



Patron:- Professor Sir Denis Pereira Gray OBE
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Response to Liberating the NHS: Local democratic legitimacy in health Consultation Paper

on behalf of:

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

Response compiled and collated by:

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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. It's primary aim is to improve the quality of care provided by the practice.

NAPP'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 Patient Participation Group 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.

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 also responses collated from PPGs across the country

Response from N.A.P.P: (Responses correspond to numbered sections of the Commissioning for Patients Consultation Paper)

Strengthening public and patient involvement:

1.5:

PPGs are ideally placed and play a pivotal role in the engagement of patients with GP Practices. It is vital that **PPGs are formally recognised in their own right as an essential component of the new involvement and engagement architecture alongside LocalHealthWatch and HealthWatch England as a statutory mechanism to involve patients** complementary to the role of Local HealthWatch as the mechanism to engage communities

PPGs 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 PPGs 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.

PPGs are at the heart of GP Practices and already collect feedback on patients' experiences. N.A.P.P. encourages 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.

PPGs 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.

Patients' control of their health records: PPGs would be key in gaining feedback in the consultation on the arrangements for access to GP records including appropriate confidentiality safeguards.

PPGs 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: PPGs have a valuable contribution to make to discussions about patients choice and should be approached to offer a perspective

PPGs 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.

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.

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

- PPGs focus on individual patients and GP Practices working from within the Practice whereas LINKs focus on outreach and engagement with the wider community with a specific remit to hear the voices of those 'hard to reach'
- PPGs have direct access to and gather feedback from individual patients about GP, primary care services and the Practice whereas LINKs gather feedback from the whole community within the local authority boundaries with a focus on health and social care services.
- PPGs focus on improving the quality of general practice and primary care based on patients' feedback localised to their practice, networking PPG's across areas for a collective voice. LINKs work on issues identified from trends in the feedback from groups and individuals across the whole geographic and population spectrum including communities of interest and faith communities.
- PPGs already have the trust and respect of the Practices in which they work.

For HealthWatch England and Local HealthWatch to work effectively with PPGs 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 PPGs for working together in localities and across GP consortia boundaries. Training about PPGs is required & should be undertaken by Local HealthWatch and HealthWatch England. This training can be provided by N.A.P.P. Similarly, PPGs will need some training to understand & work effectively with Local HealthWatch and Health Watch England.

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

- the respective roles, remit, aims and responsibilities of PPGs and Local HealthWatch
- the target population and professional groups for PPGs and Local HealthWatch
- the types and sources of feedback PPGs and Local HealthWatch will gather, collate and analyse
- the distinct benefits and outcomes of PPGs 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 PPGs 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 PPGs and Local HealthWatch will input into strategic commissioning and decision making processes in the locality including agreement around Board level representation of both PPGs 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 PPGs, 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

PPGs 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

Core funding is needed for N.A.P.P and PPGs 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 PPGs or the locality PPG network** on the Core Group or Membership/Executive Board of the Local HealthWatch organisation.

Membership of health and well being Boards:

40 & 44:

PPGs are uniquely placed as 'patient champions' at the heart of GP Practices and collect feedback on patients' experiences. **It is vital that PPGs are formally recognised in their own right as an essential component of the new involvement and engagement architecture** alongside LocalHealthWatch and HealthWatch England as a statutory mechanism to involve patients complementary to the role of Local HealthWatch as the mechanism to engage communities.

At least two representatives from PPGs needs to have a seat on each Local Authority health and wellbeing board to ensure that individual patients views are strengthened within commissioning decisions as distinct from those of the wider community represented by local HealthWatch.

Summary of key points:

- It is vital that **PPGs are formally recognised in their own right as an essential component of the new involvement and engagement architecture** alongside LocalHealthWatch and HealthWatch England as a statutory mechanism to involve patients
- **PPG's are naturally positioned, at the heart of GP Practices, as the closest lay body to the proposed GP commissioning architecture**
- 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.**
- **Core funding is needed for N.A.P.P and PPGs** 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 PPGs or the locality PPG network** on the Core Group or Membership/Executive Board of the Local HealthWatch organisation.
- **At least two representatives from PPGs needs to have a seat on each Local Authority health and wellbeing board** to ensure that individual patients views are strengthened within commissioning decisions as distinct from those of the wider community represented by local HealthWatch.

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 PPGs 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. Patients' interests must be represented by their local, independent Patient Participation Group.
- Members agreed that the Government, Healthwatch and the GP Consortia are should recognise N.A.P.P and the PPGs 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 however as previously outlined. 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 Consortia, Local HealthWatch and the National Commissioning Board. Thus PPGs 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
- PPGs 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 PPGs on a local level, particularly between PPGs 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 overarching body who will not express the needs of individual practices.
 - there should be clear structure for PPGs to communicate the views 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 respond 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