



Understanding Patient Participation Groups

A report for Healthwatch Northumberland

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EXECUTIVE SUMMARY

Healthwatch Northumberland (HWN) commissioned research to help it understand how the PPGs associated with the 41 GP practices in Northumberland currently work, their aspirations and challenges and the relationship they want to have individually and collectively not only with HWN but also the Northumberland Clinical Commissioning Group (CCG), Primary Care Networks (PCN) and local community and voluntary groups. HWN also wanted to understand how it and PPGs can most effectively communicate and exchange information and views and how this can be used for the benefit of patients, their families and carers.

The research has identified several key areas where further discussion or action would help PPGs develop in a way that is appropriate for them. The recommendations at the end of the report form an agenda for those discussions and provide HWN with a series of actions it will want to consider.

The research shows that PPGs want to engage with patients, with HWN and with the wider health community but for some this is difficult. PPGs see real benefits in engaging more widely and collaborating with others to improve the patient experience. Some PPGs would like to network and engage on a countywide basis whilst others would prefer to do this at a PCN level. This desire to collaborate must be nurtured by HWN and must be extended to include the CCG and the GP Practices it commissions. There is a real opportunity for a partnership approach to help support PPGs and improve the patient experience and HWN will play a pivotal role in this.

The research also highlights several areas of challenge for PPGs. The key areas are:

- Recruitment and retention of members who are representative of the Practice Population and who are able to understand and represent the patient perspective and work with the Practice to create improvements to service
- Engagement with patients and with the Practice to gather feedback in a meaningful way and to collaborate with the Practice to use this feedback to best effect
- Time and to a lesser extent cost – to travel to meetings, to attend meetings at a time that is suitable and to contribute effectively both within and outside the meetings

51% of the PPGs in Northumberland completed the survey that formed the basis of the research and a further 4 provided information during telephone calls meaning HWN heard from 61% of the PPG population during the research period. One of the challenges for HWN is how it engages with the whole PPG community, particularly those who opted not to engage this time.

As PCNs develop, the role of the PPG will become more pivotal because these networks will need to understand the patient perspective and identify how they can develop services that, among other things, improve population health. HWN, along with the CCG will have a role to play supporting both the PCNs and the PPGs. To be most effective HWN will need to ensure robust relationships with the CCG, PCNs and PPGs.

The report provides recommendations that are set in the context of the aims of the research and focus on the aspirations and challenges faced by PPGs and the way in which HWN can best engage to help address these.

1.0 INTRODUCTION – UNDERSTANDING THE LANDSCAPE

1.1 Primary Care in Northumberland

With 97% of its land classed as rural, Northumberland is sparsely populated having only 63 people per km² of land. Over 50% of the population live in only 3% of urban land in the south east of the county¹. In terms of the age, over half of the residents of Northumberland (58%) are of working age (19-65 years)². 22% of the population are over the age of 65 with 5% of these being over 80.

58%
of residents are
working age



The size and scale of the county creates a range of challenges within Primary Care for patients and for those who commission and deliver services to them. Currently, there are 41 GP Practices in Northumberland³ across 50 sites⁴. 18 Practices are either part of a larger group or have more than one branch of the Practice. Practice sizes vary greatly with the largest Practice comprising almost 26,000 patients and the smallest having fewer than 1600 patients⁵. Larger practices tend to be based in south-east Northumberland or around larger towns.

1.2 Primary Care Networks

Name of PCN	Number of Patients
Blyth	39,062
Cramlington/Seaton Valley	30,270
Valens	49,639
Wansbeck	46,555
Well Up North	80,558
West	80,515

Primary Care Networks (PCN) were developed as part of the NHS Long Term Plan with the intent that GP Practices would become part of networks covering (on average) 30,000 to 50,000 patients. They are “groupings of local general practices that are a mechanism for sharing staff and collaborating while maintaining the independence of individual practices”⁶. PCNs will be responsible for delivering

joined-up health and social care services through multi-professional teams to patients in the community. In Northumberland there are 6 PCNs⁷ The intention is that “new kinds of staff, including pharmacists, physiotherapists and paramedics, will become ‘an integral part of the core general practice model’⁸. They are designed to provide a response to some national key issues:

- Significant and ongoing workforce challenges
- The need to consolidate General Practice into the wider health system
- The drive to improve population health

While those PCNs in the south east of the county comprise the average number of patients, those in the north and the west of the county comprise significantly more. This poses a challenge for the PCN in terms of numbers, distance, etc. and it also poses a challenge for HWN as it considers how best it can engage with and support PPGs and PCNs in sparsely populated areas.

1.3 Patient Participation Groups

There can be no doubt that there are benefits to increasing patient participation in health policy whether that be at a local or national level. Such benefits include improving patient satisfaction, quality and safety, improving population health outcomes and reducing costs⁹. Involving patients nationally helps to ensure that policy proposals accurately reflect public health needs¹⁰ and can create real benefits from collaboration on goal setting and outcome measurement.

“PPGs strengthen the relationship between patients and their practices, which is critical in the provision of modern high-quality general practice”¹¹

Patient participation is equally essential at a local level in General Practice as it creates a *“unique partnership between patients, GPs and their practice which is essential to and results in high quality and responsive care”*¹². This is especially relevant as each GP Practice is an independent business within the NHS that has its services either commissioned by NHS England or co-commissioned with the CCG, governed by the General Medical Service Contract with Enhanced Service Specifications.¹³ Patient Participation Groups (PPGs) were first established in England and Wales in 1972 and saw some GPs forge strong links with their patients outside of the consulting room to bring the patient perspective into the wider work of the GP Practice.

While the number of PPGs grew over time it was not until many years later that the role of the PPG was formalised. From 1 April 2015 the GP contract¹⁴ included a requirement to *“establish and maintain a group known as a ‘Patient Participation Group’ comprising of some of its registered patients for the purposes of:*

- (a) obtaining the views of patients who have attended the Practice about the services delivered*
- (b) enabling the Practice to obtain feedback from its registered patients about those services”*



Although the requirement to have a PPG no longer forms part of the GP contract¹⁵, the notion of patient participation is firmly established across the health and social care sector. A clear steer to its benefits and the need to maintain it can be found across NHS strategy and policy in the NHS Constitution, The Five Year Forward Plan, The Patient and Public Participation Policy, Care Quality Commission (CQC) Inspections and the NHS Long Term Plan to name but a few. PPGs form part of the fabric of the wider community and can help GP Practices and others build relationships with the patients they serve. Of the 41 GP Practices in Northumberland, 40 provide some reference to patient involvement in their work¹⁶. It is worth noting that there is no single or definitive model for a PPG, each group is different. The PPG and the Practice should agree how they will operate but they should be representative of the Practice Patient Population.

“...use best endeavours to ensure that the PPG is representative of their registered patient population”¹⁷

PPGs are often defined a ‘critical friend’ of the GP Practice working to ensure that services are responsive to patients’ needs, and that they improve over time. Every PPG is unique, evolving to meet local needs. PPGs carry out a range of different functions depending upon the arrangement with their individual Practice. These functions include but are not restricted to:

- Providing the patient perspective to the Practice
- Carrying out research into the views of everyone who uses the Practice
- Influencing the Practice and the wider NHS to improve services provided to patients, their families and carers
- Sharing information with the wider patient population

- Organising health awareness and promotion events
- Running volunteer services and support groups to meet local needs
- Fundraising to improve services provided by the Practice

PPG members are unpaid volunteers generating minimal costs but are generally supported by the Practice with printing of documents, circulation of information, etc.

1.4 Healthwatch Northumberland

Healthwatch Northumberland (HWN) is the independent champion for people who use health and social care services. It exists to ensure that people are at the heart of care. It listens to what people like about services or what could be improved and shares their views with those with the power to make change happen. It also helps people find the information they need about services in their area.

HWN also has the power to ensure that people's voices are heard by local and national government and those running services. As well as seeking the public's views it also encourages services to involve people in decisions that affect them.

HWN recognises PPGs as an important way in which local people can influence the services on offer and how improvements can be made for the benefit of patients, carers and the GP Practice. HWN supports The National Association of Patient Participation (NAPP) in its view that *"The beauty of PPGs is that there is no set way in which they work - the aims and work of each group entirely depends on local needs - but they all have the aim of making sure that their practice puts the patient, and improving health, at the heart of everything it does"*¹⁸

2.0 METHODOLOGY

HWN commissioned research culminating in this report which provides a structured analysis of PPGs. The report aims to help HWN understand how the PPGs associated with the 41 GP practices in Northumberland currently work, their aspirations and challenges and the relationship they want to have individually and collectively with HWN, the Northumberland Clinical Commissioning Group (CCG), Primary Care Networks (PCN) and local community and voluntary groups. HWN recognised the real benefit in PPGs first talking to someone other than HWN about the issues they face, how they operate, etc. This report seeks to use the information gathered during the research to establish how HWN and PPGs can most effectively communicate and exchange information and views and how this can be used in working with the Northumberland Clinical Commissioning Group and service providers for the benefit of patients and carers.

The report anonymises all responses where possible using direct quotes from respondents unless they could lead to the identification of a PPG or an individual respondent. The report identifies key themes and trends and makes recommendations for further action.

An online survey was used to gather information from PPGs and GP Practices. The survey was open during November 2019 and PPGs received one reminder during the period to encourage those who had not yet responded. A mixed methodology approach was used with the survey being the primary source of data supported by:

- desktop research for archival data such as publications, videos, etc.
- requests for unpublished information

- review of websites of all GP Practices and PPGs
- review of third-party information such as CQC, Healthwatch, CCG, etc.
- review of PPG information held by HWN

A brief explanation of some of the techniques involved is provided below.

2.1 Triangulation of data

Triangulation involves using more than one method to collect information on the same topic. Typically, it involves examining data from interviews, surveys, written archives or other sources but it can involve different types of samples of information from the same source. The aim is not necessarily to cross-validate information but rather to capture different dimensions of the information gathered. Similarly, it is not about cross-checking information to confirm something is right. It is used to increase the level of knowledge of the topic and to strengthen the findings from a methodical framework of research.¹⁹ By way of example, the survey asked PPGs how they engage with HWN and how/if they would like to continue engaging – clearly there is benefit if considering these two items of data together. Within the responses, however, were several options for continuing to engage and many respondents selected more than one option. This data was then considered against responses to how PPGs engage now and also compared to the challenges faced by PPGs. Considering responses in this way provides the challenge to HWN to identify potential areas where it can support PPGs.

2.2 Majority Alignment Technique

21 GP Practices (51%) responded to the survey although a total of 36 responses were received as 8 Practices provided more than one response. Multiple responses were not requested but clearly some Practices believed a wider range of responses would be better. In the main however, the multiple responses did not appear to have been coordinated either with each other or with the wider PPG so variation, in some instances significant variation, was observed. Telephone calls to some Practices to resolve the variation was unsuccessful. To provide as rich data as possible responses have been aligned through the identification of common themes using a Majority Response Alignment Technique.

Majority Alignment involves finding the most common response from a series of responses from the same group. It is particularly useful when multiple responses are received from members of the same organisation or group. Responses from the same group are compared and where a majority response (identical or broadly similar) can be established that is used as the collective response for that group. Where no clear majority can be established then a nil response would be recorded. For the purposes of this research where the Majority Alignment Technique has been used all responses and the aligned responses are provided. This enables the reader to get a sense of the difference of opinion within the responses. The Majority Alignment technique is best used in 'yes/no' responses, in numerical responses or where there is little free text. Where there is more free text the Affinity Mapping Technique is more appropriate (see below).

2.3 Affinity Mapping Technique



Surveys and interviews enable researchers to learn about user challenges, motivations and preferences in a very personal way but they often yield large amounts of data.

