

# **A mapping exercise to understand how Patient Participation Groups are currently operating across Newcastle and Gateshead**

## **September 2021**



## **Involve North East**

This report was produced by Involve North East on behalf of NHS Newcastle Gateshead Clinical Commissioning Group. We are an independent organisation who specialises in involvement and engagement. We work with integrity, ensuring people's voices influence the design of services they receive.

We have vast experience and expertise in gathering the views and opinions of patients, carers, and the general public in relation to health services. For example:

- service evaluations
- changes to care pathways
- locating new services

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- Questionnaires – paper-based and online
- Participatory appraisals
- Drop-in events
- Face-to-face and telephone interviews
- Focus groups
- Informal group discussions

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# Introduction

- NHS Newcastle Gateshead Clinical Commissioning Group (NGCCG) supports GP practices to establish and maintain Patient Participation Groups (PPG). In 2019 its involvement partner Involve North East produced a toolkit to help support practices to develop their PPG in light of the emergence of Primary Care Networks.
- The NHS is going through a period of significant change. Widespread structural changes are ongoing with the development of Primary Care Networks and a strong focus on place-based working and more recently Integrated Care Partnerships and Integrated Care Systems. This is happening in the context of a global pandemic which has affected how primary care services have had to operate.
- It was therefore felt that it would be timely to conduct a mapping exercise to understand the current level of PPG activity across Newcastle and Gateshead with the intention of helping to develop a strong foundation for patient, carer and public engagement and involvement within and between these new structures.
- In July GP practice managers were contacted to complete an online questionnaire or take part in a telephone interview. There was an excellent response with 56 of the 60 practices providing feedback.
- The following provides a summary of responses to the online questionnaire. Please note that this is a snapshot of the situation at the end of July 2021. As restrictions associated with COVID-19 reduce over time, it is likely that PPG engagement activities will change.

# Newcastle practices

- We received feedback from 30 GP practices operating across Newcastle, 28 have PPGs. Key themes were:

**Value of patient involvement** – Practices understand the valuable role PPGs can play in the operation of a GP practice but struggle to develop and maintain them with time being the main barrier. A minority of PPGs have a dedicated Chair. Support from organisations outside of the practice to run the PPG on their behalf and develop links with the wider community and the sharing of best practice and tools to facilitate patient feedback were called for.

**Impact of COVID-19** - COVID-19 has had a big impact on the operation of PPGs; nearly three-quarters have paused their activities although many have been able to keep communication channels with members open. The minority who have an active PPG have found new ways of working, moving from primarily face-to-face activity to online, email and telephone and more ad-hoc meetings. Post-COVID-19 nearly three-quarters of practices are keen to continue with new communication methods or are considering new ways of working within a more structured timetable.

**Recruitment** – Despite using a range of recruitment methods, predominantly posters, leaflet, videos and website information, recruitment is an issue for many practices who have requested help in this area. The majority of PPGs had six or fewer members before COVID-19 and membership has fallen since this time. More concerning though is that the vast majority of practices do not feel that their PPG is representative of the patient population with people aged under 50 and ethnically minoritised groups in particular, absent.

**PPG links** – At present there is little communication or joint-working amongst PPGs or at a higher level as part of NGCCG's Patient, Public and Carer Engagement Forum (PPCEF) or Primary Care Networks (PCN). There was interest from two practices in their PPG operating at a PCN level as part of a joint PPG for example.

