



Patron:- Professor Sir Denis Pereira Gray OBE
Registered Charity No. 292157

Response to the NHS White Paper - Equity and excellence: Liberating the NHS

on behalf of:

**National Association for Patient Participation
(N.A.P.P)
and local Patient Participation Groups (PPGs)**

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Introduction:

The National Association for Patient Participation (N.A.P.P) is uniquely placed as the umbrella organisation for patient-led groups within general practices. It has over 30 years' experience and expertise in promoting, supporting and developing PPGs. It speaks for patients in general without being limited to any specific disease or condition. N.A.P.P. is a registered charity and, as such, is independent. Its primary aim is to improve the quality of care provided by the practice.

N.A.P.P's aims are:

- to see a Patient Participation Group (PPG) in every GP practice and that each group is based on the mutual interests of, and trust between, the primary care team and patients of the practice.
- to promote the role of Patient Participation Groups as participants in decision making within the NHS
- to maximise the benefit of sharing common interests while recognising the individual nature of groups and the differing structures in the devolved countries of the United Kingdom

The first PPG was set up by a GP in 1972 and 41% of general practices in England now have a PPG. Generally made up of a group of volunteer patients, the practice manager and one or more of the GPs from the practice, they meet on a regular basis to discuss the services on offer, and how improvements can be made for the benefit of patients and the practice.

PPGs play a pivotal role in helping to give patients a say in improving the quality of primary care services, the way services can best be delivered to meet their needs, and the needs of the local community. PPGs ensure that patients' needs, wishes and aspirations are at the heart of primary care services.

The strength of PPGs is that they operate within a community building extremely close relationships and ongoing contact with patients from within the Practice. This unique level of engagement with patients is achieved by the PPG built on the foundation of mutual trust and respect that exists between the GP's, Practice staff and PPG members.

PPGs assist GPs to develop an equal partnership with their patients. They help GPs to communicate accurately and honestly with individual patients, and with the wider community about key health matters and reflect patient need within a community.

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In practice, PPGs can play a number of roles, including:

- Advising the practice on the patient perspective
- Influencing the practice or the wider NHS to improve commissioning
Ensuring high quality care for all patients
- Communicating with the patient population
- Encouraging patients to take greater responsibility for their own and their family's health
- Carrying out research into the views of those who use the practice and their carers
- Organising health promotion events and improving health literacy
- Running volunteer services and support groups to meet local needs

Responses to the White Paper contained within this document represent the views of N.A.P.P Board members and staff and responses collated from PPG's across the country.

Response from N.A.P.P: (Responses correspond to numbered sections of the White Paper)

Section 2: Putting patients and the public first

Shared decision making: nothing about me without me:

2.4: There should be a legal requirement to involve patients, carers and the public that applies to all aspects of the proposed new NHS architecture. PPGs are ideally placed and play a pivotal role in the engagement of patients with GP Practices. **PPGs should be formally recognised in the new arrangements as a statutory mechanism to involve patients** complementary to the role of Local HealthWatch as the mechanism to engage communities. The NHS Commissioning Board should have the power to hold bodies to account in meeting this requirement and not just 'champion' involvement

An NHS information revolution:

- 2.8: PPG's are at the heart of GP Practices and already collect feedback on patients' experiences. N.A.P.P. expects PPGs to analyse and evaluate the results of annual GP Patient Surveys to feedback to the Practice ensuring that services are responsive to patients needs and wishes.
- 2.10: PPG's are in a position to facilitate the dissemination and explanation of information to patients about services that have been commissioned by their local consortia and about the performance of their local commissioners. This would ensure that patients would have information on commissioning outcomes/performance and be able to hold commissioners locally to account.

Information to support choice and accountability: Information on patient experience is available from PPG's.

- 2.11: Patients control of their health records: PPG's would be key in gaining feedback in the consultation on the arrangements for access to GP records including appropriate confidentiality safeguards.
- 2.14: PPG's could offer some support to individual patients and assist them in making decisions about choosing a provider for their treatment within the practice environment.

Increased choice and control:

- 2.19: PPG's have a valuable contribution to make to discussions about patients choice and should be approached to offer a perspective.
- 2.21: PPG's are well positioned to support the progression of patient choice through facilitating the transfer of information to patients and acting as a 'broker' in ensuring that patients with special/different needs have

access to the appropriate resources required to assist them in making an informed choice.

