



**Healthwatch Kent**

Patient Participation Groups:  
Challenges & Barriers to Great Practice



# Foreward from our Chief Executive

**We have been hearing from Patient Participation Groups (PPGs) from all over Kent about the issues, challenges and often frustrations that they face. Their issues varied hugely.**

We have also been hearing from organisations and commissioners about the need for Patient Participation Groups to be working well and supporting them in their work to involve and listen to patients.

Added to this we appreciate that huge changes will be made to what is called Primary Care in the coming years. Translated this means that there will undoubtedly be changes to both the services you receive from your local GP surgery and how you access those services. It is therefore imperative that Patient Participation Groups are working as well as they can to ensure patients have a say in what local GP services will look like in the future.

All of this combined has led us to explore in depth the challenges and barriers that Patient Participation Groups are experiencing right now. We've spoken to groups all over Kent and heard a wide range of issues.

We have shared these with each of seven the Clinical Commissioning Groups who have a responsibility to support the groups in their areas.

We have made a number of recommendations and suggestions as to how to improve the system. However, one issue is very clear - there is not one solution that will suit all groups. This is why we are now offering tailored support to individual Patient Participation Groups so we can help them address the issues that are unique to them.

By doing this we hope to make a real difference and ensure people have a say in how their GP services develop in the coming years.

**Steve Inett**

Chief Executive, Healthwatch Kent



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# Executive Summary

## Our Aim

We wanted to truly understand the issues and challenges that PPGs and the Practices were facing. We spoke with 98 PPG members and 16 Practices from all across Kent.

### Overview: What did we find?

We uncovered the following issues and themes:

- Relationship between practice and the PPG was often a huge barrier to progress
- Access to information and support was lacking for both the Practice and the PPG
- Groups were not always valued or visible within the Practice
- All groups face challenges to make their groups representative of their local community
- Strong feeling of frustration from members that felt they 'were wasting their time'
- Groups often struggled to maintain their momentum

### Our recommendations:

For Clinical Commissioning Groups:

- Provide local area information to groups
- Provide clear info on relationship between PPG & CCG
- Clarify the support available to new/struggling PPGs or groups who are facing challenges
- Consider how PPGs can play a more proactive role within the CCG
- Provide opportunities to understand and work with the whole health & social care system
- Ensure appropriate procedures for working with/supporting PPGs

### Our Pledge

Healthwatch Kent will undertake the following:

- Develop a PPG Good Practice Framework which is based on best practice and guidance. We will share this with all Kent Clinical Commissioning Groups (CCGs) and PPGs
- We will train our volunteers in the Best Practice and facilitation
- Using our knowledge and intelligence we will work with the CCGs and PPG Chairs to identify which PPGs may be in need of support
- We will offer support to three PPGs in each CCG area at any one time
- Our volunteers will meet with the PPG and the Practice and work through the Good Practice Framework.
- Healthwatch volunteers will produce a short action plan outlining the areas the individual PPG and Practice may need
- We will discuss these findings with the CCG to determine what support they can offer too
- The progress of this support will be monitored through 6 weekly meetings with volunteers
- We will review what outcomes have been achieved after 12 months
- In addition, we will involve PPGs more in our everyday work and projects.





# Introduction

**Healthwatch Kent is the independent voice for local people in Kent.**

We gather and represent people's views about any health and social care service in Kent.

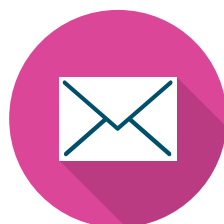
Our role is to understand what matters most to people and to use that information to influence providers and commissioners to change the way services are designed and developed.

Our FREE Information and Signposting service can help you navigate Kent's complicated health and social care system to ensure you can find and access the services that are available for you.



**Call us:**

Freephone 0808 801 01 02



**Email us:**

[Info@healthwatchkent.co.uk](mailto:Info@healthwatchkent.co.uk)



# What is a PPG?

**Broadly, PPGs are voluntary groups of patients, working in partnership with the GP Practice to make constructive contributions to services and facilities.**

**The National Association of Patient Participation (NAPP) defines a PPG as:**

...groups of volunteer patients, typically based at a single general practitioner (GP) surgery. They evolve to meet particular local needs. Each one is different, free to choose how to organise itself and where to focus its activities. They typically require support from the practice to get started but, over time, they should be run by the patients themselves. It is important that good relations with the practice are retained, so that PPGs can contribute to the partnership between practices and their patients.