Making sense of all that data and finding patterns to provide a full picture can be difficult so a technique called Affinity Mapping is used. Affinity Mapping organises ideas and information by synthesising data based upon natural relationships. Grouping responses together in common

themes makes the data clearer and more manageable. It is particularly useful when considering free text responses where many different views may be provided. By way of example, statements such as “to act as a link between the patients and the Practice” relates to the statement “assist the Practice to understand patient issues”. When mapped together these statements then form part of a group entitled ‘Link/liaison between patients and the Practice’. Similarly, the responses “being the patient voice” and “representing patients and their views” relate closely and when mapped form part of a group entitled “Giving a voice to patients”. Grouping in this way reduces the number of areas to analyse without losing the rich data gathered during the research

Affinity Mapping is not an exact science so there are instances where there are a small number of outliers – items of data that do not relate easily to any of the common themes. Example of this occur in the survey question relating to the role of the PPG. Single statements made such as “active interest in disability and incontinence issues” and “liaise with 3rd parties” do not fall naturally into any of the main groupings in the Affinity Diagram and so were treated as outliers for the purpose of analysing the data. Their value, however, is not lost as it is considered in the final analysis.

3.0 LITERATURE REVIEW AND OTHER RESEARCH

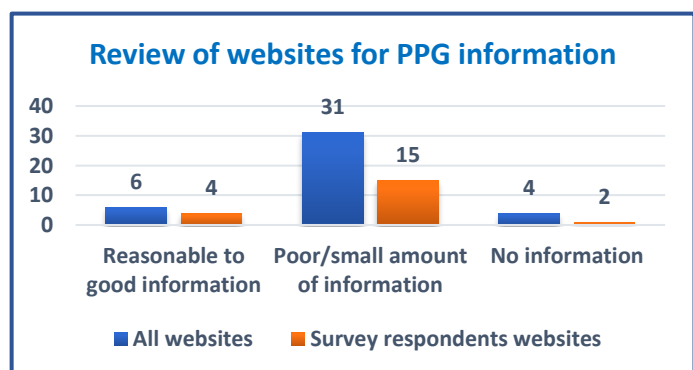
To triangulate the data gathered from the survey further research was also carried out. This included a review of literature published by Healthwatch, NHS England, Care Quality Commission, Northumberland CCG and a range of academic papers (see Appendix 2). The desktop research into all 41 PPGs was supplemented with a number of telephone calls and observational visits to GP surgeries. The desktop research included a review of the websites of all 41 GP Practices in Northumberland, a search for separate PPG information for every PPG and a review of the Care Quality Commission (CQC) Inspection Reports carried out for all GP Practices in Northumberland in the last 5 years.

3.1 PPG websites

The websites of all 41 GP Practices in Northumberland were reviewed and a thorough search was carried out for websites for any of the PPGs.

No PPG has a separate (live) website. Of the 41 websites reviewed, 4 provided no information about the PPG or provided only a reference with no supporting information. A further 31 websites provided some reference to PPGs and/some, not always useful, detail about the PPG’s work. Information was deemed useful if it was recent and/or provided clear information about the PPG, what it does, how to become a member, etc. but was not as comprehensive as some other PPG information. The remaining 6 websites provided more extensive information about the PPG and its work generally providing minutes, information about activities and how to join the PPG or contribute to its work.

The review of websites was then applied only to those who had responded to the HWN survey. The graph shows that the trend of poor/no information is similar to that of all PPGs.



A wider internet search for all 41 PPGs revealed no additional information, with all searches pointing back to GP Practice websites. While no new information was found this wider search supported what was discovered in the review of GP Practice websites.

Responses to the survey indicated a significant proportion of PPGs rely on the Practice website for sharing information with patients (86%) and recruiting new members (43%), etc. and the effectiveness of this as a tool is discussed in section 4.8 below.

3.2 Telephone calls and observational visits



Further triangulation was provided through telephone calls and observational visits. Some calls were made to Practices to clarify comments made in the survey or to help align the data by majority response. During some of these calls further information was able to be obtained but in the main it mirrored survey responses and so is included in the Findings section below. Observational visits were carried out at 4 GP Practices. In each instance the purpose of the visit was to see what patients see and to identify how the PPG portrays itself in the Waiting Room. In one of the visits there was no evidence of the PPG anywhere in the surgery despite the response to the survey describing how the PPG is advertised in the Practice. In a second visit there was lots of health information on the PPG notice board but patients would need to watch the presentation on the TV screen to understand who the PPG is and what it does. The remaining two observational visits were carried out to clarify information where there had been multiple responses to the survey from one PPG and to see first-hand what had been described in the survey. In both instances no additional information was established.

In addition, two calls were made to GP Practices who had not completed the survey. Primarily the calls were to clarify information found in the wider desktop research but time was taken to understand why the Practice had not responded to the survey. In both instances time constraints were cited as the reason.

**“Some days we don’t have time to turn around
let alone fill in yet another survey”²⁰**

3.3 A view from someone else’s hilltop

Desktop research was also carried out to understand how other organisations view or treat PPGs and what guidance they produce to assist PPGs in their development. These organisations included Northumberland Clinical Commissioning Group (CCG), NHS England, NAPP, Healthwatch England, local Healthwatch around the country and the Care Quality Commission (CQC). For the CQC the purpose of the review was to establish who else engages with the PPG. A review was carried out of the websites of these organisations along with anything else they have published in relation to PPGs or patient participation. Much of the published information concerned the changes to the GP Contract in April 2015 and related guidance. Very little public information related to the removal of the requirement for a PPG in more recent GP contracts. NHS England looks more widely at Patient and Public Involvement (PPI) and the Patient and Public Voice (PPV) so the assumption from its perspective, at least, appears to be that PPGs have been, somehow, subsumed into that work.

3.4 Northumberland CCG

The CCG “is responsible for the planning and buying of local NHS healthcare and health services” for the people of Northumberland.²¹ A significant proportion of its spend is on Primary Care so it has an absolute interest in the patient perspective. In its recently published annual report (2018/19)²² the CCG highlighted ways in which it had engaged with PPGs across the county. It appears, from the annual report, that much of its previous engagement with PPGs had been about the CCG gathering feedback whereas in more recent times it has been keen to develop effective two-way communication. The website supports this view detailing who the CCG is currently engaging with. It does not provide guidance in the development of PPGs but it does state what it believes PPGs are intended to do²³ and directs visitors to its site to their local GP Practice.



“The PPGs aim to share experiences, discuss what is working well and explore what changes are needed to improve patients’ experiences”²⁴

In April 2017 NAPP developed guidance to help CCGs engage with and support PPGs²⁵. There is some evidence in the CCG Annual Report and the website that this guidance has been considered. The website also encourages PPGs to get involved in the development of Locality Forums citing the development of the North Locality Forum and the proposed development of three more. The research did not fully support this with some respondents indicating they would not be interested in engaging more widely if this was managed by the CCG. This does indicate that perhaps a sub-county (locality or PCN) approach may be more appropriate but does not detract from the need for HWN to collaborate with the CCG to help support PPGs.

3.5 National Association of Patient Participation (NAPP)

NAPP is a registered charity and membership organisation. It describes itself as “the leading national, patient-led organisation working with Patient Participation Groups, the NHS and other key stakeholders to place the patient at the centre of the primary health and social care agenda through active participation at the grass roots of general practice and the local community”²⁶ NAPP provides a substantial amount of help and guidance (in the form of online resources) for its members. It also provides some public materials such as its “21 ways to help your PPG thrive”²⁷. NAPP holds an annual conference, workshops, etc. and works with national and regional organisations to ensure the patient voice is heard within organisations and policies. It offers affiliate memberships for PPGs and for CCGs.



3.6 NHS England

NHS England produces a significant amount of information about patient and public involvement across health and social care. There is some PPG specific information but this has not been updated recently²⁸. The focus is on wider patient and public involvement including training and even accreditation for those who get involved on a regular basis.



3.7 Healthwatch

Desktop research found that Healthwatch England does not provide any reference to or information about PPGs. Many regional Healthwatch do, however, produce information and, from the information on their websites, clearly work with PPGs in their area. There is a significant amount of information on the internet which has been produced by



regional Healthwatch either individually or in conjunction with neighbouring organisations. In considering its strategy for engaging with and supporting PPGs it is worth reflecting on what other Healthwatch have done in this area. There are many good examples of different guidance and help available. The list below highlights some of these: -

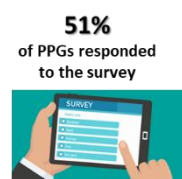
- PPG Development Toolkit – HW Peterborough and HW Cambridgeshire²⁹
- A framework to facilitate the use of patient and carer experiences to improve the quality of services in GP Practice - HW Swindon³⁰
- Frequently Asked Questions for PPGs – HW Bucks³¹
- Best practice guide for PPGs– HW Central and West London³²
- Good Practice Report – HW Oxfordshire³³

Some Healthwatch also facilitate or assist with a county or regional network of PPGs. Healthwatch Central and West London, for example, produce a PPG Network Newsletter for the members of its network³⁴. The newsletter provides details of meetings, local issues, guidance for PPGs, events, etc. A review of Healthwatch websites across the north east revealed little in the way of help and guidance for PPGs although local knowledge indicates that some of the regional Healthwatch are now focusing more attention on PPGs and the support they can provide.

4.0 FINDINGS

4.1 Who responded?

21 PPGs responded to the survey. Of those, 14 (aligned) were completed by PPG members and 5 (aligned) by Practice staff. Two PPGs who sent multiple responses had an equal number of responses from PPG Members and Practice staff and so, following Majority Alignment, are excluded from this calculation. A full



comparison was carried out of responses from PPG Members and those from Practice staff with no significant differences in approach being identified. There were a small number of instances where, as would be expected, the focus was slightly more on the impact of an issue on the Practice or the PPG depending upon who had completed the survey. Having multiple responses has provided some unexpected benefits in that it

shows the differences in views between members of individual PPGs (including where there may be confusion in certain areas or between different members of the group) but also where there is collective strength of feeling. This information is valuable across the whole survey.



Respondents were also asked if they were completing their response in conjunction with the whole PPG. Only 33% of aligned responses stated this was the case. Interestingly, there were different replies from some of the PPGs who provided multiple responses. Some respondents from a PPG advised they were completing the survey in conjunction with their PPG while others from the same PPG indicated they were not. These responses indicate a level of confusion about certain elements of PPG operation and this confusion is common throughout many of the multiple responses to questions across the survey.

4.2 Response rates

It is not known exactly how many people in the UK are surveyed each year but given the number of organisations who survey significant numbers of their customers each year logic would dictate it will be in the hundreds of millions. By way of example the National GP Patient Survey (which is now an annual survey) issued 2.3 million postal questionnaires in January 2019³⁵. Over 770,000 people responded to that survey providing a response rate of just over 33%. The average response rate for postal surveys is 50%³⁶. For email surveys (such as the one issued by HWN) which includes an invitation to complete an online survey the average response rate is 30%. HWN received 21 responses out of a survey population of 41 - a response rate of 51% which is significantly higher than the average for this type of survey and which provides HWN with a good set of baseline information. Whilst the overall numbers are relatively small, they represent over half of the survey population so are unlikely to suffer from sampling bias and can be deemed to be statistically significant³⁷. The results can also be viewed as having the same characteristics of the whole survey population, i.e. all PPGs in Northumberland. Based upon this and other triangulated data it can be assumed that the collective responses to the survey can be viewed as those of all PPGs in Northumberland.



Despite this, HWN will want to consider why 49% of the PPGs invited did not respond to the survey and how it can better engage with all PPGs going forward. There are several common reasons for non-response to surveys many of which apply to the HWN survey:

- **Survey not received/not received by correct person** – evidence shows that HWN did not have the most up to date contact information for PPGs. This raises the issue of why not but also of how can HWN maintain current contact information
- **Lack of time/inclination to complete the survey** – many respondents to the survey commented they are time poor, did this prevent others from completing the survey? Calls were made to some Practices where responses had not been received and time was reported as the critical factor here. HWN will need to consider how it addresses this issue if it is to engage with all PPGs
- **Enough incentive to respond** – respondents need to believe there is some value in spending time providing feedback to other organisations. “In other words, “what’s in it for me?” HWN will need to consider how it communicates its value to PPGs and the integral value of PPGs providing feedback
- **Did the survey stand out?** – was the contact process sufficiently interesting to encourage PPGs to complete the survey? Do HWN emails go straight to junk mail or clutter boxes?
- **Survey fatigue** – people become bored with too many surveys – has HWN considered if a survey is the best way to gather the information it needs?