- 2.23: N.A.P.P has a valuable strategic perspective to bring to the development of the NHS Commissioning Board's implementation plan and would expect to be involved in this process.

Patient and Public Voice:

- 2.25: It is extremely important that PPG's are formally recognised in their own right as an important component of the involvement and engagement architecture alongside LocalHealthWatch and HealthWatch England. The unique role that PPG's play should be understood as distinct from that of LINKs and Local HealthWatch. PPG's and N.A.P.P should be fully integrated into all future policy planning, development and implementation as a key strategic partner.

PPGs should be formally recognised in the new arrangements as a statutory mechanism to involve patients.

N.A.P.P recommends that:

- **It is made a statutory requirement for all GP Practices to have a Patient Participation Group in the new arrangements** to ensure patients' voices from every Practice in the country can supplement the feedback gathered by Local HealthWatch and be effectively represented in GP commissioning.
- **Core funding for PPGs and N.A.P.P be formally considered to maximise the potential of PPGs in the new arrangements** as they currently operate on a voluntary basis

The essential distinctions between PPG's and Local HealthWatch (LINKs currently) relevant to the new patient and public voice proposals are:

- PPG's focus on individual patients and GP Practices, LINKs focus on communities, particularly those 'hard to reach'
- PPG's have direct access to and gather feedback from individual patients about GP, primary care services and the Practice, LINKs gather feedback from the wider community on health and social care services
- PPG's focus on improving the quality of general practice and primary care based on patients' feedback, LINKs look for trends from feedback that highlight the priorities identified by local people who use services and citizens resident in the wider area. PPGs already have the trust and respect of the practices in which they work.

For HealthWatch England and Local HealthWatch to work effectively with PPG's there will need to be a clear set of principles underpinning the relationships between these three respective bodies at a national and local level also a protocol developed and agreed locally between Local HealthWatch and PPG's for working together in localities and

across GP consortia boundaries. Training about PPG's is required & should be undertaken by Local HealthWatch and HealthWatch England. This training can be provided by N.A.P.P. Similarly, PPG's will need some training to understand & work effectively with Local HealthWatch and Health Watch England.

Clinicians will also need support and training to assist them in achieving effective and meaningful engagement with PPGs and Local HealthWatch. N.A.P.P can support clinicians to build their capacity and knowledge around PPGs and can provide bespoke training to clinicians and consortia about PPGs to ensure effective and mutually beneficial engagement.

Core funding for N.A.P.P and PPGs is needed to ensure maximum effectiveness of the new arrangements and optimal relationships between PPGs, Local HealthWatch and GP Consortia.

There should be **a minimum of two places set aside for representation from PPG's or the locality PPG networks** on the Core Group or Membership/Executive Board of the Local HealthWatch organisation. **The number of places for PPGs should be proportionate to the population size of the area covered by Local HealthWatch**

Principles and protocols will, as a minimum, need to clarify and identify:

- the respective roles, remit, aims and responsibilities of PPG's and Local HealthWatch
- the target population and professional groups for PPG's and Local HealthWatch
- the types and sources of feedback PPG's and Local HealthWatch will gather, collate and analyse
- the distinct benefits and outcomes of PPG's and Local HealthWatch
- the common principles that underpin working relationships e.g transparency, equality, independence, diversity, accountability etc
- methods, frequency, named contacts etc in relation to communication and engagement between each body and with GP consortia
- the distinct contribution/input /data PPG's and Local HealthWatch will each make to strategic commissioning and decision making processes in the locality and to relevant GP consortia
- the processes by which PPG's and Local HealthWatch will input into strategic commissioning and decision making processes in the locality including agreement around Board level representation of both PPG's and Local HealthWatch on relevant GP consortia
- the respective contributions/input and representation of PPGs and Local HealthWatch on Local Authority Health and Wellbeing Boards
- the processes for sharing and dissemination of information between PPG's, Local HealthWatch and GP consortia and the types of information to be shared including agreement around confidentiality and data protection

- areas for potential collaboration and mutual support/synergy to maximise the patient and public voice and ensure the delivery of responsive services
- processes for feeding back outcomes to respective target population groups

