

Patient Organisations in the 21st Century

Since the publication of *The NHS Plan* in July 2000, Government rhetoric has consistently returned to the idea of the 'expert patient'. Patient influence, it was argued, is paramount to effective modernisation of the NHS, or, as chapter 10 put it, "care has to be shaped around the convenience and concerns of patients". This idea was elaborated, specifically in relation to the 17.5m people in the UK living with a long-term condition, in *The Expert Patient*, where the notion of patient and clinician sharing their particular "expertise" was explored¹.

The idea of the 'expert patient' was founded upon what has since become the most tired of buzzwords, 'empowerment'. This, it was argued, is to be fostered primarily through the provision of information and support. In the terms of the *Plan*, however, this is not understood as improving patients' knowledge of their disease, despite gestures towards making people more active in their own treatment. Instead the focus is on the need to understand the NHS and the way it works. In place of the Community Health Councils, the Blair government offers up a phalanx of new organisations, ideally with cute acronyms, to make the NHS intelligible and responsive. By the time a discussion document was produced in September 2001², no less than six new services and umbrella groups were being readied to enter the fray³. Discovering what has actually come into being, though, and indeed what ever will, is as hard as figuring out who you might actually want to approach for help.

Government plans, both consciously and unconsciously, have therefore increased immensely the role that patient organisations (POs) have to play in health service provision. Some traditional areas of PO activity, even if they are not supported directly, have been validated by the proposals, particularly disease and treatment related information – equal patient-clinician relationships, after all, will never be founded solely upon patient experience. New services like NHS Direct offer welcome support, but given their necessary breadth, their ability to provide in-depth support is limited.

POs, on the other hand, are usually focused on one specific disease or condition, and have thus become the major source of clear, usable information resources for patients and their families. The MS Trust produces booklets, for example, to explain simply what a diagnosis of multiple sclerosis means, both in pathological and symptomatic terms; or to explain to a child what is happening to a parent with MS. Such booklets are complemented with phone information services, internet resources, and communication through E-Mail, letters or face-to-face.

With the plans for increasing patient and public involvement in the NHS, meanwhile, still very much at

a 'transition' stage⁴, POs have also been required to provide more information for patients trying to find their way round the cloudy maze that is the NHS. The risk-sharing scheme for disease modifying drugs for MS provides a good example, as a very high profile development in NHS policy led to high levels of public confusion. The MS Trust continues to respond to numerous queries about the potential benefits or side-effects of the drugs, the differences between the various brands, who qualifies for the scheme, who to see to be selected, and which centres are currently prescribing. Until the new government bodies are functional, and possibly long afterwards, POs will continue to provide the guidance that people need as they come to grips with the NHS, helping to create the informed, 'empowered' patient body that is so central to the government's idea of effective reform.

Elsewhere, however, POs have increasingly been brought into the process of service provision itself. Many POs operate services that are complementary to standard NHS systems – for instance the Motor Neurone Disease Association's team of regional care advisers. But other POs' work is beginning to cover areas that have traditionally been the preserve of statutory services. The concept of 'self-management' that was so central to *The Expert Patient*, for instance, is ultimately dependent on their involvement. The political mileage obtained from this idea was only made possible by the successes of programmes run by organisations such as Arthritis Care and the MS Society – highlighted by the report as exemplary responses to the peculiar demands of chronic illness. Previous administrations

were perhaps afraid of the loss of control potentially involved in partnership programmes, but while 'private finance initiative' projects may still possess a controversial aspect, the current government does appreciate the utility of sharing costs with charities. The MS Society's 'Nurse Fund' for MS specialist posts is a noteworthy example of the successes that an injection of voluntary income can provide.

Such steps are reinforced by the commitment POs have given to improving the knowledge of health professionals about particular diseases and their treatment. The NHS has always lacked the resources for training its staff in such a focused manner, and so POs have increasingly taken on a wider and wider educational remit. All new MS specialist nurses, for instance, are given training in the management of MS by the MS Trust, through intensive induction courses and regular follow-ups. Further educational programmes have been aimed at a broader audience of health professionals, frequently with the purpose of facilitating effective multi-disciplinary team interaction.

These developments have been driven both by the need to improve the support that patients receive, and by the lack of government resources available to meet this need. This second factor has of course also been crucial in making evidence based practice a necessity for strategic medical planning. Driven by the need for efficiency, decisions must now as far as possible be taken on the basis of systematic reviews of RCTs. And yet the government and DoH do not generally have the funds for such research. The role of the MS specialist nurses, for instance, was defined by a piece of research funded by the MS Trust⁵, research which has since enabled the Trust to refine the training that such nurses receive.

