Patient Participation Groups and Patient Reference Groups

What’s in a name?

PRGs began during 2011 in response to an optional clause (Patient participation directed enhanced service (England)), or ‘DES’ in the GP contract, negotiated between the British Medical Association and NHS Employers. This clause applied only in GP practices in England and was in place for a limited time, until April 2014. Practices which formed PRGs received additional funding of up to £1.10 per patient. This is an amount which was deducted from the sum which practices receive through a separate Extended Hours DES.

In April 2014 a new Enhanced Service Specification (ESS) replaced the DES. The patient survey was replaced by The Friends and Family Test. The funding is now 33p per patient.

During 2011-12, many larger practices opted to form a PRG, but smaller practices did not. Where a PPG was already in place, it was often, but not always, used as the basis of the PRG. Some practices retained an existing PPG and also formed a separate PRG.

The intention behind this initiative was to kick-start more patient participation in primary care, by providing a financial incentive for GP practices to form patient groups and understand the benefits of consulting patients. The long term aim was for PRGs to contribute to the strengthening of PPGs (with better representation of all sections of the population), not the other way round. Improved PPGs with better representation of the practice population can develop as patient-focused, with a wider range of activities.

In spring 2011, our then CEO, Stephanie Varah, met the BMA team which defined the terms of the Patient Participation DES. Subsequently, she delivered training on the DES to large numbers of practice managers and GPs. This resulted in N.A.P.P.’s publication of a document setting out guidance for practices in setting up Patient Reference Groups.

N.A.P.P. produced a Quick Guide to the DES which was in the Member pages of our website.

Extract below from BMA website:

‘Patient participation directed enhanced service (England)

The aim is to promote the proactive engagement of patients through the use of effective Patient Reference Groups and to seek views from practice patients through the use of a local patient survey.

The key requirements of the patient participation arrangements were that GP practices:

- develop a structure that gains the views of patients and enables the practice to obtain feedback from the practice population, e.g. a patient reference group
- agree areas of priority with their patient reference group
- collate patient views through a patient survey
- agree an action plan with their patient reference group
- publicise the results of the patient survey
- publicise the actions taken and what is achieved as a result’
In a nutshell, PPGs are grass roots groups with their own terms of reference, whereas practices are responsible for ensuring that PRG must follow their more limited contract objectives (see below). Both PPGs and PRGs have advantages and disadvantages.

PPGs have a much wider remit than PRGs, and are usually able to follow the patients' agenda, not one defined by the medical profession and the NHS. The differences are:

1. PPGs are grass roots organisations which respond to the needs of their own patient and practice community. They aspire to contribute to continuous long term improvement in quality of patient care and improvement in the patient experience.

   PRGs had a specific imposed (top down) structure which is the same for every practice.

2. PPGs act as long term critical friends to the practice.

   PRGs provided feedback within the structure and the limited time scale of the contract.

3. PPGs negotiate with the practice to determine the group’s structure, aims, terms of reference and activities, e.g. Providing the patient perspective, health promotion, surveys, newsletters, service development, or support.

   For PRGs, practices were responsible for meeting, within a set period of two years, 6 objectives - recruitment, consultation, survey, post-survey discussions, action plan and evidence of the action taken by the practice. (See details at the foot of page 2)

4. PPGs can have autonomy and take responsibility for activities and support for both patients and practice.

   PRGs were reactive i.e. providing feedback, acting as a sounding board, managed by the practice to meet these specific objectives, for which the practice received financial remuneration.

5. PPGs rarely represent all sections of the patient population.

   The practices were required to demonstrate that they had taken steps to attract to the PRGs a range patients who are representative of the patient population in terms of age and gender and, in particular the hard to reach groups e.g. housebound, carers, ethnic minorities and those with mental health or long term conditions.

6. A PPG was often small groups of committed individuals who engage with and support the practice to support the practice in a variety of consultative and practical ways.

   PRGs had to be larger to encompass a cross-section of the patient population, which often involved an online/virtual group who never met and contributed less regularly.

7. A good PPG is a group of individuals who meet regularly and engage with one or more members of practice staff, with support from GPs.

   Some PRGs consisted of solely ’virtual ‘patients, so had no face to face or on-going relationship between real patients and practice - engagement at a distance, without interaction or discussion

8. PPGs are formed for the long term, working with the practice.

   PRGs originally had a guaranteed two-year lifespan, (extended to three years).

In April 2015, the ESS will end, there will be an expectation that every practice will have a patient group and the payment will be part of the “global sum” i.e. the standard contract.