

Patient participation in primary care: Why is it important?

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This paper clarifies the importance to GPs of involving patients in the wider aspects of the organisation of health care, as well as in their personal care, and demonstrates why GPs need to work with the patients in their practice in order to fulfil aspects of the GP curriculum and revalidation. The article explains how successful collaborative working between patients, GPs and the practices can be achieved for the considerable benefit of all.

The GP curriculum and patient participation

Professional module 2.02: Patient safety and quality of care requires GPs to:

- Understand what is involved in establishing a Patient Participation Group
- Describe the techniques for obtaining the views of, and feedback from, patients
- Involve patients and their carers in both decision making and quality improvement processes

Professional module 2.03: The GP in the wider professional environment requires GPs to:

- Be aware of the expectations that patients have of the practice and local primary care services
- Place their patients at the centre of decisions about services
- Involve patients in the management of the practice and local primary care services
- Understand the importance of involving the public and communities in managing health services, e.g. encouraging patient participation in decisions about the local provision of health care

Professional module 2.04: Enhancing professional knowledge requires GPs to:

- Encourage self-management
- Understand the need to build community engagement and resilience, and family- and community- based interventions

Why it is essential to involve patients

Since the establishment of the RCGP in 1952, general practice has changed and continues to change at a rapid rate, as detailed in Box 1.

Patient participation in general practice

Patient participation is now a phrase that is both frequently quoted in the media and used by policy makers, educationalists and practitioners. It can be argued that there is even an

Box 1. Trends in general practice.

- No longer do the majority of patients really know ‘their’ GP as practices reconfigure from smaller units to larger groups and more GPs work part time
 - No longer do GPs work with Lloyd George paper records, but rather digital medical records that patients can now more easily access
 - No longer do GPs take bloods, do dressings nor solely monitor patients with life-long conditions. These tasks are now performed by other members of the practice team
 - No longer do GPs and hospital specialists entirely manage the treatment of patients with life-long conditions, as many patients are taking increasing responsibility for the management of their treatment at home, e.g. home dialysis in end-stage renal failure, insulin-dependent diabetes
 - No longer can GPs offer lengthy appointments to all patients nor continuity of care to all
 - No longer are GPs the sole source of medical information for patients, many of whom have already consulted the internet
 - No longer is out-of-hours care provided by the patient’s own GP. Patients have to learn how to navigate their way around an increasingly complex NHS
 - No longer can patients expect to see their own or preferred GP quickly
 - No longer can patients always just phone to make an appointment with their GP. They may be triaged
 - No longer can patients expect to have long appointments. Patients need to learn to collect their thoughts and make the best use of a 10-minute consultation
 - No longer is the GP the only professional accessing the patient’s notes
- All these changes, and this is not a comprehensive list, affect and have implications for the relationship between patients and their GPs.

industry of ‘experts’ in patient participation in government organisations and in the third sector willing to offer training and advice in patient participation. Where did the concept of patient participation come from, what does it entail, and why is it important for doctors in primary care?

Patient participation in general practice began with patient participation groups (PPGs). The first PPG was established in 1972 by Dr Peter Pritchard in his practice in Berinsfield, Oxfordshire. This was followed by Dr Julian Tudor Hart, well known for the Inverse Care Law, in Aberdare, South Wales in 1973 and Dr Tim Paine in Bristol in 1974.

The philosophy underpinning patient participation was described by Reedy (1970):

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 It is essential to realise that all families whose personal and corporate health are embodied within the practice are themselves an integral part of the organisation and that operational considerations must include the patient group as a functioning and dynamic integer of the whole organisation.

This philosophy of patient participation described by Reedy is embodied in the Alma-Ata Declaration (World Health Organisation, 1978) adopted at an international conference on primary care. This declaration emphasised that health, and not just the absence of disease, is a fundamental human right, and that people have the right and duty to participate individually and collectively in the planning and implementation of their health care.

The term co-production, often used synonymously with patient and public involvement, is a contemporary development of the principles of the Alma-Ata Declaration, namely that the voices and experiences of the users of health care are included in making, commissioning, designing and delivery of services. Another concept that embraces the principles of the Alma-Ata Declaration is patient-centred care, first used by US psychologist Carl Rogers in the 1950s to describe building a relationship of trust between therapist and patient so that the patient can fulfill his or her potential in life. The term was further developed 20 years later by George Engel to include the biopsychosocial model of health as an alternative to the traditional medical model. Patient-centred care increasingly plays an important role in public policies; however, there is no consensus about what precisely the term means. All definitions include the concept of patients being involved as equal partners in the planning, developing and monitoring of health care, which is central to PPGs.