PPGs have a vital role to play to ensure the voice of patients are heard by their local GP practices.



They are also supported by a series of legal frameworks and national guidance. Including:

- NHS England aim to make “working in partnership with patients and the public central to the way we work” both in personal healthcare and service development.
- The NHS Constitution places a statutory duty on health organisations to engage and involve patients in the planning of healthcare services.
- The Health and Social Care Act (2012) advocates the evolution of the patient’s role from ‘passive recipient of medical care’ to an ‘active, empowered and informed co-producer of health’ where shared decision making becomes the norm.
- Since 1st April 2015, all GP practices in England have been contractually obliged to form their own PPG.
- Practices are obliged to make reasonable efforts for the membership to be representative of the various sub-groups that make up the practice population.
- Practices are also required to engage with their PPG at a frequency and in a manner agreed with the group, and to review patient feedback (whether from the PPG or other sources - Friends & Family Tests, patient surveys, etc.) with the aims of the practice and PPG agreeing improvements that could be made to services. They should act on suggestions for improvements, where the practice and PPG agree.
- Practices are required to declare in the annual electronic practice self-declaration (eDEC) that they have fulfilled these requirements.
- The Care Quality Commission now places increased importance on the feedback given by PPGs about practices during their inspections.





# Overview



## Methodology

We contacted both PPG groups and Practices through a range of channels including:

- Online survey
- Face to face meetings
- Telephone interviews



## What did Practices tell us?

50% of GP Practices declined to talk to us. Key issues raised include:

- Lack of support to develop and maintain a PPG group
- Good leadership was essential to success
- None represented their community
- Recruitment was a huge issue



## What did PPG groups tell us?

98 PPG members gave us detailed feedback. Key issues raised include:

- Relationship between Practice and Group was a challenge for many
- Lack of support and information available from CCGs
- None could claim they represented their communities
- Recruiting and retaining 'good' members was a challenge
- Strong feeling of frustration
- 100% felt they had no influence over commissioning decisions
- ??% of Practices still had no PPG group

**50%**  
**of GP Practices**  
**declined to talk to us**



# Overview continued.





# Relationships

**PPGs are set up in a wide range of ways. Many have evolved methods of welcoming new members, information sharing, planning work and dealing with PPG-practice concerns. However, for some, the lack of governance structures meant that there was little guidance to deal with these issues effectively when the need arose. A clearly defined and communicated set of reference points and planning strategies were seen as useful tools for maintaining good relations between practice and PPG, agreeing workplans and recording progress towards tangible outcomes.**

## Issues

- The relationship between practice and PPG can be difficult to navigate
- Some PPG members feel unable to speak out in case the practice takes offence, and vice-versa
- Some tendency to dwell on particular issues rather than focus on patient need or planned action
- Blocking of reasonable proposed activities
- Maintaining momentum in meetings and project work
- Recruitment processes may be governed by the practice, or skewed by existing PPG members
- Some members do not feel that their skills are used
- Lack of monitoring: poor outcomes/ drifting objectives not addressed
- Tendency to be reactive rather than proactive

## Recommendations

- Devise clearly defined remits for PPG & practice, seeking guidance as appropriate
- Revise existing governance tools: are they working/need revision?

- Agree reference points; clearly communicate to the PPG, practice and patients
- Support needed for induction and top-up training to PPG members
- Annual work-planning (long & short-term goals)
- Access to wider evidence, eg: good practice can demonstrate potential outcomes to the practice
- Recourse procedures where workplan plans and actions are rejected or stalled
- Audit of member skills: what is the breadth of skills and interest; are they being used well?
- Suggest period of tenure, or rotation of leadership in order to share responsibilities

## Good practice examples

### Relationship with the practice; allocated roles:

- We have a pre-meeting with the practice manager in advance of the PPG meeting so that issues do not come as a surprise; this has built trust between the PPG and the practice
- Each member of the group took

responsibility for one of the CQC patient groups with a partner from the Practice. We researched examples of good/outstanding practice from CQC reports & prepared a list of things for the practice to consider based on identified good practice

