (primary care physician), hospital consultant or epilepsy nurse specialist was their preferred route (see Graph 1).

Four of the 17 people who were members of an epilepsy patient advocacy group wrote comments in the free text portion of the questionnaire. One said more information about patient support and advocacy groups was needed, two wanted more information about side effects of medication, one wanted information about mobility scooters.

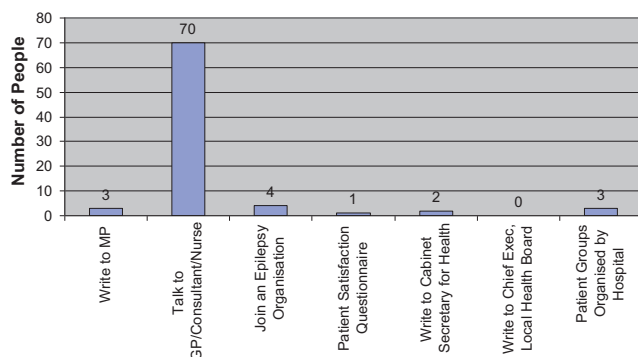
Of those who were not members of any patient group, one wanted the population at large educated on how to deal with seizures, one wanted more support at the time of diagnosis, one complained about the difficulty in getting to see the consultant at short notice and another wanted to raise his concern about the stigma associated with epilepsy.

### 4. Discussion

The present study was limited in terms of patient details. This reflected the need to produce a short questionnaire that would cause minimal disruption in a busy outpatient clinic. We know nothing of the 19 people who did not return the questionnaires. Our aim was to examine the feasibility of doing a larger study with a more complex questionnaire in outpatients. The most obvious objection to our method of patient selection is that a specialist epilepsy clinic is perhaps not especially representative of the population as a whole. Yet quality of life and other data are routinely collected from this population.<sup>2,3</sup> Conversely in one study of patients recruited through patient groups the authors speculated about how representative these patients were.<sup>4</sup> In this area of research no sample group is perfect.

Another potential criticism of our study is that our population of patient's needs might not coincide with the stated aims and intentions of the epilepsy charity/self help groups, who purport to represent patient interests. In other words there may be another population of patients elsewhere whose needs are better aligned to those of various charities. To investigate this further we visited the charities websites of which our patients were members.

1st Choice for Best Way of Influencing Health Services



\* 18 people did not answer this question.

Graph 1. First choice for best way of influencing health services. \* 18 people did not answer this question.

The Epilepsy Action website ([www.epilepsyaction.org.uk](http://www.epilepsyaction.org.uk)) has a two page policy statement encompassing everything from aiming to ensure people with epilepsy have specialist treatment and health care for their condition, to campaigning to ensure that within ten years, more people will enjoy good seizure control, fewer will have died of their epilepsy, fewer people will sustain harmful side effects from AEDs and there will be greater evidence of social inclusion for people with epilepsy. All of these aims, with the exception of the last one are reasons for people being referred to epilepsy clinics such as the one at the Western General. Epilepsy Action's website also offers information on a wide range of topics and discussion forums for members. It's members also receive a regular magazine.

Epilepsy Scotland ([www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)) which aims to be *the* voice of epilepsy in Scotland, has a one page statement of aims. The casual reader is left with the impression of a rather cerebral document, with the overwhelming message that Epilepsy Scotland is a lobbying and political organisation. It's website is less extensive than Epilepsy Action or The Epilepsy Society ([www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)), but it has information, a helpline and a menu of it's activities, including a page for carers and families, and a clear invitation to join and be involved. Like Epilepsy Action it has a regular print magazine for its members.

Epilepsy West Lothian ([www.epilepsywestlothian.co.uk](http://www.epilepsywestlothian.co.uk)) has a modest website which says they are keen to work with people with epilepsy, their families, carers, colleagues and employers, where they can be found and their aims in terms of reducing stigma, improving standards of care, and promoting integrated care.

The Epilepsy Society has an attractive and easily navigable website. Its stated aim is a full life for everyone affected by epilepsy. On the website there is easy access to information leaflets and lively discussion forums for the newly diagnosed, carers, and those who wish to be involved with the society.

The Scottish Paediatric Epilepsy Network ([www.spen.scot.nhs.uk](http://www.spen.scot.nhs.uk)) – of which one of our patients is a member states it aims to “promote the delivery of high quality care to children and young people with the disorder”. SPEN has developed a patient held record. Beyond that there is little on the website to encourage lay participation – if that was ever the intention.

The overwhelming impression given by these organisations cyber-facades is an enthusiasm to get as many people involved as possible, to provide as wide a portfolio of services as their funds allow, and an assumption of literacy on the part of the community they are striving to serve. Estimates (erring on the generous side) of the numbers of people in the UK or Scotland with epilepsy are made, but no breakdown of either membership numbers or the number of visits the site has received that month are seen. Yet on the evidence of this small study these organisations do not seem entirely successful in attracting members. One possible reason for this may be ignorance on the part of patients, their families and carers of the work of epilepsy charities. Yet our clinic is festooned with posters from these charities, we regularly use patient information leaflets from them, and direct patients to their websites.