PPG's will also provide a valuable source of intelligence for HealthWatch England about the quality of primary care services and whether GP's and the Practice are meeting the required registration standards

N.A.P.P's strategic role is:

- to ensure the unique contribution of PPGs as grass roots organisations embedded in primary care GP practices is appropriately represented, recognised and effectively integrated into the national architecture, policy and strategic decision making processes of the NHS landscape
- to strengthen the patients voice locally and nationally by ensuring that the role, remit, value and benefits of PPGs are understood by all key stakeholders as distinct from that of other mechanisms and that PPGs have influence within the system
- to support and build capacity of PPGs as an effective strategic mechanism for listening to patients and improving the quality of primary care general practice.
- to support effective relationship building and local joint working between PPGs, GP's, Practice Staff, GP consortia and other patient and public involvement mechanisms/groups to ensure services are responsive to patients.
- to support and build capacity of GP's and all other clinical/non-clinical Practice staff in assisting the development and effective operation of PPGs in GP practices nationwide
- to support and build capacity of GP practices to integrate, action and learn from PPG activities demonstrating positive outcomes for patients
- to support and encourage the growth and development of a PPG in every UK General Practice

The role of GP commissioning consortia:

4.4: A key principle of the redesign of patient pathways should be **co-production with patients** emphasising the importance of patient feedback informing GP consortia commissioning decisions. By using services patients are able to challenge clinical assumptions about the effectiveness, safety and responsiveness of pathways, identifying where gaps exist, where improvements and innovations could be made thereby helping to target resources more effectively. Patients are also specialists in their own care and should be involved in discussions about pathway design from the outset. There is much evidence and research available that demonstrates the effectiveness of co-production.

4.6: PPGs were originally introduced and designed **by GP's** in the early 1970's who recognised the value and benefit of working closely with patients and carers to hear their ideas and suggestions about improving the quality of services and tapping into their experience and skills. PPG's have close working relationships with GP practices built on mutual trust and respect and are already involved in PBC commissioning processes in many parts of the country. PPG's are naturally positioned, at the heart of GP Practices, as the **closest lay body to the proposed GP commissioning architecture** facilitating the development of early and effective relationships between GP consortia and PPG's where they exist. In many parts of the country networks of PPG's are already forming around PBC consortia which will facilitate transition to the new arrangements.

N.A.P.P is participating as a strategic partner in the Department of Health GP consortia early adopter programme testing and demonstrating how PPGs and LINks/LocalHealthWatch can effectively work together to ensure the views of patients and the public can be fed into commissioning consortia and identifying how effective working relationships between PPGs and LINks/HealthWatch can be built.

In the context of commissioning, PPGs are uniquely placed to represent a collective unbiased view of patients' needs and priorities. PPGs are key therefore in supporting GP consortia to make informed commissioning decisions that drive up the quality of general practice, ensure services are responsive and target resources more effectively. Feedback from PPGs may include intelligence that may assist commissioners to:

- Identify current & future health and wellbeing needs
- Identify where needs are not being met
- Obtain intelligence on purchased services
- Inform the design of new approaches and pathways also issues to be prioritised
- Identify priorities for action
- Define problems with existing pathways of care and develop solutions
- Monitor changes in services
- Decide how savings should be spent
- Determine service specifications and improvements
- Determine the scope and level of quality indicators in contracts and agreements
- Develop Business Cases & Commissioning Plans
- Challenge assumptions about priorities

For the new arrangements to function effectively it would be imperative that a PPG existed in every GP practice in the country. **N.A.P.P recommends that it is made a statutory requirement for all GP Practices to have a Patient Participation Group in the new arrangements.** This concept is supported by feedback from GP consortia already working with PPG's and many individual GP's. N.A.P.P is working towards this goal and has valuable strategic knowledge, contacts, networks and expertise to play in support the effective implementation of the government's proposals.

To ensure that PPGs reflect the diversity of the population spectrum N.A.P.P is supporting the development of 'virtual PPGs' which operate primarily through email networks to ensure that all patients, particularly those that may have special needs or may not normally be heard are encourage to have a dialogue with the PPG and Practice so that their perspectives are reflected. Virtual PPG's will ensure that all patients voices can be heard and that the outcomes and changes that are made in response to this feedback are widely circulated to the patient population.