To better understand why so many Practices did not respond to the survey, follow up telephone calls were made to two Practices. Staff were asked why they had not completed the survey and, in both instances, time was cited as a major factor. One Practice advised it had passed the survey on to the lead person for patient engagement and also to the PPG Chair and was surprised to learn that the survey had not been completed. Interestingly though, neither saw enough benefit to the Practice to make time to complete or follow up on the survey. In addition, two different Practices replied to the original email advising they would never have time to complete the survey. If these four cases are representative of those who did not respond then the challenge for HWN is to consider how it can best engage this group of Practices whilst still supporting those who are able or willing to engage. Options, of course, include carrying out a different type of survey (e.g. face-to-face), reducing the length of the survey and incorporating the

survey into an event or workshop. Given, many respondents are keen for HWN to engage at a PPG or PCN level, perhaps this would be a more productive vehicle for HWN to consider for gathering data.

4.3 PPG models and modus operandi

Currently, there is no specific model for PPGs. The model is agreed between the Practice and the PPG and the expectation is that these will not all be the same but will be responsive to the needs of the Patient Population and be reflective of it. The ratio of committee only to other models is 3:1 but within that there are a variety of operating models ranging from very formal (producing minutes, issuing agendas, publicising meetings, etc.) to ad hoc. One respondent advised that the Practice calls a meeting when there is something to discuss but no agenda or minutes are prepared. Only one PPG reported operating solely as a virtual entity while 4 PPGs advised they operate a combination of committee and virtual group. As HWN develops its engagement strategy it will want to consider how it supports PPGs that do not operate a face-to-face model.

5 respondents also advised that their PPG has recently been or is planned to be refreshed but none indicated the model is likely to change.

While some of the responses were not clear on certain areas of their PPG model, in the main there was a clear split between those PPGs that are run by the Practice (47%) and those that are run by Lay Members (36%). Of the 6 responses that were unclear, 2 respondents did not know how the PPG operated supporting the notion that there is confusion or at least differing views about certain aspects of PPG operation. A further 4 respondents were not explicit on whether those leading were from the Practice or Lay Members. 72% of all respondents indicated that Practice staff attend some or all of each meeting. Some Practices are part of a larger group and the Practices in one such group described significant control by the Parent Group rather than individual Practices within the group. Another group of Practices that is under the control of one Parent Group advised it is exploring how to create single PPG for all its Practices. Both areas will need to be factored into HWN's engagement strategy.

4.4 The role

PPGs provided a range of clear descriptions of the role they believe they should fulfil. In response to other questions, however, some PPGs cited confusion over what their role is and that this is a challenge to them. After Affinity Mapping was completed there were three clear areas of work that PPGs felt defined their role: a) Giving a voice to patients, b) Being a Critical Friend to the Practice and c) Being the link between patients and the practice.

“A group of people representing patients within the practice”³⁸

76%
of PPGs operate
as a committee



5
PPGs have recently or
are planning to
refresh their group




36%
of PPGs are run solely
by Lay Members



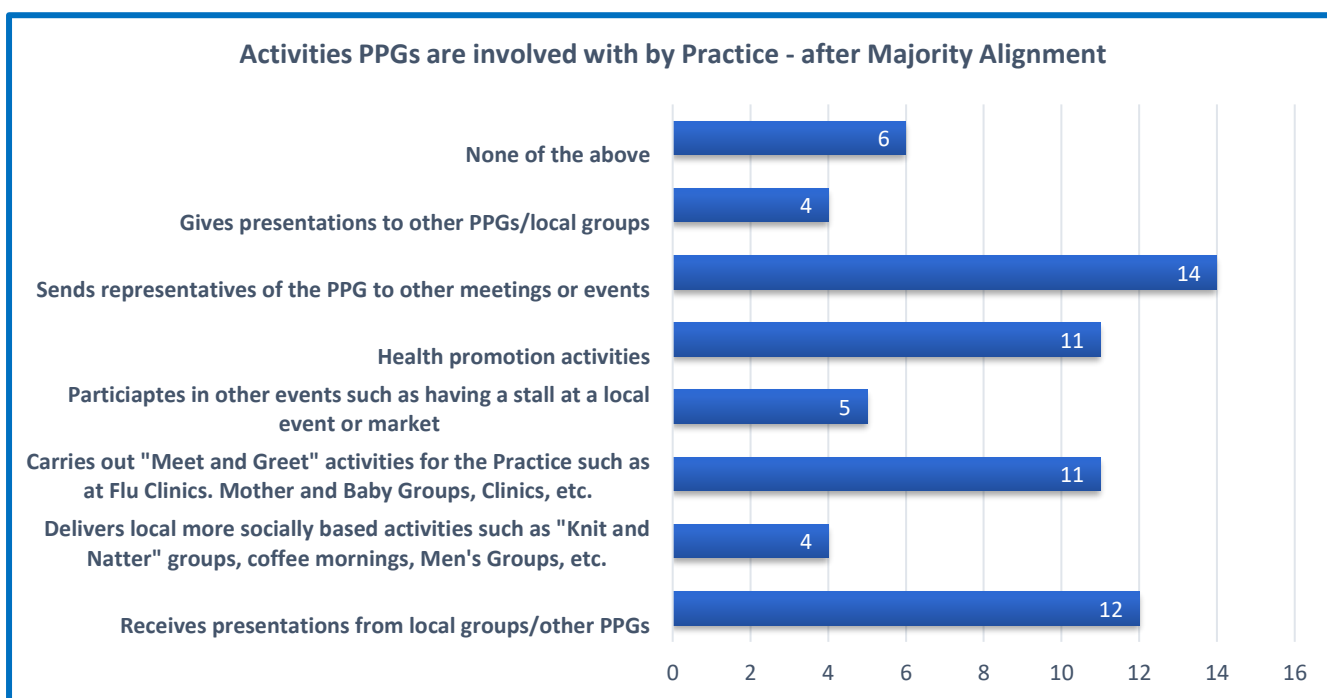
These descriptions chime with the way PPGs were originally intended to operate with PPGs acting as the patient voice by working closely with the Practice gathering patient feedback and developing plans to monitor and improve services. Regardless of the role identified by individual PPGs 76% of respondents believe their PPG fulfils its role.

76%
of PPGs believe they fulfil their role



4.5 Different activities

Within the models there are PPGs who also play an active role in their community either through social prescribing activities, meet and greet activities, fundraising, etc. or because they share data and engage with a wide range of community groups. The graph below shows the breakdown of other activities PPGs say they are involved with.



Clearly, some PPGs are involved in a range of activities alongside gathering feedback or representing the patient perspective. This chimes with NAPP’s view that all PPGs are different. PPGs are also involved in giving presentations to local groups (19%), in local events (23%) such as a stall at an organised event and in assisting the Practice through ‘meet and greet’ activities. There is a clear sense of community in the responses to this question.

A small number of PPGs (19%) reported that they focus more on social prescribing or other social activities and so have little to no time to act as the patient voice with the Practice. Engaging with this group will pose a slightly different challenge for HWN who will want to factor this into its engagement strategy.

“The role of the PPG at our practice has changed. We are now setting up groups for Social Prescribing i.e. Knit and Natter, Walking Group, Cinema Club, Crossword Group and more. This leaves us thin on the ground for gathering feedback etc.”³⁹

4.6 Representing the Practice Population

81%
of PPGs believe their
committee is not
reflective of the
Practice Population



The intent, as described above, is that PPGs make efforts to be representative of the patient population of their Practice. Representative PPGs are the barometer of the patient population. Despite this, 81% (Majority Aligned) stated they do not believe their PPG is representative of its Patient Population. The limited guidance that has been produced by NHS England, Clinical Commissioning Groups, etc., indicates that PPGs should try, wherever possible, to be as reflective of their Practice Population as they can. This covers all demographics not just age, although it is the age profile of groups that proves the biggest issue for PPGs. Comments centred on the fact that PPG members tend to be retired

or at least over 55 and that recruitment of younger and working age members is particularly difficult. Some respondents believe this is due to a shortage of time for younger people or the timing of the meetings.

“All PPG members are over 55, its hard to attract younger people to join”⁴⁰

The remaining 19% of respondents believed that other factors such as gender, ethnicity or the fact that PPGs Members are volunteers were the main issue with one respondent citing the fact that only one of their branches is represented on the PPG which means it will never be reflective of the Practice Population. The age profile provides challenges in recruitment and retention as well as in being reflective of the Patient Population. Challenges are considered in greater depth in section 4.11.

“I don't really know if the PPG is representative but I guess it isn't since volunteers are rarely representative of a cross sectional population”⁴¹

4.7 Gathering information from patients

In order to give a voice to patients and users of the Practice, PPGs need to listen to their views. Responses to the survey indicated that only 67% of PPGs gather feedback from patients and Practice users. It is unclear how the remaining 33% establish what is important to patients or are able to represent their views? Once the data was triangulated with other responses in the survey it became clear that the 67% figure may not be an accurate reflection of the number of PPGs currently gathering feedback.

67%
of PPGs gather or
have gathered
feedback



Triangulation of the data revealed that 100% of respondents described using the results of surveys to improve performance. This means that more PPGs described how they use data gathered than actually gather data. Some PPGs reported developing an action plan in conjunction with the Practice to monitor improvements and to advise patients of actions taken as a result of feedback gathered. Others advised that the Practice use the data to improve services but did not refer to monitoring improvements.

“We use the information to make things better”⁴²

Calls to Practices for clarification revealed that some Practices (rather than PPGs) carry out their own surveys or that they or the PPG have carried out surveys in the past. The likelihood, therefore, is that some respondents were referring to these surveys. Further triangulation of the data underpins this assumption

because responses to the question about how surveys are carried out revealed a higher response rate (86% - Majority Aligned) the number who say they gather feedback. This further suggests that some respondents are referring to surveys carried out elsewhere in the Practice or in the past. The important thing to note, however, is that in many Practices patient views are collected and then listened to.

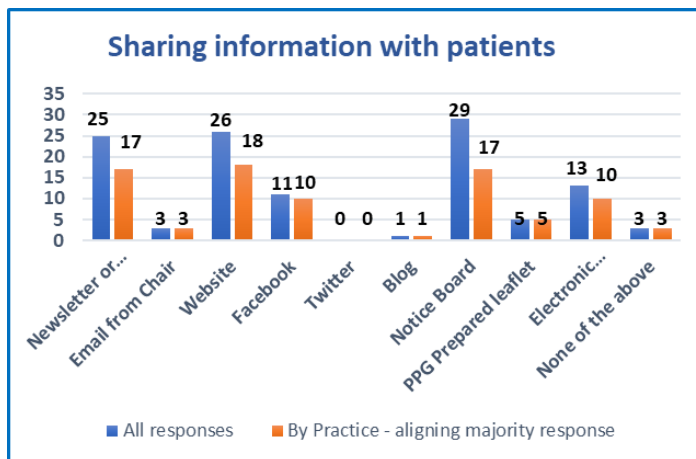
Responses also showed that, those who complete a survey do so, in the main either annually or twice a year. 4 respondents advised that they carry out surveys on an ad hoc basis with others advising it has been quite some time since a survey was last completed. Respondents indicated that surveys are either carried out as a paper exercise or as a combination of methods - online and paper surveys. Two PPGs reported face to face surveys as being their only method of gathering feedback.

The research also revealed that, in the main, the Practice analyses the data gathered. There were a small number of respondents who said the PPG or the PPG and the Practice analyse the data. There were also some respondents who were unsure who carried out this task. Analysing data can be time consuming and sometimes quite challenging. Given that PPG members are volunteers it can be a big ask for them to analyse large volumes of data. Similarly, Practice staff constantly reported being time poor so the additional task of analysing data may prevent some from carrying out the survey in the first place.

During the calls to Practices some staff asked for guidance on how surveys ought to be carried out and data used. This lack of confidence in managing surveys was also reflected in some survey responses. HWN will wish to consider further how its strategy might facilitate the support required.

4.8 Sharing information with patients and others

Gathering information and feedback is, of course, very important but if one of the functions of a PPG is to inform and educate patients then it is equally important to understand how information is shared with them in order to satisfy this function. From the responses it is clear that patients receive some information from PPGs. This information varies depending upon the model the PPG operates and ranges from minutes of meetings to action plans, health education awareness and community information, etc. 18 out of the 21 PPGs who responded to the survey advised that they produce material that is shared with patients.