We did not ask how many of our patients had access to the Internet and how many used that source to find out about their epilepsy. In retrospect this is probably a significant oversight because informal discussions with office bearers of epilepsy charities reveal large numbers of hits and downloads of their material.<sup>5</sup> This activity, however does not seem to be transformed into active fee paying membership. That few of our patients appear to join these associations or use their services is disappointing as Warsi et al. (2004)<sup>6</sup> showed that short self help management courses run by voluntary groups improve knowledge and coping behaviour.

We found a trend for those who had suffered the disease longest to be more likely to be members of HCGs and there was a

tendency for some people to be members of more than one group. People taking more than three AEDs were significantly more likely to be members of HCGs, presumably because their epilepsy was more intractable and they found some of the pastoral activities of the HCGs they belonged to helpful. We were surprised that the free text box was not used more. Whether this reflects general contentment with services or widespread apathy is impossible to tell. It was interesting to observe that patients felt talking to their consultant or epilepsy nurse was the best way to improve services, despite these two professional groups often being painted by politicians and some HCGs as tainted by “provider interest”.

A systematic review of user involvement (UI) studies<sup>7</sup> suggested in some cases it was little more than tokenism, a way of validating decisions about health care provision that have already been made. Other studies allude to difficulties between service users and staff. Some studies report positive outcomes, many do not measure specific outcomes. One study of a project to improve stroke services in two London boroughs invited 500 stroke survivors to attend meetings to explain the aims of the project.<sup>8</sup> Sixty patients attended, which based on the known prevalence of stroke in those London boroughs this represented 3.3% of stroke survivors. Those that did attend were not interested in undertaking administrative or project management roles but wanted to be involved in writing leaflets, and staff training, suggesting people who got involved want to see something tangible for their efforts.

Equally interesting were the reasons given for getting involved. Some saw it as a way of learning about the latest stroke research, others as a way of meeting people like themselves or as a way of accessing social services.

Another study surveyed UI in mental health services in Greater London.<sup>9</sup> Questionnaires about UI were dispatched to the CEO of all NHS trusts providing psychiatric services. Questionnaires were also sent to all UI groups in the locality. The questionnaires were complimentary and covered the organisation of user groups, and their relationship to trusts, methods employed to involve users and outcomes and factors that promoted and impeded UI. In the questionnaire sent to the user groups the researchers asked what support they had had from NHS trusts and to rate their overall satisfaction with the commitment trusts had shown to this type of working with patients.

Ninety-four (94%) of the mental welfare trusts in the Greater London area replied to the questionnaire. Of the HCG's contacted 12% of responses came from groups described as “no longer operational”, 7% from groups not working in NHS mental welfare services, 48% did return questionnaires. Of these groups the median number of members was 35 with an average of 10–15 members regularly attending meetings. This study suggested the HCGs were fragmented and catered to small numbers.

These studies imply UI is the preserve of a small band of enthusiasts. Reasons for this may be resistance on the part of professionals to lay involvement, lack of funding, absence of coherent UI policies on the part of hospital trusts such as providing childcare or transport for those who express a wish to become involved. If patient representative groups and charities do not attract large numbers of active members they may not be able to put forward enough people to take part in decisions, and again raises the question of how representative of patients are those patients who answer the call to become involved.

An example of why some patients might not get involved can be found on the Scottish Medicines Consortium website. Their advertisement for lay representatives is 403 words long, requires a commitment of 3–4 days a month for meetings, up to four hours long which take place in Glasgow.<sup>10</sup>

As the power of HCG's increase an examination of their influence on health care providers is timely. A survey by the

Consumer Association in the UK of 125 leading patient groups' websites showed just 32 listed their donors and only 2 their funding policy.<sup>11</sup> Ball et al. found that although most patient groups were clear about their aims, only 54% had annual reports available on the internet, and in less than half of these were pharmaceutical donations itemised separately from donors in general. Thus there is a clear potential for conflict of interest.<sup>12</sup>

On the basis of this pilot study, patient representative bodies do not seem to be very representative. Yet through their websites these organisations have the capacity to reach many people and there is no reason why drafts of guidelines and other documents should not be posted and public comment invited. Equally these third sector organisations in receipt of public funds could be required to undertake transparent and inclusive surveys of the public using their websites, before making any substantive policy statements.

British medicine is in an era where doctors must submit to compulsory revalidation to continue practicing. Nurses are expected to demonstrate clinical competence in all areas of their daily practice to remain registered and clinical academics must satisfy the rigours of the research assessment exercise for career progression. Institutions must prove they have policies and procedures to ensure patient safety. Yet HCGs do not have to declare their membership numbers or prove how representative they are. Service user representation may not be mandatory in the United Kingdom, but it is increasingly compulsory. This raises issues of legitimacy especially as many of these organisations are in receipt of public funds, and in a position to influence the organisation and delivery of health care purely by virtue of being HCGs.

So how representative are the representatives? And how can clinicians, who see large numbers of patients every day, help them to become more representative?

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