The essence of patient participation underpinning PPGs is that the receivers and providers of health care work together in a spirit of mutual understanding to improve all aspects of the system of health care, particularly at the community level (Paine, 1983). Furthermore, PPGs strengthen the relationship between patients and their practices, which is critical in the provision of modern high-quality general practice (Wilkie, 2016). It was argued in the 2002 Wanless Report (Wanless, 2002) that an annual saving of some £30 billion could be achieved by 2022 if patients became ‘fully engaged’ in their health care provision.

National Association for Patient Participation

In 1978, the National Association for Patient Participation (N.A.P.P.) was formed to promote patient participation in general practice by encouraging people to be actively involved in their own health care as well as in the wider organisation of

health care, supporting new PPGs and sharing good practice (N.A.P.P., 2017a). The N.A.P.P. argued that better health results, along with happier staff and more satisfied patients, can be best achieved when patients, their doctors and other staff work together in a spirit of mutual understanding and respect. In 1978 these were challenging ideas, questioning the appropriateness of some of the beliefs of professionals who assumed that they knew best. They also recognised the very positive contribution that can, and should, be made to the health of a community by all those who live in it. As Joan Mant, a founder member of N.A.P.P, so succinctly said 'Patients have more to offer their doctors than their illnesses' (Mant, 1978).

It is salutary that in 1981, the late John Horder when President of the RCGP wrote (Horder, 1981):

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It reflects poorly on medical care, as we provide it, that patient participation should need promotion. It betrays a world divided into consumers and providers, when the alternative is for the consumer to be the first provider; a world in which the providers plant a hedge around their garden, when no hedge is needed; a world where expertise flowers, a special language is talked, and trained people enjoy special privileges and feel different; the weeds in the hedge are misunderstanding and mistrust.

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Patient participation and the RCGP

In 1982, encouraged by John Horder and following an initiative by John Hasler, the RCGP established a Patient Liaison Group (PLG) composed initially of equal numbers of lay and medical members. The lay members were recruited from consumer organisations aiming to ensure sufficient knowledge and confidence in discussion with medical colleagues about the concerns of patients. An equal number of GP members were recruited. The group was chaired by a lay member and reported directly to Council.

According to Williamson (1993) the PLG was both radical in its function for lay and medical members discussing professional practice as equals and in its composition of approximately equal numbers of lay and medical members. In 1998, the lay chairman was invited to attend Council with speaking, but not voting, rights. This helped strengthen the patient voice within the College, enabling the lay chairman to communicate directly with other Council members. All issues of interest and concern to both patients and doctors were discussed.

An excellent example of the ability of the group to discuss what concerned patients was the removal of patients from GP lists. These discussions eventually became a much cited college paper (RCGP, 1997).

The RCGP was the first of the medical royal colleges to establish a patient group (Wilkie, 2003). Other colleges have adopted the same format as the RCGP. According to Paine (1983) the College recognised patient participation to be most realistic and relevant at a local level and has, therefore,

encouraged Faculties to take up the challenge. In 2017, less than half of the Faculties have a lay/patient member (RCGP Faculty Office, 2017, personal communication).

There is a wealth of information about the work of PPGs including early studies by Paine (1983), Pritchard (1984), and Richardson and Bray (1987) and from intelligence collected by N.A.P.P. and in their Corkhill Award. The Corkhill Award (N.A.P.P. 2017b) is given annually to a PPG for work that is replicable, inspiring and improves services for patients and that has been carried out in the previous 18 months (see Building Better Participation, (N.A.P.P. and NHS England, 2016)).

Establishing a PPG

Statutory obligation to establish a PPG

Revisions to the General Medical Services contract 2006–07 introduced a payment to practices for carrying out certain components including a patient survey. This was not specifically about PPGs, but did require a degree of patient involvement. In April 2011, the patient participation direct enhanced service (DES) was established in England to ensure that patients were involved in decisions about the range and quality of services provided and commissioned by their practice. A payment of £1.10 per registered patient was made with achievement of the six DES components, evidenced in a practice report.

In 2013, the DES was replaced by the patient participation enhanced service and in March 2015 it became a contractual requirement (British Medical Association, 2016) for GP practices to have a PPG and to make reasonable efforts for this to be representative of the practice population. It is now also an expectation for the Care Quality Commission (CQC) inspection that the practices have a PPG. The CQC consults the PPG during a visit. Practice engagement with the PPG needs to include patient feedback demonstrating action on agreed suggestions for improvement.