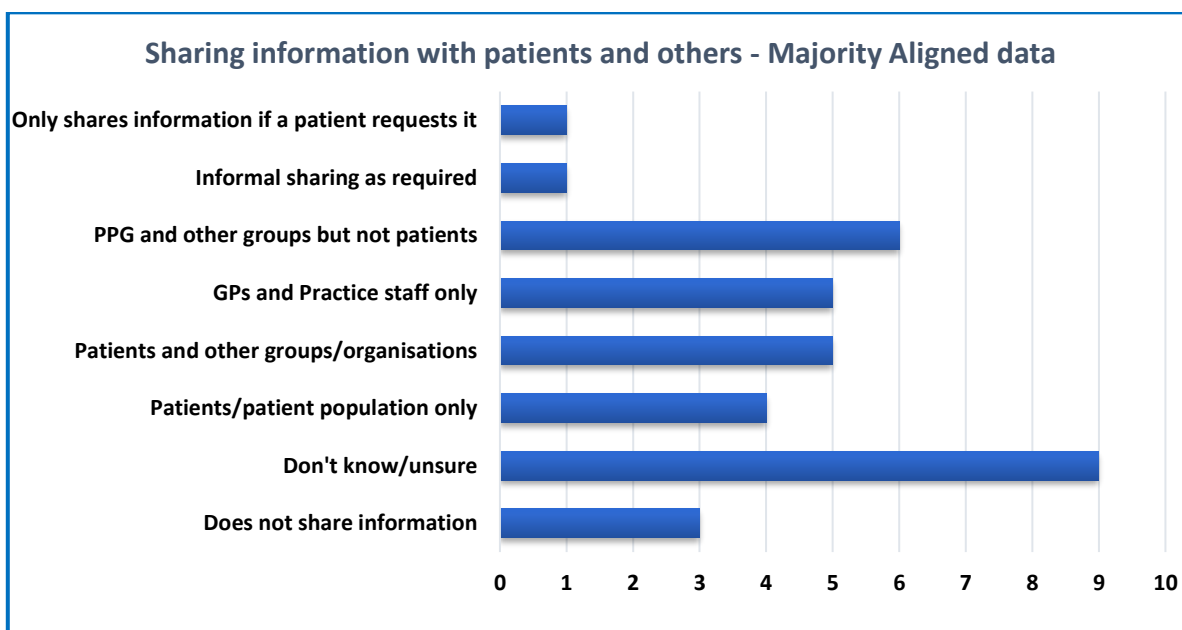
The data shows that hard copy information, such as posters, leaflets, newsletters, etc. in the Waiting Room is a common means of providing information, with Practice notice boards being particularly popular vehicles for this. Some PPGs share minutes of meetings in this way while others advertise meetings in the Practice. Facebook was cited by 10 PPGs as a method of sharing information. No PPG reported using any other social media and an internet check confirmed this to be the case. Whilst hard copy material is popular for many, one PPG reported that it is prevented from publishing any information not sanctioned by its parent company. Another PPG (from the same group) reported it does not publish information. A small number of

PPGs indicated they share information via the Parish Council or local shops. Interestingly, in the area of information sharing, there was no difference of opinion within PPGs who provided multiple responses.

Given that information is predominantly shared via the internet or displayed in the Practice the issue of access must be considered for those who do not or cannot use the Practice or the internet. This is explored further in section 4.13

Three PPGs advised that they do not share information with patients via any of the methods used by other PPGs with one respondent saying they use *“One to one contacts between PPG members and other patients”*⁴³. Two further PPGs reported having shared information in the past but that they found it difficult to maintain with one saying it did not *“feel supported by its Practice in this area”*. One PPG also advised that in addition to other forms of engagement it uses a patient leaflet prepared by the PPG providing general information but is in the process of updating this due to a *“recent influx of new patients”*.

When the *“how information is shared”* responses are compared to *“who”* PPGs say they share information with the picture is somewhat different. Three respondents stated they do not share information with anyone while a further 5 reported only sharing information with Practice staff. A further 6 PPGs advised they share information with their PPG and other organisations but not patients. In total only 9 PPGs advise they share information with patients (4 with patients only and 5 with patients and other organisations. It is somewhat surprising that more PPGs did not report sharing information with the patients of the Practice as this seems to represent a conflict with the central aim of a PPG.

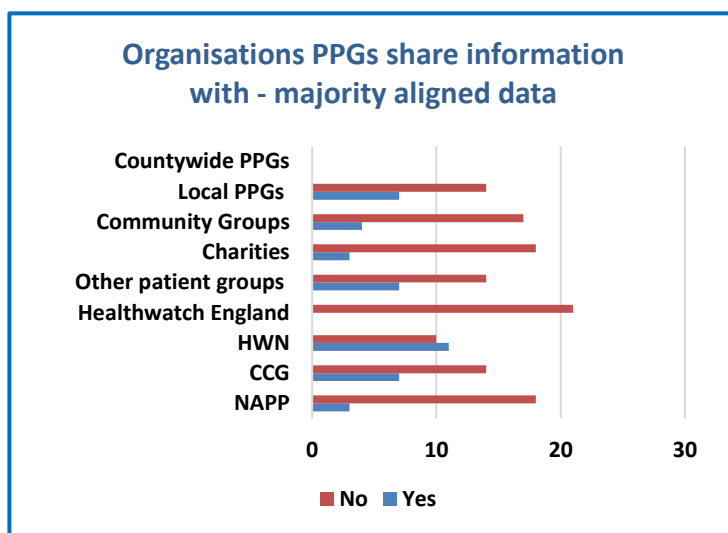


The data becomes more difficult to understand when it is compared to the review of all Practice websites. Many PPGs advised they use ‘the website’ as a vehicle for sharing information with patients. The review of websites revealed only 6 provided information of the type described relating to the work of the PPG. There appears to be a disconnect between what PPGs believe is happening and what is happening in practice. Whilst not a feature of the survey, no PPG reported checking what information was placed on the website, the quality of it or the number of times it was accessed. This may be a feature of split roles – where one party prepares information and a different party uploads it to the internet.

A lack of engagement from patients is highlighted as a challenge for PPGs and this is discussed further in section 4.11 below. If information is not being shared with patients in a way that they can access it then it not difficult to see why engagement from patients may be a challenge. HWN has significant expertise in the areas of developing and sharing information across the county. This is a sensible area for further discussion with PPGs and Practices and one which HWN will want to consider the extent to which it is able to provide support.

4.9 Sharing information beyond the patient

Respondents were asked who their PPG shares information with outside of the Practice and 34 responses were received. As with other free text responses Affinity Mapping was applied to this data to identify relationships between comments and capture broad themes. The data here supported responses to other questions in that information is shared predominantly with HWN and the CCG. Some PPGs share information with their immediate neighbours whilst others share with community groups and other local groups. Given these relationships exist there is scope to share best practice as well as information. This may help PPGs with some of the challenges they reported such as recruitment. There are opportunities for HWN to support these conversations



4.10 Gathering information from elsewhere

Respondents also reported gathering other patient related information. In the main, this was 3rd party information such as the results of the Friends and Family Test, National GP Patient Survey, NHS Reviews, CQC Inspections, etc. This information does add another dimension when looking at how a Practice is performing or is perceived by its patients. It is only useful, however, if the information is used to improve performance or inform decisions.



Not all respondents reported gathering all data but everyone reported gathering something. Few respondents, however, provided details of how frequently they gather and review this information or how they use it. Only one PPG advised that it looks at the regular information sent to the Practice by HWN. It was not clear from the responses whether all Practices share this information with their PPGs although a call to one Practice revealed they have only just started sharing in the last quarter. No PPG referred to the Northumberland CCG Communications and Engagement Quarterly Reports which are presented at the quarterly CCG Governing Body Meetings which are open to the public. This is despite the CCG describing in its Annual Report how it has strengthened its “links with Patient Participation Groups which belong to practices to enable two-way communications with the CCG”⁴⁴. Opportunities exist here for HWN and the CCG to explore how information can be better shared with PPGs to increase communication.

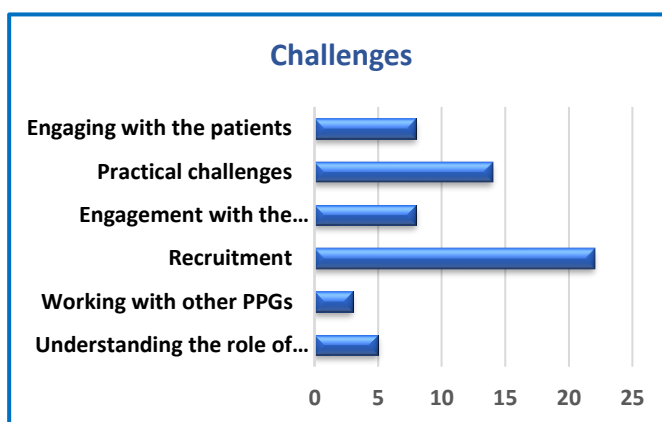
A small number of PPGs also reported reviewing complaints against the Practice. Whilst this is not the role of the PPG it does provide a wider perspective on Practice performance and patients' views which will be beneficial when considering improvements or changes to services.

One PPG provided reported reviewing data and patient feedback on a specific area of performance – triage call back waiting times. A call to the Practice revealed that this is a feature of the appointments booking system and is an issue that is important to their patients. Again, this provides a wider perspective in terms of patient preference and Practice performance and will be valuable to that particular Practice. Jointly or severally, this type of information is also useful to the wider PPG community who may encounter similar issues in the future.

When the data was triangulated (via review of newsletters, websites, telephone calls, observational visits, etc.) there was little evidence of PPGs using the 3rd Party information they gather. One PPG, as part of the survey results it published, did demonstrate, however, including 3rd Party data as part of the development of an action plan for improvements. There is a significant amount of information available to PPGs in relation to GP Practice performance which may complement or underpin feedback they receive from patients and users of the Practice. Part of the agenda for discussion that HWN is developing should include how intelligence, such as the specific issues reported in the survey, is shared more widely to help PPGs and Practices develop. HWN and PPGs will want to consider the value of information from a range of sources, including individual PPG experience data, and how this can be shared more widely within the PPG community.

4.11 Challenges

Volunteers and volunteer groups regularly face challenges and as volunteers, PPG members are no exception. Across the research, PPGs reported a variety of issues but 3 main areas of challenge permeated all the research: recruitment, practical issues such as time and logistics and engagement (both with patients and the Practice). As the research sought information on who leads the PPG it was pertinent to compare whether the challenges were the same for those PPGs led by Practice staff and those led by Lay PPG Members.



No trends were identified when comparing data from both groups. Each reported the same top 3 biggest challenges. To triangulate this data further a desktop review was carried out to identify whether the issue of challenges facing PPGs had been considered elsewhere. Two pieces of research were found.

4.12 Learning from the past

In November 2013 NAPP outlined what it believed were the most common challenges for PPGs⁴⁵. At this point PPGs did not form part of the GP Contract but many CCGs were keen to help develop them in order to better engage with patients. At that point the challenges it believed PPGs and CCGs would face were:

Initial Challenges	Long Term Challenges
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PPGs are often small groups and not representative of wider population	Sustaining groups and volunteer enthusiasm
Takes time to build relationships, mutual trust and respect <ul style="list-style-type: none"> - within the patient group - between practice and patient group - for benefits to show 	Avoiding the development of a 'clique culture'
Encouraging GPs and practice teams to recognise the value of PPGs	Continual recruitment is essential
	Involving the young, housebound, carers, some ethnic groups other hard to reach
	Persuading PPGs to network
	Engaging with: <ul style="list-style-type: none"> • issues outside the practice in the wider area • the CCG

In 2015 ahead of PPGs becoming part of the GP contract Healthwatch Kent carried out some research into the areas PPGs and Practices felt may be challenging in the first year⁴⁶. That research identified the following 4 themes:

- Patient representation: membership & engagement
- PPG-practice relationship and governance structures
- Access to information and support
- Visibility and status

In 2016, Healthwatch Surrey carried out a survey of PPGs⁴⁷ looking to identify barriers to success one year on from PPGs becoming compulsory in the GP Contract. The challenges it identified were:

- Recruitment of a diverse and representative PPG group
- Retention and motivation of existing PPG members
- Getting 'buy in' / support from GPs at the surgery and getting them to attend the meetings to represent the surgery
- Establishing a primary purpose of the group to give clear direction and ensuring that personal agendas are not brought to the group Ensuring members are there to constructively contribute to meetings
- Finding the right time to meet to allow a cross section of the surgery to attend e.g. day vs evening meetings

The challenges identified by NAPP in 2013 resonate with the challenges identified by the research in 2015 and 2016 and also with this piece of research which was carried out over 6 years later.

