Editorials

Patient participation groups in general practice:

building better partnerships

RESPECTED INSTITUTIONS

The NHS and general practice are generally respected institutions. Indeed, the public, 69% of those sampled, continue to remain relatively satisfied with GP services.[1] One of the great advantages for patients in the UK is that health care is provided free at the point of delivery, with the majority of funding, 76%, paid for out of general taxation and 18% from National Insurance.[2] And yet in 2016 patients and the public know rather little about how general practice is organised, the implications of guidelines, protocols, and targets on how GPs consult and work, how GP practices are funded, and the standards of care patients can expect.[3]

In September of 1978 the Declaration of Alma-Ata was adopted at an international conference on primary care.[4] Several important recommendations, still very relevant today, were made, including that people have a duty and a right to participate individually and collectively in the planning and implementation of their health care. NHS England states that it is committed to working with and listening to patients, carers, and the public, and to embedding the patient and public voice in the commissioning process.

This is done in the governance structure by having lay members on committees and through effective and ongoing engagement activities, working with patients and the public to jointly design and develop services.[5] The NHS constitution sets out a principle for the government to ensure that:

'... there is always a clear and up to date statement of NHS accountability and a transparent process of accountability that is clear to the public, patients and staff'.[6]

This is indeed progress. However, these recommendations do not specifically apply to general practice. A further recommendation of the 1978 Alma-Ata Declaration was that primary health care:

'... requires and promotes maximum community and individual self-reliance and participation in the planning, organisation, operation and control of primary health care, making the fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate'.[4]

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Despite this, it was not until April 2016 that all GP practices in England were required to have in place a patient participation group (PPG) as part of meeting the GP contract.[7] However, there is no particular requirement, nor description in statute, of what constitutes a PPG, what it can do, how it should be organised, and whether it should be a face-to-face group or a virtual group, or both, making it difficult for practices. This role has been filled through information provided by the National Association for Patient Participation (N.A.P.P.). In addition, commissioners of primary care expect patients to be involved in the process.

It has taken almost 40 years, a long generation, for there to be a statutory response to the importance of patient and public involvement and accountability in general practice. This statutory support for patient and public involvement in health care has only come recently and is to be welcomed. One focus of this paper is to highlight the very considerable potential of PPGs to enhance practice and help practices adapt and change for the benefit of all. In 1978, N.A.P.P. was formed by visionary GPs in the west of England to promote PPGs as participants in decision making in the NHS as well as in their own health care. The majority of practices in England now have a PPG,[8] with an increase following the 2-year period of the enhanced service, 2011–2013. N.A.P.P. reaches out to more than 13 million patients across the UK.

THE SCOPE OF PPGS

The scope of PPGs in general practice is wide and includes: providing the patient perspective, promoting self-care among patients and other health matters such as improving communication between the practice and its patients, influencing the development of services, liaising with other organisations both statutory and voluntary, contributing to the gathering of patient views including supporting and publicising patient surveys, and encouraging research. PPGs should also understand how they can work with the practice regarding regulators and other inspection bodies. They can contribute to Care Quality Commission (CQC) inspection visits and their contribution may be referenced by the CQC in its report. The PPG can contribute to the revalidation of the practice doctors and nurses when asked. PPGs talk to non-regulatory organisations that inspect practices and ensure that PPG comments are included in their reports. The PPG gives the practice feedback that reflects the full range of patients' experiences.

All PPGs are different. They serve both large and small practices in urban, suburban, and rural locations. Some are in one site; others cover two sites. Some serve a stable population; some have a high proportion of older people or a large mixture of different ethnic groups and a more transient population: there is no one size to fit all. PPGs strengthen the relationship between patients and their practices, which is critical to the provision of modern, high-quality general practice. The work that many PPGs, made up entirely of volunteers, have done over the years is outstanding. This has included:

- gaining the trust of the homeless and learning their health needs so that these can be met;
- working with Travellers;
- working with and involving minority groups;
- supporting and in some cases organising the annual flu clinics and other health promotion clinics;
- stimulating and supporting rambling groups, swimming, dancing, and other similar recreational and physical activities;

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- identifying and helping with the information needs of patients with several long-term conditions;
- identifying a shortage of midwives in their area resulting in an increase in midwives there (this PPG worked with neighbouring PPGs and liaised with the Royal College of Midwives);
- identifying a need for computer skills; running a weekly silver-surfers computer drop-in session and partnering with the local voluntary service, using its bus to run a 6-week computer course for the wider community;
- running a course on English as a second language for Asian women, based around medical services; introducing 'my medication passport', a diary to be used for visits to GPs and clinics; and introducing a health pledge to encourage patients and the public to consider their health choices; and
- working with local schools and colleges, and involving young people in their work.

PRACTICES NEED TO RESOURCE PPGS APPROPRIATELY

In all of these examples from N.A.P.P., including some PPGs that have won prizes, PPGs have identified a need and responded to their patient population to the benefit of the practice and the wider community. In these examples the work was always done with the cooperation of the practice GPs and practice managers, but with the actual work being done by PPG members.

Another focus of this editorial is to emphasise the importance of the need for practices to resource their PPG appropriately. This is essential for PPGs to achieve their potential and be better able to engage in the range of work described above, as recommended by N.A.P.P. in *Building Better Participation*.[8] Gillam and Newbould, in a recent article,[9] criticised the amount of money spent on PPGs. During the enhanced service period, 2011–2013, practices were paid £1.10 per patient to establish and support PPGs, but with no requirement that PPGs would actually be funded. Sadly, many were not and are still not well resourced, making it difficult, frustrating, and challenging for such PPGs to nurture and develop good collaboration and relationships with their practices.[10]

Different and imaginative methodologies now need to be developed to evaluate both the importance of and impact of the work of PPGs while acknowledging their diversity. The variation among PPGs may make it hard to assess the impact of their work but it is this same diversity that makes for engaged PPGs working to meet local needs and knowing their own community.

The work done by PPGs, members of whom are all volunteers, is often time consuming and labour intensive; these are resources that practice staff currently do not have. Moreover, many PPG initiatives are likely to be more effective when the message is coming from patients.

Good practices tend to have good PPGs. These are indeed precious relationships and should be encouraged, developed, and strengthened for the benefit of us all.

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