When the patient participation enhanced service ceased in March 2015 the associated funding was reallocated to practice core funding. Hence, there are funds available to support a PPG. Many PPGs are still not well resourced, making it difficult and challenging for such PPGs to develop good collaborative relationships with practices (Wilkie, 2016; Wilkie and Devlin, 2016).

Early PPGs were formed allowing practices to link with their local communities. Patients, as tax payers, have a right to a say in how their services are provided and have much to offer their practices. PPGs in UK general practice have grown steadily since they were first established 1972 without any statutory obligation on practices to have a PPG. Important considerations when setting up a PPG are described in Box 2.

Each PPG is unique, as it responds to the needs of the patient population and the local community. Initially, a PPG often reflects the enthusiasm and energy of a small group of people, for example, a GP, a practice manager or a group of patients. This requires commitment and some dedicated time

Box 2. Considerations when setting up a PPG.

- How to get started
- How to recruit a group of patients
- Being representative
- Type of group – face to face or virtual
- Terms of reference and constitution
- What sort of activities PPGs can be involved in
- Evaluating progress of work of the group
- Time commitment of staff and patients
- Cost
- How to maintain enthusiasm

from GPs, practice staff and patients who also give their time voluntarily. The N.A.P.P. provides useful information on its website (N.A.P.P., 2017a) and in Building Better Participation (N.A.P.P. and NHS England, 2016) and Starting, Growing and Sustaining Successful PPGs (N.A.P.P., 2017c).

Ideally, the group should reflect the demographics of the practice population, including patients from different age groups, ethnic groups, more socially deprived groups and with different health conditions. Communication may need to be tailored to the particular group, for example, those whose native language is not English or those who experience communication difficulties. The PPG goal of being representative of the practice may be difficult to achieve. It is important to start with the enthusiasts.

According to the N.A.P.P., the most effective PPGs are those that develop a strong partnership with their practices based on mutual trust and respect. This partnership involves discussions and agreement on shared objectives, terms of reference and a constitution. This partnership is most successfully achieved through face-to-face meetings between a group of patients and members of the practice team. A virtual group can complement and extend the knowledge and feedback by reaching out to those unable to attend meetings, younger people and some harder to reach groups. Face-to-face groups supplemented by a virtual PPG are the most effective methods of engaging with the widest practice population.

PPGs can be involved in many activities. These will vary from practice to practice and will include helping the practice to improve services, offering support to other patients, providing information, arranging special health events, and acting as representatives on different statutory and voluntary organisations.

The most effective way of evaluating the work of the PPG is to use Building Better Participation (N.A.P.P. and NHS England, 2016).

It is sometimes difficult for PPGs to maintain enthusiasm, as reported by both practice staff and PPG members. The qualities of a sustainable PPG include:

- An inclusive and representative membership
- Having a clear understanding of the purpose of the PPG and its role

- Having an established and effective way of working
- Development of strong supportive relationships and practice culture

Practices may need to learn to engage with their patients in a different way, to be open to the views of patients and to show real interest in what patients can offer.

Patients, on the other hand, need to be able to work with the practice as colleagues, to learn what practices can and cannot do, as well as how the PPG can contribute to a successful, constructive relationship between the practice and its PPG built on mutual trust and respect. Such a relationship can encourage more self-care for individual patients and the wider community. When patients are part of the decision-making process they are more likely to support changes in the organisation of their health care.

Involving patients

PPGs as a source of feedback

Practices can get the views of patients from a patient satisfaction survey or simply rely on the national GP Patient Survey (www.england.nhs.uk/statistics/statistical-work-areas/gp-patient-survey/) This is an England-only survey.

This usually entails surveying patients who have recently attended the surgery. With the help of a PPG, different and more imaginative methods can capture the views of the wider patient population such as holding open meetings attended by patients and their families. These events may be held at the surgery or in various venues including town centres, and are opportunities to capture patients' views, including some harder to reach groups.

The PPG may also carry out surveys on topics of concern to the practice and patients. Many PPGs have a member in the waiting room listening to patients, and engaging with them. Some PPGs have a suggestion box to collect feedback.

A PPG newsletter, adopted by many PPGs, is a useful method of both providing and collecting information. It can be displayed in surgeries, in local pharmacies, hospitals, care homes and schools. Practices can help by sending the newsletter electronically to patients. Some PPGs discuss their work on local radio, and increasingly, PPGs use social media to communicate with the wider patient population. PPGs also give talks about their work to mother and baby, pensioner and disease organisations.

PPGs as a source of feedback about patient expectations of the practice

It is important for practices to know what patients are expecting of the services they can receive. By adopting some of the methodologies described above, practices can easily assess the views of their patients. However it is also important that patients understand what GPs can and cannot offer, for example, with reference to NHS contracts, CQC and General Medical Council regulations and NICE and SIGN guidelines. PPGs are often able to identify problems in local primary care

services and can work at solutions with the practice and, where appropriate, other PPGs.