The challenges identified in 2015 were broadly similar to the barriers to success identified one year later by a neighbouring Healthwatch. This is not necessarily surprising considering PPGs were still in their infancy.

Comparing the three pieces of research particularly the barriers to success identified by Healthwatch Surrey to the challenges reported in the HWN survey the issues are almost identical. It is interesting that two

surveys almost 4 years apart and separated by more than 320 miles identified such very similar challenges. It does not seem unreasonable, therefore, to assume that other PPGs in other counties today are facing or have faced broadly similar issues. Consideration of this will be a significant factor for HWN as it develops its agenda for discussion with PPGs and its engagement strategy going forward. There are opportunities to learn from other Healthwatch and PPGs and to develop a more widespread approach to supporting PPGs either by providing freely available national resources or by creating regional support networks.

4.13 Recruitment

PPGs reported that recruitment is the biggest challenge for them both in terms of recruiting numbers of members and of recruiting members of sufficiently different demographics to make the PPG most effective. Regularly, PPGs reported difficulties recruiting anyone under the age of 55 or retaining members for any length of time. There was a sense that not only does a committee of a similar age group prevent PPGs from being reflective of their Patient Population but it also restricts the breadth of enthusiasm and new ideas required in the role. While recruiting younger people was described as a significant issue, the recruitment of a range of age groups was also described as a challenge. One respondent also felt that the demographics of the PPG more generally needed attention whilst another felt that the PPG was lacking because it did not include patients from the different branches of the Practice or from different demographic groups. The notion of PPG Members being volunteers with different amounts of time was also popular.

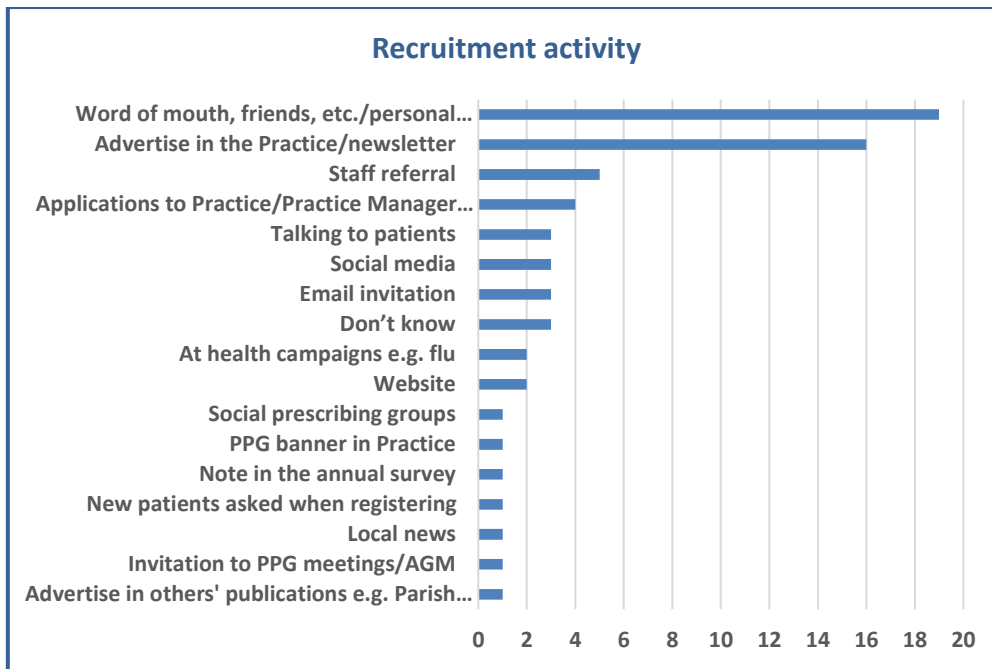


Respondents reported a variety of methods for recruiting new members with all adopting a combination of several methods.

While there are a wide range of methods adopted for recruitment a significant number of PPGs use Word of Mouth or personal recommendation when recruiting new members. This technique introduces selective influence and so increases the likelihood of PPG members recruiting “in their own image”. It is unsurprising, therefore, that PPGs struggle to recruit outside of a particular age group or demographic.

“Recruitment of young people and males is the biggest challenge”⁴⁸.

Similarly, the majority of PPGs use some form of newsletter or bulletin as a recruitment tool but again these will be restricted to those who regularly use the Practice and are aware of the existence of the newsletter. This assumption is underpinned by observational visits to Practices where the newsletters and advertising described in the survey was not evident in the Waiting Room. This issue is considered in more detail in section 4.13.



Across all respondents recruitment activity has largely remained static in terms of the method used and the recruitment challenge have remained the same. A small number of PPGs reported trying different methods of recruitment but with limited success. One PPG, for example, advised that along with the usual posters in the surgery GPs and Practice staff are issued with a slip to issue patients they believe may be suitable candidates and that this has brought some success. That same PPG, however, noted that the membership is not reflective of the Patient Population as most members are female and over 55, again selective influence is in play. Some PPGs have approached local schools and colleges to recruit younger people and one has experimented with Google Hangouts but in the main recruitment activity is restricted to Word of Mouth and adverts in the Practice either by a poster or the newsletter.

Selective influence and unsuccessful advertising are not the only reasons for unsuccessful recruitment. Other reasons cited across the research include:

- Lack of knowledge of or interest in what the PPG does
- Lack of interest in the topic more generally
- Lack of awareness of recruitment opportunities
- Lack of engagement with patients/potential new members by existing PPG
- Inability to attend meetings due to time constraints or the burden additional work brings
- Inability to attend meetings due to timing of them – many PPGs meet in the afternoon or very early evening as it suits their current membership rather than creating meeting times that will fit in with working age people

Further research^{49 50} indicated that these challenges are broadly similar to those experienced in the wider Voluntary and Community Sector (VCS). Some organisations have experienced success in recruiting members who are representative of their population so there is scope for PPGs to engage with the VCS to help with recruitment. This would be a sensible addition to the agenda for discussion with PPGs.

The reasons for unsuccessful recruitment cited above are also evident in the other two main areas of challenge for PPGs: Engagement and Practical Issues.

4.14 Engagement

Engagement with both patients and the Practice poses a challenge for the majority of PPGs who responded to the survey. For some the challenge is about getting patients involved, getting feedback, etc. For other PPGs the challenge is engaging the Practice or the Parent Company. Both of these challenges are reflected in the research carried out between 2013 and 2016 as described above.

“Patients are (I believe) reluctant to get involved when they don't understand what if anything they can contribute”⁵¹

Patients – alongside difficulties recruiting patients to become members of the PPG, respondents also report that engaging them in activities, including surveys, is also a challenge. Being interested or engaged is not necessarily the responsibility of patients. They will choose to engage or not depending upon a range of factors including time, interest and their ability to engage. The research shows that engagement tends to be via the website or hard copy materials in the surgery or Waiting Room. Elsewhere in this report is a description of the review of websites and the lack of relevant, useful information for patients from or about PPGs. This will be a barrier to engagement. Similarly, PPGs reported publishing newsletters, leaflets, etc. and displaying these in the Waiting Room. Whilst a significant number of each Practice population attend the surgery each year not all patients do or are able to. There will be patients who are only seen in their own homes or in Care Homes who never attend the Practice and so will never be aware of information displays. These patients are, however, still users of the Practice and its services and so will have a view which they may wish to share. Equally, the majority of those who do attend the Practice are unlikely to spend a significant amount of time in the Waiting Room so may be unaware of or not have time to read all of the material displayed. Further, there is another group of patients who find reading and understanding information a challenge such as those with learning difficulties or those for whom English is not their first language. Again, this group may remain unaware of the information being displayed but again will have a view of the Practice and its services which they may wish to share. The unintended consequence of this is that the information so carefully crafted by PPGs/Practices may go unseen by a significant majority of its intended audience.



Similarly, whilst the internet is available to many it is not accessible by all. PPGs who rely heavily of information being shared on websites (irrespective of the quality) will again fail to engage with a proportion of patients who have a perspective to share but for whom internet access is a challenge or, many cases, non-existent

One interesting feature of the data when it is compared as a whole is the way PPGs view engagement themselves. As described above, 18 out of 21 PPGs reported communicating with patients via their websites whilst only 9 PPGs said they share information with patients. This juxtaposition may exist because, in some cases, PPGs are aware that the websites are not serving them well or that not all patients will access the site or see newsletters, notice boards, etc. Equally, it may be that PPGs believe information is being placed in Waiting Rooms when it is not – one observational visit found no reference to the PPG in any area of the Waiting Room despite the respondent from that particular PPG advising to the contrary. Two further

observational visits found reference to the PPG but not to the extent that was described in the survey. By way of example, one visit to a GP Practice showed a notice board clearly marked “Patient Participation Group” and on it was an interesting display of a health topic. The notice board, however, was one of many in the Waiting Room, was not in a prominent place and only visible to patients as they are leaving the surgery.



PPGs who reported they are involved in social prescribing activities such as ‘Knit and Natter’ groups or walking clubs did not report using these as vehicles to engage patients about the work of the PPG, gather feedback or seek new members through discussion. There may be several reasons why this is the case but ultimately, they are opportunities to increase engagement with patients, particularly as the patients involved are already engaging, on some level, with the PPG. Those PPGs who reported struggling to recruit/engage may wish to consider other engagement opportunities such as these.

PPGs are clearly experiencing challenges in engaging patients to help them better understand their perspective. As HWN develops its agenda for discussion with PPGs engagement will be an area for significant consideration.

Practices – several respondents reported challenges engaging with their Practices. One Practice reported that they do not believe that their “Doctors realise how important and useful the PPG could be” while another believes that the CCG ought to do more to encourage “GPs to fully engage with their PPG”. Some respondents recognise the pressures Practice staff are under so accept a lack of engagement but believe patients “lose out as a result”.

“A lot of issues for the PPG come down to staffing levels and increased demand for appointments”⁵²

For others, changes to the Practice or the formation of larger groups of Practices under one parent company is creating challenges for the PPG. One PPG believes that its parent company does not encourage “local autonomy” nor does it understand local issues so engaging with it and the local Practice is becoming increasingly difficult. Another respondent said of its parent company “We have had a number of resignations as members do not think they [the parent company] listen. They do not like any form of criticism. They respond very badly to constructive criticism and this led to more than one resignation. PPG members then feel that they are wasting their time.” There are ways to address this particular challenge at both a local and organisation level which HWN could be well placed to support.

The findings from the survey indicate that PPGs are working hard to develop and that they face a range of common challenges. The findings identify a need for PPGs to:

- improve their recruitment techniques i.e. improve the website
- extend their reach in terms of engaging patients,
- find better ways to share information with patients (on what the PPG does)
- explore new techniques to attract volunteers from different demographic groups
- examine whether their processes inadvertently exclude certain groups

There is a useful discussion to be had which should include how PPGs learn from others, how they share best practice and activities such as recruitment and how they do this taking into consideration the needs of their local area. HWN may be a useful source of help here.

4.15 Practical issues

Time was identified as a challenging factor in both preparing for and attending meetings as was a shortage of time in meetings to discuss issues properly.



“PPG meetings are time-precious”⁵³

PPGs also recognised that a lack of time generally manifests itself in quite different ways for example engagement is an issue but there is usually insufficient time to focus on developing engagement materials. Time is also a factor in other ways with one PPG feeling that there is an imbalance between the time involved in delivering social prescribing activities and the remaining time available to gather and consider patient feedback. For some PPGs there are cost implications either because they have to fundraise for the Practice or because there is no funding for printing of newsletters, posters, etc.

PPGs also reported a range of different practical issues many of which they feel relate to the challenges the staff of their Practices face. Another facet of the challenges surrounding recruitment is stagnation of the group. Some PPGs indicated they have recently or are looking to refresh their group in an attempt to make it more effective. Stagnation is an issue for many PPGs as are other challenges reported such as failing attendances of members, lack of representation, etc. A slightly different challenge in this category came from a PPG who felt that as their Practice performed so well in local and national surveys it was sometimes difficult to find issues to “get their teeth into”.