### Reviewing & evaluating existing governance structures

- The group's partnership is reviewed to ensure it remains fit for purpose and aligned to our objectives (annually at least), helped by having written guidance to fall back on

### Practice participation

- Consider writing consistent practice participation (by practice manager and GP) into the PPG governance document (CSU guidance)

### Structured planning cycles to inform activities

- Having a structure (strategy) for the work of the PPG over a rolling annual period would be helpful and set direction and target setting, rather than falling from one agenda item to another without any clear framework or goals



# Access to information and support

Although many PPGs had been running for a number of years, they still required access to clear information about their local population, the relevance of commissioning structures, the evolving health context and policy developments regarding primary care. Some PPG members were involved in wider groups, but others were not and there was a need for the sharing and accessing of good practice without the added commitment of meetings.

## Issues

- Lack of easily identifiable information on PPGs, practice population, health context etc.
- Changing rules around PPGs and GP obligations: sometimes PPGs lack important information
- It takes time to search for information
- Some PPGs felt that the practice did not provide balanced information for decision making
- Some PPGs and PPG members can feel isolated without supportive networks
- Time lapses between meetings can affect information sharing and ongoing discussion
- Relationship with the practice & internal dynamics within PPGs can inhibit exchanges

## Recommendations

- Local information in an easily digestible format (plain English)
- Accessible material on health context and PPG/primary care patient involvement good practice
- Opportunities to ask questions and raise issues through a common forum
- Awareness of & introduction to local networks
- Partnership working and resources to enable members to attend conferences and training
- Allocated roles, partnering PPG and practice/clinical team representatives, to be able to share perspectives and info needs
- Training for members at induction and ongoing
- Practical support: analysis of PPG, training, action planning & skills workshops
- Access to practical guidance for aspiring PPG members and practices in need of start-up or development support

## Good practice examples

### External networks

- Building understanding of Sepsis: one of the group attended a seminar & gave feedback. Invited nurse to visit group for further learning & information resources
- Named representatives on stakeholder boards and wider PPG/Health Reference Groups, with feedback procedures

- South Kent Coast CCG is developing a 'dashboard' on the website: information about each GP practice in the area.

### Allocated members/sub-groups with specific roles

- Work in sub-groups with nominated practice members on newsletter development

### Partnership working

- Helped local social action charity to set up a support group for patients with diabetes. The PPG booked the venue and the Surgery sent out invitations to patients; sessions planned by Imago. When the 6 week group finished, the PPG has continued to attend and facilitate the monthly meetings for diabetic patients

### Research

- Each member of the group took responsibility for one of the CQC patient groups with a partner from the Practice. We researched examples of good/outstanding practice from CQC reports & prepared a list of things for the practice to consider based on identified good practice

### Practice as a resource

- Bi-monthly talks with speaker & GP/PM to give national/ local updates





# Visibility & Status:

## The practice, the patients & beyond

**In the first instance, PPGs wanted to be recognised and valued at a practice level as part of the culture of the organisation. Among patients, the PPG needed a range of communication routes and evidence of their work in order to generate interest and be memorable. Those PPG members interested in the wider context wanted recognition as named components in an open dialogue between patients, providers, and commissioners as opposed to being seen as contact points for sporadic data collection.**

### Issues

- Communication barriers with patients due to data protection
- Information about PPGs on practice website status often out of date
- Inconsistent understanding of the PPGs role across groups
- PPGs not taken seriously by some practices
- In commissioning, some PPGs were looking for a more solid role as partner rather than 'consultation point'
- Dynamics between voluntary groups and paid staff members (internal & external)
- Difficult to progress when PPG is 'blocked' - who can mediate?
- Frustration & demoralisation at lack of voice within practice and beyond

### Recommendations

- Nominate a named 'External Liaison' PPG member/sub-group
- Set up an official, monitored PPG email with a named contact
- Suggest an 'opt out' rather than an 'opt in' email contacts list among patients
- Consider a communication strategy for (aims, history, methods & skills, range, message)
- Social media and partnerships suggested to improve visibility
- Troubleshooting with CCG to improve involvement opportunities at practice and commissioning level; support from Lay Member or Healthwatch
- Practical support mechanisms for PPG members as volunteers. Eg: timely travel expense reimbursement; consideration of administrative costs associated with the work (eg: printing etc.)