Such activities have resulted in improved practice appointment and telephone systems, the provision of physiotherapy (when the physiotherapy facilities closed at a local hospital), the appointment of a practice pharmacist, the provision of language courses (for access to medical services in a practice serving a large immigrant population) and improved communication with young people through working with sixth form college students using social media to communicate with young people.

Patients and PPGs at the centre of decisions

The founders of patient participation in practices believed in the involvement of PPG members in staff meetings and in discussions about proposed practice changes. Some PPG members have been involved in staff selection interviews, though such involvement is not uniform. It is difficult to know why GPs do not universally fulfil this part of the curriculum. Lack of time, lack of knowledge, and a failure to understand and appreciate the importance of patient participation may all explain lack of involvement or engagement with PPGs.

Placing patients at the centre of decisions about services should be a priority for GPs and practice managers, who unlike GPs, do not have a professional relationship with patients or a contractual arrangement to have a PPG. There are many demands on GPs and their practices, but involving patients when services are being configured can help ensure that patients understand the benefits and implications of the new service and use services appropriately.

PPGs and political advocacy

There is growing evidence of patients being effectively involved in local primary care services. The patient community can often identify problems facing patients, mobilise interest and find solutions, for example, surveying transport needs in a rural community and publishing the results.

For example, a PPG learnt of plans to build more houses without a commensurate increase in health services. The PPG was particularly concerned about the lack of midwives and met with the local service providers, the Royal College of Midwives as well as communicating with politicians. Their efforts helped secure an increase in midwives. Practices do not necessarily have the time nor staff to do such work. (See Corkhill Award winners 2017 on the N.A.P.P. website (N.A.P.P., 2017b).

In 2002, the Wanless Report (Wanless, 2002) argued that an annual saving of some £30 billion could be achieved by 2022 if we could move to a scenario where patients were “fully engaged”.

PPGs involving the local population and providing voluntary assistance

In December 2015, Storm Frank moved across the UK leaving devastation in its wake. In Tadcaster the town bridge collapsed

on 29 December 2015 as the River Wharfe reached historic levels. Residents and businesses were divided and faced a 10-mile detour to visit families and friends, to get to shops and schools. The local GP's surgery was flooded, but work by 30 PPG volunteers enabled the surgery to open the next day. The bridge reopened in February 2017, but the effects on the community persisted. On 6 September 2017, the PPG ran a workshop to build on lessons learned from their experience of flooding and that from other geographical areas, and to explore the nature of community resilience and what could be done to support communities in the future. The workshop was attended by clinical staff, CCG and local authority representatives, and patients. It is an outstanding example of community involvement and community resilience with the PPG and the practice working together. It is unlikely that either could have been so successful without the support of the other.

Other examples of community-based interventions include running transport systems, collecting prescriptions and home visiting. All of these can be done by PPG members with the agreement of the patients and carers concerned and in collaboration with the practice. A GP surgery in Lincoln has a new look children's area after it was redesigned by two college students. The practice PPG decided it was time to freshen up the area and commissioned the students to redesign and paint a mural in the children's area of the surgery. This initiative gave young people an opportunity to use their skill in a permanent way and to demonstrate how therapeutic art can be in a clinical setting (Lincolnshire West, 2017; Stuckey and Nobel, 2010). A PPG in another urban practice helped gain the trust of the homeless by involving a part time social worker and to learn of their health needs so that these could be met more effectively (N.A.P.P., 2017b).

All of these examples demonstrate how working with patients in the practice can help to build community engagement and resilience together with community-based interventions. Encouraging patient participation in decisions about the local provision of health care encourages such community engagement (Box 3).

Box 3. PPGs and self-care.

Since their inception, PPGs have been active in promoting self-care. Such activities include:

- Running lectures on giving up smoking, obesity and alcohol abuse
- Special events on men's health
- Discussions in local schools on teenage lifestyle
- Specific events for Carers Week
- Organising change for life exercises such as swimming, dancing and walking
- Flu clinics

Involving patients and carers

Individual patients are increasingly being involved in their own care. GPs are aware of the importance of patient-centred care (RCGP, 2014) a concept that embraces the principles of the Alma-Ata Declaration and was first used by US psychologist Carl Rogers in the 1950s to describe building a relationship of trust between therapist and patient so that the patient could fulfill his or her potential in life. The term was further developed 20 years later by George Engel to include the biopsychosocial model of health as an alternative to the traditional medical model. Patient-centred care increasingly plays an important role in public policies, however, without a consensus about what precisely the term means being available. The term 'patient-centred care' is an all-embracing concept that includes involving patients and their carers in their care. However patient-centred care can imply that something is being done *for* the patient. Perhaps *collaborative care* as is suggested by Michael Millenson (Millensen, 2017) better incorporates the concept of patients and their doctors working together to ensure that the question is "What matters to you?" rather than "What is the matter with you?"