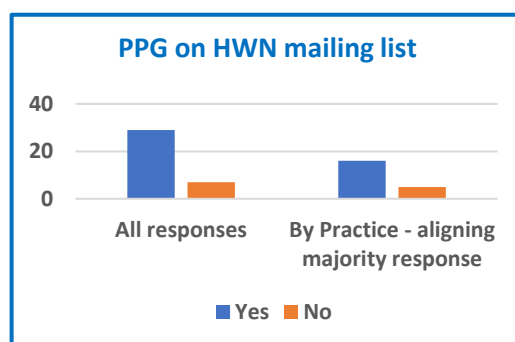
While the lack of time is a common issue for many some of the other practical issues were specific to smaller numbers of PPGs. As HWN develops its agenda for discussion and potential support for PPGs it will need to consider whether it is best placed to assist with some of these issues or whether it needs to strengthen relationships with individual Practices and the CCG who may be better placed to assist.

4.16 Relationships

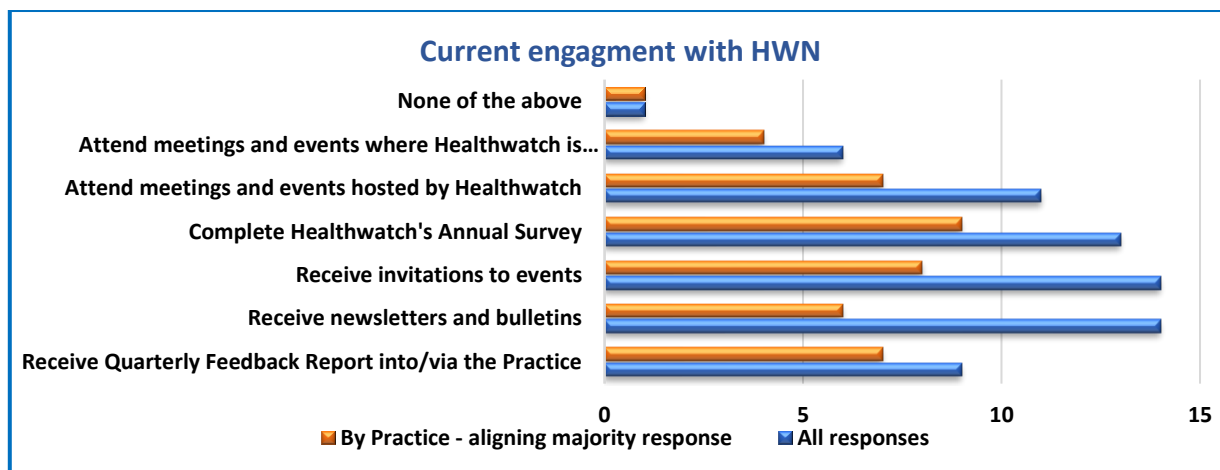
Alongside trying to better understand how PPGs work and their aspirations, HWN is acutely interested in the relationships they want to have individually and collectively with HWN, the CCG, PCNs and local community and voluntary groups. This section looks first at the relationships with HWN and then at those with the CCG and NAPP.

4.17 Healthwatch Northumberland

HWN operates a mailing list from which it sends newsletters, bulletins, updates and surveys. Respondents were asked if their PPG is part of that mailing list. As the graph shows fewer than half of PPGs (Majority Aligned data) are currently on the mailing list. Examination of the mailing list revealed that it does not differentiate between signatories to the list. HWN cannot, therefore, easily identify who on its mailing list is an individual patient, carer

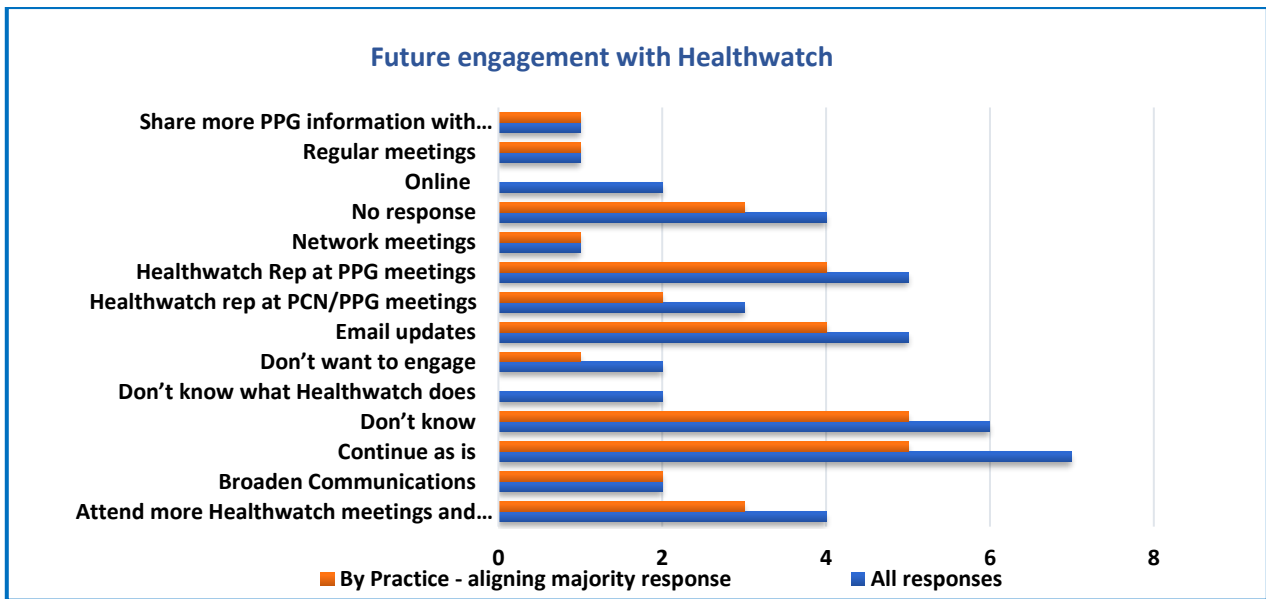


or family member and who is representing PPGs or other organisations. This is a challenge for HWN as it strives to create and sustain a robust database of PPGs as well understanding who engages with it through this mechanism. If HWN is not easily able to contact PPGs then its engagement strategy will be at risk. Those responding to the survey were also asked how they engage with HWN now and how they would like to engage going forward. The information provided here is key to the way in which HWN develops its discussions with PPGs and its strategy for engaging with and supporting them. Several respondents reported engaging with HWN by attending events/meetings where HWN is present whereas many more reported more passive engagement such as receiving communications in the form of newsletters, notification of upcoming events, updates and feedback reports.



The prevalence of more passive ways of engaging is evidence of a desire to engage but does not provide a strong demonstration of the two-way communication HWN strives for. The graph above shows the differences in views between individual members of some PPGs and the collective response when the data is Majority Aligned. When this feedback is triangulated with responses elsewhere in the survey and with HWN’s own data there is a disparity between those PPGs who say they engage with HWN (including sharing information) and those HWN has robust two-way communication with. Exploring PPGs’ understanding of engagement will be a key element of future discussions between HWN and the PPG community.

When asked how PPGs would like to engage with HWN going forward, again there was a range of responses. Respondents were provided with a free text box for this question so were able to suggest more than one option. This means that individual pieces of data must not be considered in isolation. It would be unwise, for example, for HWN to focus solely on the response “continue engagement as is” when, in several instances the same respondents also sought more HWN meetings and events and looked for HWN to attend PPG meetings.



What can be identified from the data are trends. Popular options within the data were to increase email updates and include HWN at PPG and PCN meetings. As previously mentioned, engaging with HWN at a PPG or PCN level is a golden thread running through the whole survey. In response to this section of the survey some respondents suggested HWN engage at a PPG level, at a PCN level and both rather than at a countywide level. This information should provide a clear steer for HWN when considering how it supports PPGs going forward. The issue for HWN, however, will be how can this level of support be sustained given the number of PPGs in the area and the size and spread of the county.

AS HWN considers its agenda for discussion with PPGs and its engagement and support strategy it should bear in mind that only 5 PPGs reported seeing or using the quarterly feedback it sends to all Practices. A further 2 PPGs said that, as a result of the survey, they would now be asking to see this information. Whilst, of itself, the feedback information provided by HWN will not give a full picture of the performance of the Practice it will be useful to PPGs 'in the round'. The key is to understand how this information can be seen to be of value and, therefore, used by the PPG. This may be a challenge for HWN as some PPGs/Practices, for example did not respond to the survey because they did not see sufficient value in it to make time to do so. Linked to this challenge are considerations about how visible HWN is to PPGs and Practices and how it can demonstrate its intrinsic value to the PPG community as well as the value of the feedback it provides to Practices either on a one-off basis, as an ongoing resource or as a combination of both. An important element of this will be for HWN to identify how best to share this information with PPGs or alert them to its presence.

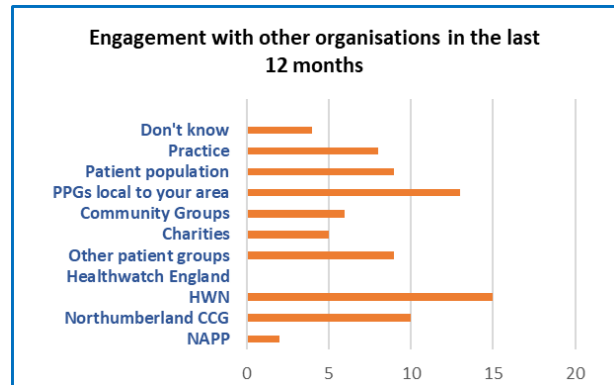
4.18 Engaging more widely

While HWN is particularly interested in how it can strengthen its relationship with PPGs it also needs to understand who else PPGs engage with and whether it needs to strengthen its relationship with those groups too. All PPGs reported engaging with other groups and these are wide-ranging. The survey did not ask how they engaged, the frequency or the outcome but it did seek to understand where PPGs see benefit in wider engagement. 32 individual comments were received which fell into two broad categories – increasing knowledge which in turn improves performance (66%) and

66%
Believe wider engagement increases knowledge and improves performance



don't know (28%). Whilst 28% (don't know) is not an inconsiderable figure, there is a clear sense (68%) that PPGs believe that wider engagement with others can improve their own knowledge and increase performance, both their own and that of the Practice. This information will be extremely valuable to HWN as it develops its agenda for discussions with PPGs and Practices.



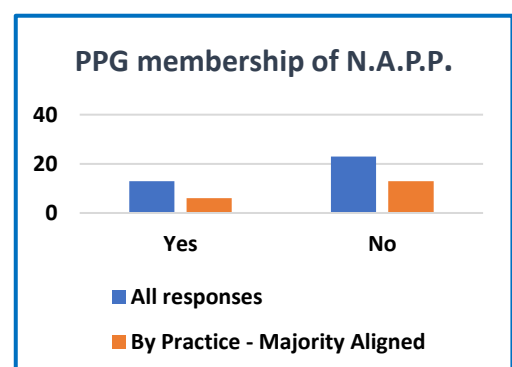
“Engaging with other agencies can bring new ideas into the Practice”

There were two strong negative comments included in the responses about engaging more widely and they were made by PPGs whose responses indicated they were more reluctant to engage beyond their GP Practice. One related to the countywide PPG where the respondent believed that the engagement had not helped their PPG as the focus seemed to be on issues in a different part of the county. The second comment in this category related to the lack of help that had been provided when a particular PPG had engaged with the CCG on a wider basis to seek help in relation to a specific issue. Whilst these are individual comments, they may indicate a lack of willingness to engage more widely for PPGs who have had a negative experience. This is an area for consideration as HWN develops its discussions with PPGs and the wider community.

4.19 NAPP

Respondents to the survey were asked specifically about their relationship with NAPP. After Majority Alignment of responses, 13 PPGs identified as being members. There was significant difference, however, in responses from PPGs who provided multiple responses and in one case the same PPG reported that it is, is not and is not sure if it is a member of NAPP.

