

Inaugural meeting of the National Association for Patient Participation in General Practice

DURING the past five years a new enterprise has emerged in general practice—patient participation. There are now several practices in England and Wales which provide an opportunity for their patients to have a say in how the service they receive can be improved and extended. Patient participation groups (PPGs) such as these (alternatively called patients' committees or practice associations) also act as forums for health education and sources of voluntary community care. Several PPGs have extended these activities considerably further.

At a meeting of members of the existing PPGs at Bristol in May 1977, it was agreed to form a National Association. A small steering committee was elected and as a result an inaugural meeting was held in Oxford in February 1978.

The roles envisaged for the Association were:

1. To act as a link between existing PPGs.
2. To be a source of useful information for those thinking of starting a group.
3. To promote the principles and benefits of patient participation.
4. To win official support and encouragement.

The aim of the meeting was to investigate these roles and discuss them; to discuss a constitution for the Association; and to elect a committee. About 90 people attended the meeting, including representatives from 12 PPGs.

First session

Dr Alistair Wilson (Aberdare)

Dr Alistair Wilson chaired the first session and introduced Sir George Godber (Chairman, Health Education Council) who had agreed to accept nomination as President of the new Association.

Sir George Godber

Sir George said how apposite he felt the idea of patient participation was in these days of limited NHS resources. The growing need to spread understanding about health and disease meant that 'simple' medical skill was not enough; a more effective sharing between

the medical profession and the public was necessary.

The community now found it easier to identify with health centres than with hospitals. The blending of patient participation with health centre services was potentially an ideal arrangement.

Sir George likened doctors to arthropods—the need for a protective carapace went with the need for periodic moulting if their health was to be maintained. The resulting demystification of medicine could contribute enormously towards an effective continuum of self-care and professional care. The new Association stood for the best hope for total health care in the future.

Dr Wilson then briefly related how the Association had been set up, and remarked on the exciting growth in numbers of PPGs over the past year or two.

Dr Tim Paine (Bristol)

Dr Tim Paine spoke about the growing need for a link between existing PPGs. It was increasingly difficult to keep pace with the numbers of new groups, let alone with what they were doing. A 'national grid' was needed of ideas and experiences flowing between groups, steered by someone who would collect together and distribute the information. This 'lynchpin' would be supplied with facts by 'link' people in each group, whose job it would also be to keep their groups informed of developments around the country. This information could be made available in two forms: in a compendium of the philosophies and activities of existing groups, and in a periodic newsletter which would keep groups up to date with new ideas, activities, and experiences.

Dr Paine also stressed the need for careful evaluation of patient participation schemes. He hoped that funds would be made available from official sources for this research.

Mr Alec Dakin (Bristol)

Mr Alec Dakin spoke of the need for "a source of useful information for those thinking of starting their own group". A central record was needed of how each PPG had started, how it worked, and in what kind of practice it operated.

He then described how the Bristol group had evolved, and how it had extended its role and its involvement. It was important also to record failures, he felt, so that

needless repetition of mistakes could be avoided.

Second session

The second session was chaired by Mr Alec Dakin.

The Reverend Stephen Barnes (Glyncorrwg)

Mr Barnes felt that the Health Service was in danger of becoming impotent as health became more the preserve of modern medicine and less the concern of ordinary people. Patient participation aimed to provide a consumer voice towards improvements in the health services, and to break down the barriers which had been erected between medical teams and the people they served.

He cited several examples of positive and effective discussion and co-operation in his own community between health staff and patient representatives, which had led, for instance, to improvements in the chiropody service, and in the attitudes of nurses in the local children's ward.

If patient participation was successful in the ways he had described, then it would promote itself. There was, however, a need to promote the potential of patient participation particularly in health care provision, health care organization, and health education. He felt that there was a need for a newsletter to help spread the gospel and encourage other groups to start.

Dr Alistair Wilson (Aberdare)

Dr Alistair Wilson spoke on the role of winning official support. "Why should such groups be created?" he asked. "Because they are an example of democracy in the NHS, a group of patients who represent their fellow patients in a medical practice and who are accountable to the rest of the patients; because the patients themselves can use *their experience* to participate with the doctors and the other members of the health staff in the provision of primary health care services; and because a group of patients can help in the necessary work of providing health education and in improving the services available."

Many examples were then given of the achievements to date in Aberdare.

"I feel that the new National Association for Patient Participation should approach the DHSS to ask the Secretary of State to encourage health staff at health centres to set up patients' organizations. They should also encourage health authorities to provide financial help to patients' groups in particular to help them in their work of health education."

He went on to describe how the Aberdare group had won support and encouragement from the Health Education Council, both South Wales faculties of the RCGP, a number of Community Health Councils, some MPs, and the Mid-Glamorgan Area Health Authority (AHA). The group had received a substantial grant from the AHA to help with its health education programme and had also used the services of the AHA

film unit in making health education films to be shown to patients.

Mr D. R. Davies (Aberdare)

Mr D. R. Davies spoke on the importance of publicity in the spread of patient participation.

"Publicity is what you say, write, see, and hear. It is not what you think. It has been described as a double-edged sword. Effective publicity, in the long run, must be truthful. It must not exaggerate; it must not lie. We would do well to remember these dicta in the initial excitement.