Encouraging self-management and self-care

Patients can learn about illnesses and treatments from the internet and other sources, but they also need professional help to learn about treatments and choices available and how to have the confidence to be involved in self-management and self-care.

The focus of patient care still tends to be on dealing with one disease; however, many patients have more than one life-long condition (Barnett et al., 2012). GPs and practice teams are in a unique position to enable such patients to manage more, often complex, treatment regimens at home. It is now necessary for patients to have easy access to their medical notes, including test results, to help them in their ability to self-manage at least some of their health problems.

The Houghton Thornley Medical Centre (2017) award-winning practice-based web portal (Houghton Thornley Medical Centre, 2017) signposts patients, staff and others to trusted local information to help people get a better understanding of their care needs. This helps to ensure that people can continue to learn and educate themselves while being supported by the practice. This system can also be personalised to include specific information for individual patients. Opening the complete electronic health record to allow patients to read and to comment on their records increases their ability to manage their own health (Walker et al., 2015). Sadly not all UK patients can access their digital medical records and be involved in the way described.

An aim of all PPGs is to help promote good health, and some run special events for self-care week. Many PPGs help run annual flu clinics, often assisting with transport and refreshments, and signpost people to activities including walking groups, swimming, Tai Chi and dance classes.

The 2013 Corkhill Award winners organised 'Change for Life' lectures where practice doctors, hospital specialists and representatives from local health clubs provided advice and information on diet and life style. The same PPG organised a teenage lifestyle event with doctors nurses and other specialists to discuss smoking, sexual health, diet and exercise. These topics were raised by the student members of the PPG. Many PPGs run events targeting harder to reach groups, including men's health and events for carers around Carers Week.

Conclusions

Successful collaborative working between patients, GPs and the practices can achieve considerable benefits for all. The different ways that PPGs contribute to successful collaboration are summarised in Box 4.

Box 4. The contributions made by PPGs.

PPGs are good for patients because:

- Patients become more responsible for and take an active interest in their own health
- Patients become actively involved in developing the arrangements for their primary health care before decisions are made
- Patients can offer peer support to others in managing their conditions, making healthy choices and accessing information
- Patients have a better understanding and knowledge of the practice and its staff and how it must operate within the structure of the NHS

PPGs are good for GPs and practices because:

- PPGs can take pressure off practices by helping patients with non-medical and social issues
- PPGs can encourage more self-care for minor ailments, encouraging patients to use services more effectively and appropriately
- PPGs are an additional resource for the practice, raising awareness of and signposting to wider services, providing practical help and administering specific campaigns
- PPGs help to ensure shared decision making with patients and with the wider community about key health matters, thus reflecting patient needs

PPGs are good for the community because:

- Patients have a say in shaping local services through local PPG networks feeding into commissioning arrangements
- Patients are able to get an idea of what is needed to improve health care
- Patients will have an opportunity to become involved in other community groups e.g. CCGs and Healthwatch

Adapted from N.A.P.P. (2017c).

The structure of general practice is changing for GPs and patients. The recommendations of the GP Forward View (NHS England, 2016), working to scale, the changing roles of primary health care professionals, an ageing population with increased multi-morbidity, opportunities offered by the digital age, all present enormous challenges for GPs and their patients. It is surely now essential for GPs to embrace the opportunity to work collaboratively with patients in an atmosphere of mutual trust and with the PPG as an additional member of the practice team. Such collaboration should enable GPs to meet both their statutory obligations and the requirements of the GP curriculum while ensuring a degree of accountability to patients – the users of the services.

KEY POINTS

- Working with patients in an atmosphere of mutual trust is essential for accountability and to meet

statutory obligations and requirements of the GP curriculum

- Involving patients in decisions about health care and in their organisation is to the benefit of all and can assist with the many problems facing general practice
- Starting a PPG requires knowledge and understanding of the benefits of working with the PPG, including how to set up a PPG and an appreciation of the importance of supporting and respecting the PPG
- PPGs can encourage self-management, in particular through collaborative sharing of the patient record
- PPGs can help identify marginalised and disadvantaged groups of patients
- PPGs can identify and pursue issues important to patients, liaising with other organisations and publicising as appropriate

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