Information provided by NAPP⁵⁴ indicates that, currently there are 5 (12%) PPG members of NAPP in Northumberland. Three PPGs/Practices allowed their membership to lapse at the last renewal and a further 2 withdrew their membership at the last renewal. It is possible, therefore, that some of the confusion over membership has occurred because PPG members were unaware that membership had lapsed or been withdrawn at the time of completing the survey. Of those who stated membership of NAPP only one PPG advised that it shares information with NAPP and it does this only as a member of NAPP's 'Group of 100' PPGs.

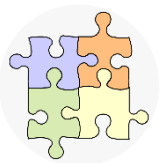


NAPP is a significant source of help and resource for its members yet 88% of PPGs in the county are not, for whatever reason, taking advantage of that. This is difficult to understand given the challenges reported by PPGs and the wealth of information NAPP provides which could alleviate some of those challenges. For example, one PPG advised that “we need a commitment from the practice to refresh the group, stand down current members and start again via a public engagement strategy to work up an updated purpose, member recruitment strategy and training programme”. NAPP would be a useful starting point to provide help and guidance for these activities but the PPG involved was not a member of NAPP.

Several Healthwatch have worked with NAPP to develop resources, share information, etc. As part of developing its strategy HWN will want to consider whether it utilises these existing resources, works with NAPP to develop new ones or to promote the benefits of membership. HWN may also wish to consider how it engages with NAPP going forward.

4.20 Northumberland CCG

48%
of PPGs have
engaged with the
CCG in the past 12
months



29%
of PPGs share
information
with the CCG



In its role as Commissioner of Primary Care Services, the CCG is an integral part of the PPG/GP Practice network. It also has a unique relationship with HWN in that just as the CCG has a duty⁵⁵ to involve patients and the public in its decision making, HWN in its role as the Independent Champion for people in Northumberland who use health and social care services seeks to “find out what matters to people and make sure their views shape the support they need”.⁵⁶ HWN will want to consider these clear links and the benefits they can bring and ensure it has a strong relationship with the CCG.

In addition, CCGs have the opportunity to become Affiliate Members of NAPP and, indeed, NAPP has worked with some CCGs to develop resources for them and for PPGs. This is an area for further exploration by HWN as it develops its strategy for supporting PPGs.

Ten PPGs (48%) advised they had engaged with the CCG over the past 12 months while 6 (29%) stated they share information with the CCG. One PPG provided information on how it had engaged with the CCG across a specific issue. Whilst not conclusive, this data does suggest that, some PPGs at least, have an ongoing relationship with the CCG. Triangulation of the data revealed that while some PPGs have a relationship with the CCG there are others who would prefer that the CCG not be involved in the running of a network of PPGs (see section 4.20 below).

4.21 Countywide network of PPGs

The findings across the survey indicate that there is a strong appetite from PPGs to engage outside of their own groups with all PPGs engaging with at least one group outside of their own organisation and some engaging with several.

There is an initiative in Northumberland to develop a countywide network of PPGs. HWN is keen to understand the PPG perspective on this initiative and how it may contribute to it in a meaningful way. During the survey, respondents were asked about their level of interest becoming part of a countywide network of PPGs along with their reasons for this and the expectations they have of it. With 38% definitely interested and 33% maybe interested (after Majority alignment) the data represents a reasonable level of interest in this initiative. Before Majority Alignment, however, the data painted a slightly different picture with 33% being definitely interested and 41% maybe interested. This result indicates that there is less certainty among individual PPG Members than PPGs as a whole which may become significant going forward as PPGs decide whether to join this initiative.



Several themes emerged from the data once Affinity Mapping had taken place. Some themes were common to more than one category. The table below shows the various themes and the numbers of responses associated with them.

YES		NO		MAYBE	
Already part of it/previous involvement	2	Size and makeup of the group	3	Time is a factor	4
Benefits of increased knowledge/sharing information	4	Time poor	3	Travel/distance is a factor	3
Benefits of having a bigger group	3	Concerns about CCG involvement	1	Need more info/discuss with PPG	9
Needs to be operated by PPGs and not external bodies such as CCG	1	Our issues are local	1	No clear purpose or identity	1
Better than we have now	2			Benefits in sharing best practice	1
				Prefer PPGs to join with PCNs	1
				Other	2

Those who are definitely interested in the initiative are either already part of the group or see real benefit in being so. This information correlates with the feedback received around engaging more widely in other areas of the survey. For those who are still considering the notion of a countywide group a lack of understanding of what is involved or how it might work was a key factor for them. This was the largest group of responses in this section of the survey which provides an opportunity for those developing the network to better engage with all PPGs and provide more information that can be shared with PPG members. Many respondents also wondered how such a widespread group could benefit their patients or how it will work in practice.

“How can it work when all of the Practices are separate businesses?”⁵⁷



Those who are not interested in becoming part of the initiative, some of whom also engage more widely, are concerned more with the makeup of such a group and its relevance to them. Local issues were cited several times across the research as being the reason for not casting a net too wide. One respondent has already explored this group and felt that it was not representative of the county as it did not consider the needs of all patients.

“Patients talked about access issues that our patients couldn't relate to”⁵⁸



Time and distance were also an issue particularly among the ‘maybe’ and ‘no’ categories. Northumberland is a large county and for many the distance to an event or meeting always involves a long journey which usually means a lot of time out of their day (or evening). One respondent commented that no matter which meeting they attend it involves a significant journey

There was a strong sense across all responses, however, that there is merit in engaging more widely than is done now. Some respondents believe that a larger group would give them access to better information and increase knowledge.

“The more information from a wider source the better”⁵⁹

Those who are definitely interested in becoming part of a countywide group were also asked about their expectations for such a group. Their expectations of such a group varied considerably. The small number of responses coupled with this variation made Affinity Mapping impossible. Instead the data are presented in a table format.

Response	Number
Joined up service	1
Ensuring service provision is standardised across the county	1
Common aims to improve patient experience	1
Puzzled	1
Help them understand the pressures of GP services and surrounding services	1
Virtual meetings with annual get together	1
Regular quarterly PCN meetings	1
Work together to broaden information base, generate new ideas, improve communications	2
Don't know	1
Training and support for PPG members	1
Create common expectations from Practice members	1
Should be based around PCN Network with each PPG having a rep on the PCN then a rep from each PCN attends county PPG	1
Interested to see how we can develop	1

When viewed together, the strongest themes emerging from this part of the research are a desire for collaboration and for some form of consistency. There were some responses suggesting commonality of

purpose and of information are also important factors. Some respondents made suggestions for how a countywide group ought to be managed, expressing the view that it should be based around the PCN networks and not require representatives from every PPG to attend every meeting. Across all categories there was a feeling that if such a group were to develop it ought to be led by PPGs and not a 3rd party organisation such as the CCG.

When the data above is triangulated with responses to other questions, particularly how respondents would like HWN to engage with them the golden thread is that the PCN Network is becoming increasingly important and that PPGs would like to see HWN more involved with it. With limited resources for both HWN and PPGs, HWN will need to consider whether it would be better placed supporting PPGs at a county or PCN level.

5.0 LESSONS LEARNED

An integral part of good research is to be self-reflective and review what went well and not so well during the research.

There are three key lessons to be learned from the research process:

1. Given the number of multiple responses received to the survey, HWN will need to be unequivocal about the need for only one (combined) response from each PPG
2. One comment received in the survey was that some elements of the survey were not compatible with the browser being used by the respondent. HWN will want to 'road test' its survey more robustly to prevent barriers to access from some respondents
3. Potentially because of a lack of routine engagement with PPGs the survey highlighted a gap in the contact information held by HWN – the data held by HWN indicated there were 48 GP Practices in Northumberland. Mergers of some Practices and closures of others means that there are currently 41 GP Practices in the county. HWN must take steps to ensure its maintains robust contact data for all PPGs and Practices

6.0 CONCLUSION

Successful collaborative working between patients, GPs and the Practices can achieve considerable benefits for all and PPGs can play a key role. By necessity, PPGs are all different. The findings of this research show that they serve both small and large practices in urban, suburban, and rural locations. Some are based in one site; others cover two or more sites. Some PPGs serve a stable population; some have a high proportion of older people or a large mixture of different ethnic groups and a more transient population: there is no one size to fit all. PPGs strengthen the relationship between patients and their practices, which is vital at this crucial time for Primary Care.

PPGs can bring about real, positive change within their GP Practice and across Primary Care. They play an important role in helping to give patients a say in the way services are delivered to best meet their needs, and the needs of the local community. At this important time for Primary Care with the introduction of PCNs and new forms of social prescribing, PPGs will have an even more important role. It will be essential that all channels of communication will be open with and to patients to help HWN and others understand their view of the care they receive. The research identified many positives in the way PPGs operated but

alongside these there are fundamental issues to address by PPGs and Practice. PPGs and Practices recognise this and, in many case, asked for help via the survey. HWN is keen to work with them and the CCG to help address the issues raised.

There are several key themes coming out of the research which will form part of an agenda for discussion with PPGs and Practices:

Engaging patients and the Practice – Many PPGs are clearly very active either in their Practice or in their community and all appear focused on improving the patient experience. Some PPGs are involved in gathering feedback from patients (including carrying out surveys) and then expanding that knowledge by comparing it to other information that is available such as Friends and Family Test or NHS Reviews. PPGs reported difficulties, however, in getting patients and the Practice involved in their work and in gaining feedback on the issues that matter most to them. Some PPGs reported not engaging with patients, which is in conflict with the central aim of PPGs, while others reported difficulties in carrying out surveys, etc. For many PPGs the website and Waiting Room were the main vehicles for engagement but the research highlighted that, for some PPGs, these are not necessarily working to the best effect. Some PPGs carry out regular surveys and use the data to create improved patient experiences but then rely on the website or a newsletter to share the results with patients. As many patients are not engaging in these ways much of the good work done may go unnoticed.

Recruitment – PPGs also face significant challenges in the recruitment and retention of members who are representative of the Practice Population. Recruiting across the demographic of patients is difficult for a variety of reasons not least because time and distance are a critical factor. Over half (58%) of the Patient Population is of working age so time and capacity to attend meetings and events is limited for this group. The result is that PPGs tend to recruit from older age groups. Some have experienced success recruiting young people but again time and capacity is a factor.

Time – for a significant number of respondents time is a critical factor. For many this is time to prepare for and contribute to PPG meetings and events but for others time is also compounded by distance. Some PPGs reported that there is always a long journey to every meeting or event. This reflects the population density of the county and will be a critical factor in HWN's discussions with PPGs going forward.

Differing views – the survey sought a single response from each PPG but 8 PPGs sent multiple responses. While this provided a rich seam of data to inform the research it also highlighted differences of opinion and, in some cases, a lack of understanding of how particular PPGs operate. In some cases, opposing responses were received where, for example, one respondent advised a PPG acted in a certain way and another respondent from the same PPG advised that the PPG acted in a different way. Alongside this, the triangulated data of the responses of all PPGs indicated differences between what PPGs believed is happening and what is happening in practice. This was most noticeable in those PPGs who stated certain information was prevalent in the Waiting Room or on the website and a review of these proved this is not the case.

Engaging more widely – many PPGs reported engaging with a range of organisations including other PPGs, HWN, the CCG and community groups. While some PPGs are keen to engage with others at a county level the research provides a clear steer to HWN that many PPGs are more inclined to engage at a PCN or even

PPG level. The research also highlighted that many PPGs gather topic specific information that may be of benefit to other PPGs experiencing a similar issue but currently no mechanism exists to do this.

Social prescribing activities - Many PPGs are involved (to a greater or lesser extent) in social activities either in the Practice or in the community. Over half (52%) of PPGs carry out 'meet and greet' activities to aid the Practice with clinics, health promotion, etc. while 19% of respondents are involved in delivering or facilitating social prescribing activities such as 'knit and natter groups', walking clubs, etc. Interestingly, some of the positives in the research, particularly around social prescribing, are also identified as challenges by some PPGs who feel they do not have enough time to deliver or facilitate social prescribing activities and be the voice of the patient to the Practice.

Support - PPGs appear to be involved in this range of activities without necessarily receiving the support they need. This is highlighted by a low level of membership of NAPP, an organisation primed to provide support to PPGs, little guidance and support from other organisations who have a vested interest in patient participation as a means of improving services and health outcomes and a lack of time/support from some Practices for their PPG. Despite this the data provides a real sense that there is a lot of good work going on in PPGs, sometimes under difficult circumstances but with a real desire to make things better for patients.