In light of the recent 'cross cutting' Treasury review⁶, and the allocation of over £200m for its implementation and the creation

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Outside Parliament in April 2001. The picture shows (L-R) Bernadette Porter (MS specialist nurse, National Hospital for Neurology & Neurosurgery), Paul Burstow MP, Christine, and Sue Thomas, Royal College of Nursing, at the launch of the document Key Elements for developing the MS specialist nurse services in the UK.

of the 'futurebuilders' investment fund, it seems that these developments in the level of PO involvement in the NHS will continue to grow. Despite this extra cash, however, the potential dangers for organisations that directly depend on the good will of their supporters must also be kept in sight. For POs have not only had to commit massive amounts of time, energy and money to information, research, education and other services; they have also had to put their name behind projects whose direction they cannot necessarily control. This is nowhere more apparent than in their participation in service design. The government needs PO input in this seemingly endless consultation process to fulfil their intention of representing the patient's voice in the reformation of the NHS. The paradoxes of such an aim are clear, however, when it is realised that National Service Frameworks and NICE guidelines are themselves intended to create clearer national standards "so that patients can see what to expect from high quality services". POs are there to represent the needs of their supporter groups, but unavoidably become part of a system that can only work through compromise, and which is ultimately aimed at telling patients what they can expect. This is rational enough, but in one step POs have been separated from the basic source of their strength, and the very idea of patient-driven reform seriously debased.

This situation is perhaps a suitable emblem for the difficulties facing POs as they enter the 21st century. They face the most testing of tight-rope walks, balancing between government and public, pushing for achievable changes while maintaining the integrity of their guiding principles. The possibility of the NHS being effectively reformed depends to a large degree on their active participation; but if they become too closely associated with projects that are perceived by the public as fundamentally flawed, they risk losing the support on which their own existence depends. The risk-sharing scheme is a most apposite example. The agreement offers the potential for great benefits for a large number of people with MS, but the difficulties

involved in its implementation, and the compromises already made to allow it to reach this stage, are increasingly apparent. The MS Trust's involvement in the selection of the group that will run the scheme, and the monitoring of its progress, has meant not just a huge commitment of resources but also an association that might prove highly damaging should the scheme not take off – even though many aspects of its implementation lie in the hands of the DoH and the SHAs. In this respect the co-operation of different POs and relevant professional bodies such as the ABN continues to be vital. Neurology remains a particularly under-funded and under-manned area of the NHS, but together such organisations are much more powerful in improving services, indeed too powerful to be ignored. Governmental pragmatism will always prove a stumbling block for patient expectations, but if professional and PO voices and efforts are directed to similar and consistent ends a health service that directly serves the needs of its patients remains wholly achievable.

References

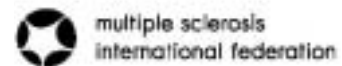
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2. DoH, 'Involving Patients and the Public in Healthcare: A Discussion Document', 2001.
3. Patient Advisory/Advocacy and Liaison Services; Independent Complaints Advocacy Services; Patient Forums; local authority Overview and Scrutiny Committee; local community 'Voices'; and their national counterpart.
4. The latest progress report from the Transition Advisory Board (September 2002) states that the DoH 'hopes' that working arrangements, guidance for SHAs and funding allocations can be decided within six months.
5. Johnson, J. et al., 'Evaluation of MS Specialist Nurses: A Review and Development of the Role', 2001.
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International MS website launched



The Multiple Sclerosis International Federation (MSIF) has launched its expanded new look World of MS website www.msif.org. The site provides information for people affected by MS, healthcare professionals and researchers alike. Information is delivered in 6 main sections:

- **International MS Portal:** A gateway to national MS societies worldwide
- **MS: The Disease:** Outlining current understanding of MS, its causes, distribution, diagnosis and various subtypes
- **Symptoms and Treatments:** An overview of MS related symptoms and advice on all the latest MS treatments, including an online version of the unique authoritative reference book, 'Multiple Sclerosis: The Guide to Treatment and Management'
- **People with MS:** An interactive section which encourages the sharing of information between those affected by the disease and the formation of virtual mutual support groups.
- **Research:** Latest research news and a medical and scientific literature database provided by an expert team at



the Institute of Neurology, with Information on clinical trials and MSIF research projects/awards

- **Publications:** MSIF publications for download
- A free weekly email update service brings news and information to users worldwide. Content includes national MS Societies' news, the latest research findings and people profiles highlighting individual experiences of living with MS.

From early 2003, a free magazine 'MS in Focus' will be available online in English, Spanish and German.

The new World of MS website has been graphically and technically designed to simplify use for people disabled by MS.

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