There should be **a minimum of two places on each GP Consortia Board set aside for representation from PPG's or the locality PPG network** to ensure that feedback from patients can be fed directly into commissioning decisions. **The number of places for PPGs should be proportionate to the population size of the area covered by each consortium.** A clear structure, principles and process should be developed by consortia to ensure effective and meaningful engagement and input of PPG's at Board level.

The capacity of PPG representatives and GP consortia members respectively needs to be developed to ensure both parties have an appropriate understanding of engagement and making it work at Board level. PPG representatives need appropriate support and information in Plain English to assist their understanding of commissioning and the issues being considered. Representatives should also have appropriate practical support and reimbursement of out of pocket expenses to facilitate their engagement.

Information about commissioning decisions, particularly where these are contentious, needs to be explained to patients in practices or using services affected by these decisions. PPG's can support/facilitate GP consortia in feeding back information to patients thereby improving consortia public accountability and patients' satisfaction.

An autonomous NHS Commissioning Board

- 4.10: N.A.P.P has valuable knowledge and expertise to support the NHS Commissioning Board in developing commissioning guidelines for good practice. NAPP's input into this process will ensure that GP commissioning is responsive to patients' needs, wishes and aspirations and will assist consortia in appropriately and effectively meeting their duty of public and patient involvement. See strategic role of N.A.P.P under point 2.25.
- 4.11: The NHS Commissioning Board should have the power to hold GP consortia accountable for meeting their duty of public and patient involvement. This should be a legal duty upon consortia and the NHS Commissioning Board should have a much stronger leadership and

monitoring role than merely 'promoting' and 'championing' the interests of patients.

The involvement of patients in the development of commissioning guidelines is critical and N.A.P.P has a valuable input to make to this process from the patient participation perspective.

Similarly, the involvement of patients should be integral to the majority of Board functions as listed. In addition to setting commissioning guidelines, patient involvement should be integral to the following:

- designing model contracts for commissioners
- setting standards for the quality of NHS commissioning and procurement
- making available accessible information on commissioner performance
- All functions listed under promoting and extending public and patient involvement and choice
- Holding consortia to account for delivering outcomes (particularly in relation to patient and public involvement)

Feedback from PPG's needs to be integral to the commissioning processes undertaken by the NHS Commissioning Board in relation to GP, dentistry, community pharmacy and primary ophthalmic services. PPG's in dental practices are beginning to emerge. These will gather views from patients about dental provision. A process for integrating feedback from PPG's into commissioning needs to be developed by the Board.

Establishing the Board and managing the transition

4.12: As stated in 4.10, N.A.P.P has valuable strategic knowledge and expertise to support the NHS Commissioning Board from its position as the UK-wide umbrella organisation supporting and developing Patient Participation Groups in general practice and from its strategic role in promoting the voices of patients through PPG's to influence and improve the quality and responsiveness of primary care services.

N. A.P.P works closely with the RCGP and BMA jointly producing support materials for PPGs and presenting at RCGP annual conferences. N.A.P.P has experience of working with the Council of the RCGP as their Patient and Carer group as well as with the BMA.

N.A.P.P. has published articles in academic journals and are grantholders for research projects on quality and safety in health QSN (Quality and Safety in the NHS) with Aston University and with Leicester University on a NIHR SDO project which will examine the measurable attributes of responsiveness in primary care.

During 2008-2010 N.A.P.P worked closely with the Department for Health's Access and Responsiveness team, led by Dr Mike Warburton.

Initially this involved workshops to provide patient feedback on the major issues concerning patients. From this, the Growing Patient Participation Campaign developed, in which N.A.P.P. was the major contributor, with co-sponsors, the Royal College of General Practitioners (RCGP), the British Medical Association (BMA) and the NHS Alliance. The campaign has promoted the benefits of PPGs and developed a website and resources to assist practices and patients in the formation and maintenance of effective PPGs. N.A.P.P. now maintains the legacy of the campaign through a conflated website.

N.A.P.P is a key statutory partner and should be allocated a place on the NHS Commissioning Board. See strategic role of NAPP point 2.25

Local democratic legitimacy

4.19: Local Authorities and their new Health and Wellbeing Boards need to ensure that they integrate the feedback from PPG's into commissioning plans in addition to that fed in by Local HealthWatch organisations.