### Good practice examples

#### Practice relationship

- Pre-meetings with PM in advance of main PPG meetings have been useful to build trust & discuss issues of concern

#### Planning & structures

- Structured plan of work which includes 'quick gains' as well as longer-term objectives; monitoring for publicity (photos & actions, not just reports)
- We allocate a sub-group, partnered by a practice rep to take this forward so the practice is kept updated

#### Demonstrate influence; 'you said, we did...'

- After feedback from the patient survey & follow up work, a bus company improved its route to the surgery
- Decoration to reception area (local artists, schools involvement), new signage, secure pram/cycle area: creating better environment, PPG seen to have influence

#### Partner/participate in 'high-footfall' events

- Supported healthy living event focussing on elders around the flu vaccination events at the 2 surgeries. Very good engagement with many attendees, free tea, coffee, soft drinks and cake encouraged people to stay and look at the stalls

#### Social calendar

- Monthly Coffee mornings attended by a practice representative: informal way to share info and listen

#### Referrals to PPG activities - social prescribing

- We organise walking groups to improve lifestyle & tackle isolation; these self-help groups bring patients to us





# Patient representation: Membership & engagement

PPGs and practice representatives acknowledged that their groups and patient contacts were not representative of the wider patient population. Some developing PPGs were in the process of building membership, however for most, the issue of maintaining momentum among their existing membership was a more pressing concern. The fact that the membership was not representative was also of lesser relevance for some who pointed to the fact that the breadth of engagement should be the focus in order to listen to and project the voice of the community. However, evidence of the PPG's role and outcomes were important in building commitment to both membership and engagement, with PPGs that had struggled to deliver work finding it difficult to fulfil this.

## Issues

- Membership and patient engagement not reflective of the wider patient population.
- Need more input from younger, working age people, and other more excluded groups.
- Barriers: time constraints, competing responsibilities, relevance & perceptions.
- Wide rural spread hinders participation.
- Membership and engagement conflated as PPG concerns.
- Where outcomes are few, difficult to show the value of the PPG-led adaptations to develop engagement and membership may be time consuming.
- Most adaptations are internal rather than external, though evidence points to better outcomes from external adaptations.

## Recommendations

- Separate work-plans for 1. building and maintaining membership; 2. extending engagement.
- Plan and document segments of work within set time frames and collaborate: allocate roles.
- Be realistic about what you can do.
- Collaborate with specific targeted organisations to broaden engagement base, but with a clear remit.

- Can the PPG adapt meeting time or venue.
- Identify outreach points and appropriate messages to share.
- Identify what support the practice could provide, eg: crèche, contacts.
- Audit of PPG activities & mechanisms in order to illustrate PPG value.
- Demonstrate value: plain English; use a range of communication strategies (eg: newsletter, in-practice screens & noticeboards).

## Good practice examples

### Build relevance

- A practice which was moving premises contacted all patients, inviting them to a meeting about the planned move. In the process of discussions about the move, the PPG was able to prove its relevance to 'non-traditional' members who have now joined and continue to participate

### Target raised concerns - timeliness

- Responding to health concerns raised in the patient survey; 'Hot topics' could be used as interest stories to get people involved. eg: '7 day working'.

## Partner with wider events/organisations with resources or expertise

- Organised 'elders' info day around the flu-jab sessions. Tea, refreshments.
- Initial support to Imago-led diabetes project; after training and 6 weeks, they handed over the project to the PPG.
- Partnership with Age UK; good links forged between the Practice & sheltered housing complex.
- Development of video materials or social media strategy with support.

## Referrals to PPG activities - social prescribing

- Walking groups to improve lifestyle & tackle isolation; self-help groups and wellbeing groups such as Community gardening build conversations with new people.
- Connection with new networks: eg: the Big Local.

## Outreach

- One PPG holds its meetings in a local care home in order to widen access (Scottish Health Council).
- Similar suggestions for outreach to English classes, schools, leisure centres, and public health campaigns.



**Healthwatch Kent**

Seabrooke House, Church St. Ashford, TN23 1RD

**Tel** 0808 801 0102

**Twitter** @HealthwatchKent

**Facebook** hwkent

info@healthwatchkent.co.uk

www.healthwatchkent.co.uk