"We know that there is a major war on between some doctors and the NHS, and we know also that in war the first casualty is truth. We don't want a Dr Goebbels on either side."

General discussion

Many of those attending the meeting were able to express their points of view about what had been said, and about their feelings and experiences of patient participation as a whole.

The problem of the small proportion of patients interested in being involved in PPG meetings and activities was raised, and whether those who were involved were adequately representative of their fellow patients. This was clearly a major source of anxiety among those running groups, and a reason for scepticism in those with no groups. There was reassurance, however, from one member of the audience who stated that no 'representative' group was in any way representative! A doctor in a tower-block practice in Birmingham had found a lack of interest in lectures and talks, but had increased the involvement of his patients enormously by introducing activities such as 'jogging'.

The idea that patient participation could, or should, fill the gap in NHS resources was challenged. The onus on PPGs was to fight for better finances and a better health service. "If we don't do this we might as well not have started."

Several speakers related how their own group had started, and what it was doing. Those who had started groups ranged from a general-practitioner theologian working in a predominantly Asian community in Birmingham to a doctor and patients from a patients' collective in South-East London. One myth that died was that PPGs were viable only in middle-class practices!

Mrs Joan Mant offered the services of the Central Information Service for General Medical Practice in filling the role of lynchpin for the Association.

Dr Godfrey Fowler, Reader in General Practice, University of Oxford, said that he was most enthusiastic about the idea of patient participation. He felt, however, that with the better education of doctors, particularly those who are to become general practitioners, such groups would no longer be necessary.

There then emerged two quite distinct views of what patient participation was all about, prompted by a question from a community worker and Community Health Council member: "What evidence is there that there is a discernible transfer of power from doctors to patients within existing groups?" A patient from the Limesgrove Patients' Collective, Ms Beryl Steel, put it in a nutshell: "If you see patient groups simply as a support for the doctor, or a way of making the doctor understand what the average patient might want, then with the better education of doctors, and perhaps more sensitive doctors, we might not need these groups. But if you see patient groups as people wanting to take back into their own hands control of their own health, and if we are to say what health is to us, rather than allow doctors to tell us, then it is going to need more than a sensitive doctor." To work successfully, however, whatever a group's basic philosophy, the goodwill of the

doctors concerned was needed.

Business meeting

The meeting decided to set up a National Association, to elect Sir George Godber as President, and to re-elect the steering committee, with the addition of one representative from each PPG; to ask the Committee to arrange another meeting at Oxford in October 1978; and to accept the offer of the Central Information Service to act as a link between PPGs and distribute material for the October conference.

It was also agreed that each PPG would pay £2 towards the cost of the next meeting, and that each would have up to four votes.

Councillor Elfed Morgan, Acting Secretary, was thanked for his work towards making the inaugural meeting such a great success.

T. F. PAINE

Symposium on developmental paediatrics

THE North of England Faculty of the Royal College of General Practitioners and the Regional Postgraduate Medical Institute arranged a symposium on developmental paediatrics at the Postgraduate Medical Centre, Bishop Auckland on 7 and 8 April 1978.

The symposium was chaired throughout by Professor S. D. M. Court, late Chairman of the Court Committee on child health services and Emeritus Professor of Child Health at the University of Newcastle. The meeting was attended by about 75 people, including general practitioners, clinical medical officers, vocational trainees, health visitors, and paediatric nurses.

Friday 7 April

Dr E. Ellis

Dr E. Ellis, Consultant Paediatrician at the Child Development Centre, Royal Victoria Infirmary, Newcastle-upon-Tyne, spoke about the principles of developmental assessment. He paid tribute to the early pioneering work of Dr Mary Sheridan and her inventory and concept of developmental milestones. He found Dr Neligan's idea of linking percentile performances for key stages in development such as sitting, walking, saying one or two words, or forming sentences printed on developmental charts, particularly valuable. Among the other methods described he illustrated the Denver developmental charts and Dr Sheridan's Stycar tests.

Dr P. Pinkerton

Dr P. Pinkerton, Consultant and Senior Lecturer in Paediatric Psychiatry at the University of Liverpool,

spoke on the chronology of emotional disorder in childhood. He considered that the seven phases of childhood could be usefully separated: prenatal, perinatal, infancy, toddler, pre-school, primary school, and postpubertal. He emphasized that many of the behaviour disorders could be caused either by over-acceptance or under-acceptance and illustrated the multifactorial causes of emotional disorder in childhood. He demonstrated some slides showing the cumulative effect of social disadvantage and, for example, obstetric hazards.

As far as numbers were concerned, he considered that about ten per cent of the entire school population were at risk to some emotional problem and showed in tables that particular patterns of disorder occurred at particular ages and in relation to particular patterns of family behaviour.

He concluded by suggesting that prenatal and perinatal phases of infancy were characterized by compliance, the toddler by contrariness, the preschool child by consolidation, the primary school child by conformity, and the secondary school child by a phase of community. He hoped these five 'C's' would be a useful mnemonic.

Dr J. D. Andrew

Dr Douglas Andrew, Consultant Paediatrician, Bishop Auckland General Hospital, examined the problem of children who were too small. He considered that the third percentile was a useful concept in identifying those children at risk who needed careful consideration and investigation, and had found that 17 such children had