HWN is committed to strengthening relationships with PPGs and GP Practices and this research provides an agenda for discussion, some key areas to prioritise and a set of recommendations to help achieve this. HWN will need to consider its own resources and those of the PPGs and Practices when developing its engagement strategy and determining the level of support it can provide or facilitate but the sense is that the door is open with PPGs to do this.

7.0 RECOMMENDATIONS

The research aimed to provide HWN with an understanding of how PPGs in Northumberland work, their aspirations and challenges and the relationship they want to have individually and collectively with HWN, the CCG, PCNs and local and community groups. HWN also wanted to understand how it can best communicate with PPGs and exchange information and how this can be used in working with the CCG and other service providers for the benefit of patients and carers.

What is clear from the research is that there is a need for further exploration into the needs and aspirations of PPGs not least their understanding of and capability for meaningful engagement. Success will be achieved through pooling resources and effort to address the challenges PPGs face, most importantly recruitment. The need for collaboration between HWN, PPGs and, the CCG is clear.

These recommendations are set within the aims of the research and set the agenda for future discussions with PPGs and Practices while providing HWN with options to help address some of the challenges it and PPGs face.

Aspirations

The research clearly demonstrates that PPGs want to improve the patient experience and they want to engage with HWN to help with this. In particular PPGs are seeking support on how to recruit more

successfully, gather and use feedback more effectively and work more effectively with other groups at a PCN level.

- HWN should discuss the findings of this research with the CCG to determine joint work to address the challenges identified
- HWN should facilitate an event that brings PPGs and Practices together to present this report, discuss reactions and begin working on solutions. This can be at a county or PCN level but should include examining PPGs understanding of engagement, how Practices can work with their PPGs to address some of the challenges, how other stakeholders can work with PPGs to help improve the patient experience, etc.
- HWN should bring together a group of PPGs to develop and pilot a toolkit that is relevant to Northumberland but takes account of the help and guidance that already exists. Initial suggested items could include:
 - Increasing membership and ongoing recruitment
 - Publicising the PPG and its work
 - Gathering feedback (including capturing seldom heard voices)
 - Making the best use of limited time and resources
 - Understanding and using 3rd Party information
- Together with PPGs, HWN should identify training and development needs for PPG members and explore ways to help address these

Challenges

Recruitment is a significant challenge for PPGs as is better understanding what is happening in the wider community:

- In partnership with PPGs and the CCG, develop a county-wide recruitment drive that uses a range of media to reach the biggest number of patients – not only will this aid recruitment it will raise the profile of PPGs in the county
- Create and maintain a directory of 3rd Party information that PPGs can access to enhance their understanding of Practice performance

Engagement

Whilst the will to engage with HWN is clear there are some practical implications associated with this. The size and spread of the county will pose logistical problems for PPGs and HWN. In addition, PPGs do not all want the same methods of engagement:

- Develop a robust database of contacts for all Practices and PPGs which includes mechanism to keep this up to date and enables sharing of HWN Practice feedback with PPGs or alert them to its presence each time it is issued
- Explore how relationships with PCNs can be strengthened as they develop and where HWN can add most value to the networks
- To help PPGs better understand what is happening HWN to develop a regular “Network News” type publication (at either a county or PCN level) aimed specifically at PPGs which could include information from each PPG (possibly drafted by PPGs), news items relevant to PPGs, data and trend information from surveys, etc. and information on events

- HWN to develop a regular PPG networking event aimed at two-way sharing of information for those who want to engage in this way – include Practices and other community groups
- Identify how HWN can support PPG events either by attending or publicising, helping to encourage attendance, etc.
- Develop an engagement strategy that, amongst other things, takes account of the differences in PPG models and is able to facilitate engagement with ‘Virtual PPGs’

Response from Northumberland Clinical Commissioning Group



20201007 RM_DN
PPG Report Respons

7 October 2020

Dear Derry,

Understanding Patient Participation Groups Report

I am writing today to thank you for sharing a copy of the report entitled ‘Understanding Patient Participation Groups’ from February this year, which documents the research you commissioned to help you understand how the Patient Participation Groups (PPGs) in Northumberland function. Please accept my apologies for the delay in responding to you, but as you are aware, shortly after you shared the report with us the CCG was understandably occupied with our response to the first wave of the COVID-19 pandemic and supporting our member GP practices.

I have now had an opportunity to review the report which is very well written and details some excellent research. The findings are very useful and timely, as they will help us in our current work to strengthen CCG engagement. We are implementing a new model of engagement to create a regular cycle of activities to support the connectivity to the communities we serve. The model aims to develop ongoing, two-way conversations with our local communities so we can understand their needs and what matters most to them when designing services.

As part of this work, our ambition is to work closer and have more meaningful involvement with PPGs, by enabling them to influence the CCG commissioning cycle. In co-production with PPGs, we are proposing to develop a countywide CCG engagement forum which will link directly to the CCG Governing Body. I was pleased to note in the report that there is already appetite amongst some PPGs to be involved in this work. Furthermore, we intend to support Primary Care Networks to engage with their local populations by building stronger relationships with their PPGs and developing a Community Champions programme to better

understand their local population's health needs.

I note the recommendations of the report and I can confirm we would like to work collaboratively with you to address the issues, such as recruitment and engagement that PPGs face. As a consequence of the COVID-19 pandemic, the CCG much like Healthwatch Northumberland, has adapted our engagement methods to address the complexities it has placed on effectively engaging at a distance. Inevitably many of our interactions are now digital, through the use of Microsoft Teams and online community platforms. It is our view that digital platforms may in fact enhance the way we engage with our local communities and open up opportunities for those previously unable to take part because of time or travelling constraints. It is possible that these new methods may assist PPGs with their recruitment and engagement, particularly with younger audiences.

I would welcome the opportunity to discuss the recommendations with you and the report author with a view to developing a project plan which sets out how these can be achieved and incorporated into the CCG's plans. My Personal Assistant, Barbara Allsopp, will be in touch with you to arrange a convenient time for us to meet on Teams with Emma Robertson, the CCG's Communications and Engagement Manager.

Thank you once again for sharing the report with us, we welcome the support of Healthwatch Northumberland as we build on our engagement.

Yours sincerely,

Rachel Mitcheson

Service Director Transformation and Integrated Care

APPENDIX 1

Footnotes and citations

All footnotes and citations are listed in numerical order (as they appear in the body of the report).

¹ <http://www.ca-north.org.uk/about/about-northumberland>

² Source Northumberland CCG

³ Source NHS England correct at January 2019

⁴ Source Northumberland CCG

⁵ Source NHS England correct at January 2019

⁶ <https://www.health.org.uk/sites/default/files/upload/publications/2019/Understanding%20primary%20care%20networks.pdf>

⁷ Source Northumberland CCG

⁸ <https://www.health.org.uk/sites/default/files/upload/publications/2019/Understanding%20primary%20care%20networks.pdf>

⁹ Souliotis, Kyriakos; Agapidaki, Eirini; Peppou, Lily Evangelia (September 2017). "[Assessing Patient Organization Participation in Health Policy: A Comparative Study in France and Italy](#)" (PDF). *International Journal of Health Policy Management*. **6(x)**: 1–11. AND Carman, Kristin L.; Dardess, Pam; Maurer, Maureen; Sofaer, Shoshanna; Adams, Karen; Bechtel, Christine; Sweeney, Jennifer (2013-02-01). "Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies". *Health Affairs*. **32** (2): 223–231. doi:10.1377/hlthaff.2012.1133. ISSN 0278-2715. PMID 23381514.

¹⁰ Souliotis, Kyriakos; Agapidaki, Eirini; Peppou, Lily Evangelia; Tzavara, Chara; Samoutis, George; Theodorou, Mamas (2016-08-01). "[Assessing Patient Participation in Health Policy Decision-Making in Cyprus](#)". *International Journal of Health Policy and Management*. **5** (8): 461–466. doi:10.15171/ijhpm.2016.78. PMC 4968249. PMID 27694659.

¹¹ Wilkie P (2016) Patient participation groups in general practice. *British Journal of General Practice* 66(652): 548–549. DOI: 10.3399/bjgp16X687613.

¹² <https://www.napp.org.uk/overview.html>

¹³ <http://www.nhsemployers.org/your-workforce/primary-care-contacts>

¹⁴ <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/06/gms-2015-16.pdf>

¹⁵ From 2019/2020 GP Contract

¹⁶ Source desktop search of 41 GP Practice websites, wider internet search

¹⁷ Source NHS England

¹⁸ <https://www.napp.org.uk/ppgintro.html>

¹⁹ https://www.researchgate.net/post/What_is_triangulation_of_data_in_qualitative_research_Is_it_a_method_of_validating_the_information_collected_through_various_methods

²⁰ Quote from a telephone interview

²¹ <https://www.northumberlandccg.nhs.uk/>

²² <https://www.northumberlandccg.nhs.uk/wp-content/uploads/2018/06/NCCG-Annual-Report-accounts-unsigned-2018-19-FINAL.pdf>

²³ <https://www.northumberlandccg.nhs.uk/get-involved/find-your-patient-participation-group/>

²⁴ <https://www.northumberlandccg.nhs.uk/get-involved/find-your-patient-participation-group/>

²⁵ <https://www.napp.org.uk/Guidance%20for%20CCGs.pdf>

²⁶ <https://www.napp.org.uk/vision.html>

²⁷ <https://www.napp.org.uk/vision.html>

²⁸ <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2016/09/ppg-introduction.pdf>

²⁹ <https://www.healthwatchpeterborough.co.uk/wp-content/uploads/PPG-Toolkit-16-March-2018.pdf>

³⁰ <https://www.healthwatchswindon.org.uk/sites/healthwatchswindon.org.uk/files/PPG%20Framework%20final%20document.pdf>

³¹ <https://www.healthwatchbucks.co.uk/how-we-work/client-services/patient-participation-group-support/>

³² <https://healthwatchcwl.co.uk/wp/wp-content/uploads/2019/02/PPG-Best-Practice-Guide-2019.pdf>

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- 33 https://cdn-hwoxfordshire.pressidium.com/wp-content/uploads/2019/08/Good_Practice_report_final.pdf
- 34 <https://healthwatchcwl.co.uk/wp/wp-content/uploads/2018/08/2018-PPG-Newsletter-August.pdf>
- 35 <https://gp-patient.co.uk/faq> and <https://www.england.nhs.uk/statistics/2019/07/11/gp-patient-survey-2019/>
- 36 <https://surveyanyplace.com/average-survey-response-rate/>
- 37 <https://www.genroe.com/blog/acceptable-survey-response-rate-2/11504> and https://en.wikipedia.org/wiki/Statistical_significance
- 38 Quote from a survey response
- 39 Quote from a survey response
- 40 Quote from a survey response
- 41 Quote from a survey response
- 42 Quote from a survey response
- 43 Quote from a survey response
- 44 <https://www.northumberlandccg.nhs.uk/wp-content/uploads/2018/06/NCCG-Annual-Report-accounts-unsigned-2018-19-FINAL.pdf>
- 45 <http://www.croydonccg.nhs.uk/news-publications/publications/Documents/Growing%20Healthy%20PPGsET%20-%20Edith%20Todd.pdf>
- 46 <https://www.patientlibrary.net/tempgen/104929.pdf>
- 47 https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/reports-library/20161102_Surrey_PPG-Fact-Finder-Analysis-02.11.16%20backlog.pdf
- 48 Direct quote from the survey
- 49 <https://www.cranfieldtrust.org/posts/28-5-hr-challenges-facing-small-charities>
- 50 https://www.acf.org.uk/downloads/GOB_Crisisintrusteerecruitment_v6_pages.pdf
- 51 Quote from a survey response
- 52 Quote from the survey
- 53 Quote from the survey
- 54 Membership in Northumberland - NAPP
- 55 <https://www.england.nhs.uk/wp-content/uploads/2016/07/guid-annual-reprting-legal-duty-july16.pdf>
- 56 <https://www.healthwatch.co.uk/what-we-do>
- 57 Quote from the survey
- 58 Quote from a survey response
- 59 Direct quote from the survey