Economic regulation and quality inspection to enable provider freedom

4.27: CQC should ensure it receives information from PPGs about services in addition to feedback received from Local HealthWatch. CQC is already planning to pilot work with PPG's to gather feedback on GP services and, in the future, on dentistry.

Conclusion: making it happen - Engaging external organisations

6.2: As stated throughout this document, NAPP has valuable strategic knowledge and expertise to support the development and implementation of the government's new proposals. **N.A.P.P is participating as a strategic partner in the Department of Health GP consortia early adopter programme** testing and demonstrating how PPGs and LINKs/LocalHealthWatch can effectively work together to ensure the views of patients and the public can be fed into commissioning consortia and identifying how effective working relationships between PPGs and LINKs/HealthWatch can be built.

6.3: PPG's need to be directly consulted on the implementation of the reforms as distinct from the more generic consultation with LINKs and other patients and public organisations. N.A.P.P can facilitate engagement, consultation and communication with PPG's to ensure their input into future consultation activity and the views expressed by PPGs are consistent with the needs of the community in which they are located.

Summary of key points:

- PPGs are ideally placed and play a pivotal role in the engagement of patients with GP Practices. **PPGs should be formally recognised in the new arrangements as a statutory mechanism to involve patients** complementary to the role of Local HealthWatch as the mechanism to engage communities
- **N.A.P.P recommends that it is made a statutory requirement for all GP Practices to have a Patient Participation Group in the new arrangements** to ensure patients' voices from every Practice in the country can supplement the feedback gathered by Local HealthWatch and be effectively represented in GP commissioning.
- PPG's are naturally positioned, at the heart of GP Practices, as the **closest lay body to the proposed GP commissioning architecture**
- **Core funding for PPGs and N.A.P.P be formally considered to maximise the potential of PPGs in the new arrangements as they currently operate on a voluntary basis**
- **Core funding for N.A.P.P and PPGs** is needed to ensure maximum effectiveness of the new arrangements and optimal relationships between PPGs, Local HealthWatch and GP Consortia.
- There should be **a minimum of two places set aside for representation from PPG's or the locality PPG network** on the Core Group or Membership/Executive Board of the Local HealthWatch organisation. **The number of places for PPGs should be proportionate to the population size of the area covered by each Local HealthWatch**
- There should be **a minimum of two places on each GP Consortia Board set aside for representation from PPG's or the locality PPG network** to ensure that feedback from patients can be fed directly into commissioning decisions. **The number of places for PPGs should be proportionate to the population size of the area covered by each consortium.** A clear structure, principles and process should be developed by consortia to ensure effective and meaningful engagement and input of PPG's at Board level.
- **N.A.P.P is participating as a strategic partner in the Department of Health GP consortia early adopter programme** testing and demonstrating how PPGs and LINKs/LocalHealthWatch can effectively work together to ensure the views of patients and the public can be fed into commissioning consortia and identifying how effective working relationships between PPGs and LINKs/HealthWatch can be built.

- **N.A.P.P is a key statutory partner and should be allocated a place on the NHS Commissioning Board.** See strategic role of NAPP point 2.25

Individual Responses from Patient Participation Groups:

N.A.P.P circulated the White Paper and Consultation Papers to all PPGs on their mailing list and encouraged them to make individual submissions to the White Paper team. There were common themes that emerged from all PPG responses which are summarised below:

- Patient participation groups in GP practices are the bedrock for achieving strong and effective user and carer voices across health and social care. If they existed in all practices, it would give the biggest outreach possible into the community
- The important role of PPG's cannot be over stressed in ensuring the patient voice is heard at a practice level or even higher up the system.
- N.A.P.P should be taking a leading role in implementing these changes.
- it must be a legal requirement for Patients to have an input into any of the processes that concern their healthcare. Patient's interests must be represented by their local, independent Patient Participation Group.
- Members agreed that the Government, Healthwatch and the GP Consortia should recognise N.A.P.P and the PPG's as an effective, relevant and vital part of the new structure.
- There must be clear lines of communication, responsibility and accountability between PPGs, Local HealthWatch and Health Watch England. Adequate appropriate training needs to be given to ensure each of these bodies develop effective relationships and understands the others distinct role and contribution in the new arrangements.
- It is essential that a direct line of communication exists from PPGs to their Local HealthWatch and that this is clearly defined. This however must not be the only means for PPGs to communicate their wishes and aspirations to the GP consortia or the National Commissioning Board.
- it is essential that there direct lines of communication be established between the PPG's to all or any of the following GP's Consortia,

Local HealthWatch and the National Commissioning Board. Thus PPG's thoughts and aspirations can be directed to the body most likely to influence their decisions.

- Clear areas of responsibility and roles should be established between Healthwatch and the PPG's to avoid duplication of efforts.
- Members felt it was vital to build long lasting and open relationships based on respect and openness between the PPGs, Local HealthWatch and HealthWatch England
- PPG's in many ways if effectively run do not need the Local Health Watch as they can communicate directly with GP consortia or the National Commissioning body as they do now with PCT's and Strategic Health Authority. The Local HealthWatch only comes into play if there is an item of interest or concern to the wider medical community and not just individual practices.
- Members felt that PPG's do an excellent job at grass roots level and in essence would like the role of the PPG to remain as it is, i.e supporting their local practice and its patients.
- PPG 'hubs'/networks need to be formed from Practices within each GP consortium locality to ensure patients voices are fed into commissioning
- Each 'hub' of PPGs needs to build up strong relationships with their GP Consortium to enable a two way communication between commissioner and patient.
- Members thought that there should be greater communication between PPG's on a local level, particularly between PPG's within the same GP Consortia
- PPGs are close to their individual Practice's and Patient's needs, and therefore are vital as the initial gatherers of the first level of information about patients needs.
- the individual voice of each PPG should not be absorbed into one over arching body who will not express the needs of individual practices.
- there should be clear structure for PPGs to communicate the feelings and aspirations of their own group to either the GP consortium and/or direct to the NHS commissioning Board.
- N.A.P.P should have a much higher profile in establishing links between the different parts of the new system and coordinating the role and formation of Patient Participation Groups.
- N.A.P.P to be at the forefront in promoting the formation of new PPGs and also to act as the strategic coordinating body for all PPGs

- Members felt that the PPG could provide an effective voice into the GP Consortia and Local Healthwatch. There should be at least one patient representative from the PPG on the Board of each GP Consortia and Local Healthwatch in order to have an input into decisions and policy making.
- Members also thought it very important to have a PPG representative(s) on the GP Commissioning Consortia Board to give a patient led perspective.
- It is important to retain the identity and role of PPGs
- Although the functions of a PPG may certainly include championing the rights of patients as consumers, equally important is the promotion of health by encouraging patients to take an active involvement in their own healthcare. The white paper is concerned almost exclusively with the former.
- PPGs would expect GP practices to discuss relevant issues with their PPGs, and keep them informed of the work of the GP consortium. The other main avenue of influence on commissioning would seem to be via local HealthWatch. Both GP consortia and the NHS Commissioning Board will presumably have an obligation to response to comments from both individual patients and representative bodies.
- There should continue to be a financial incentive for GP practices to have PPGs.
- Involvement and whatever else is needed to improve the quality of health services through engagement of patients and carers should be contractual and enforceable.
- Lay people who are members of decision making bodies – commissioning consortia, health and wellbeing boards etc – must be paid an appropriate attendance allowance in recognition of their time and the shared accountability they are taking on.
- Consortia must have boards with lay people (lay members) recruited and paid to be on them. There should also be lots of opportunities for patient representatives to influence what the consortia do. This should be in the consortia’s contract with the National Commissioning Board
- Consortia should focus on achieving outcomes that improve the patient experience and reduce inequalities as well as making better use of less resources
- Local Authorities should have strong scrutiny powers to see that consortia are involving patients and carers and making themselves accountable to the community.

- Patient groups in practices should be able to and encouraged to join Local Healthwatch but not required to join it. They should be part of the wider reference and intelligence networks of the Health and Wellbeing Boards and commissioning consortia. There should be a duty to involve patients and the public including patient groups.

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On behalf of the N.A.P.P Board and Patient Participation Groups