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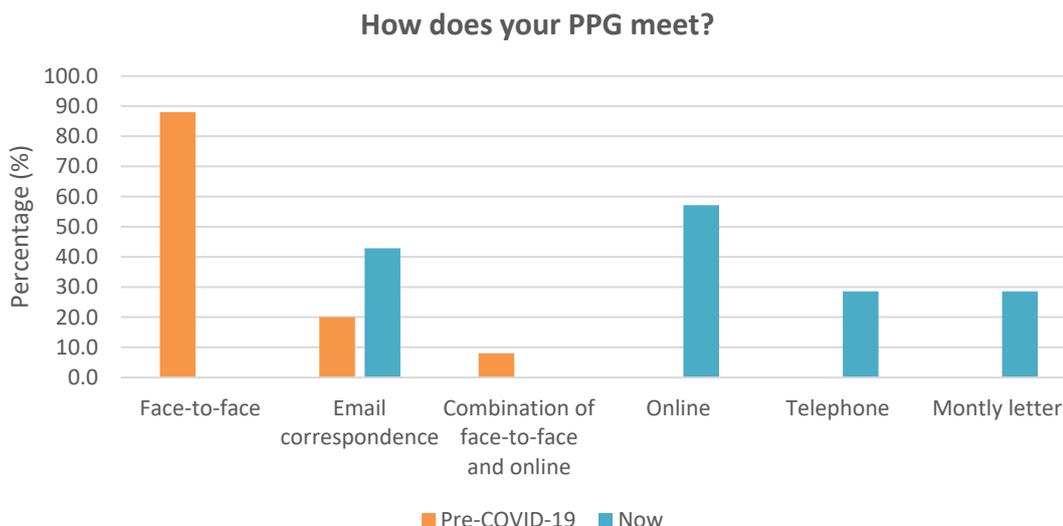
## Active PPGs

- Of the 30 practices responding to our survey in Newcastle, all but two (93.3%) have a PPG.
  - The majority (20, 66.7%) have however paused their activities due to COVID-19.
  - Eight (6.7%) are active.
- The two practices without a PPG cited reasons for this:
  - Pressures on the practice which meant they were unable to organise meetings.
  - Failed recruitment activities.
    - One practice is working to rectify this having recently created a new position with part of the remit being to increase diversity in patient participation.

## Chair

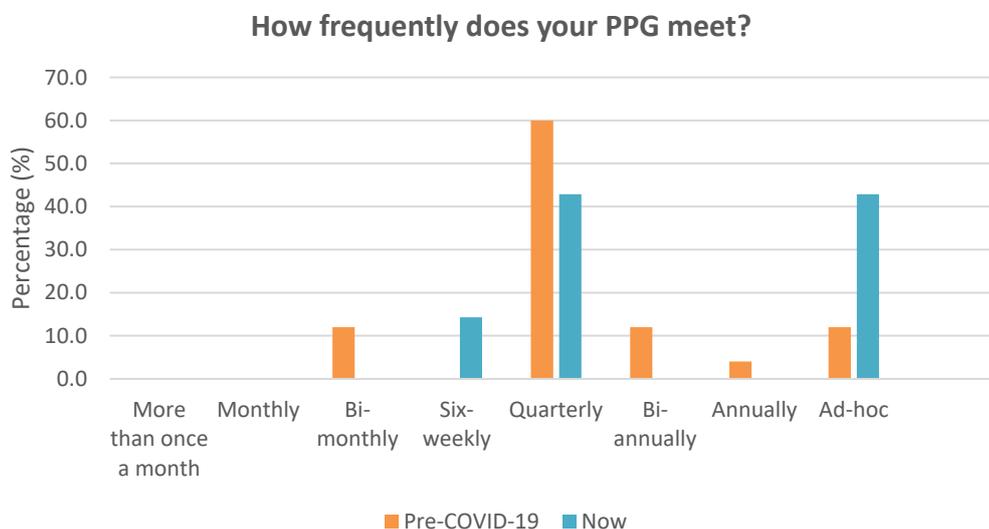
- Only seven (23.3%) practices have a dedicated PPG Chair; three are patients of the practice, the others are practice staff.

## How the PPG meets



(Pre-COVID active PPGs – 25, PPGs active now – 7)  
(Practices could give more than one answer)

- Pre-COVID nearly nine-in-ten practices held face-to-face meetings with their PPG, currently no meetings take place in this way.
- Instead, the eight practices with active PPGs are using online, telephone, paper-based and email communication methods to interact with patients.
  - Post COVID-19 two of these practices said that they would revert back to their face-to-face only meetings whilst the remainder will use a combination of pre-COVID-19 methods and methods they are currently using.
- Additionally, although 20 practices have paused activities, more than half have been in contact with their PPG:
  - Nine are in email correspondence.
  - One has contacted patients by telephone.
  - One has written to patients.
- Post COVID-19, of those who have paused their PPG:
  - Six said that they would revert back to face-to-face meetings.
  - Ten said that they are considering new ways of working with the PPG.

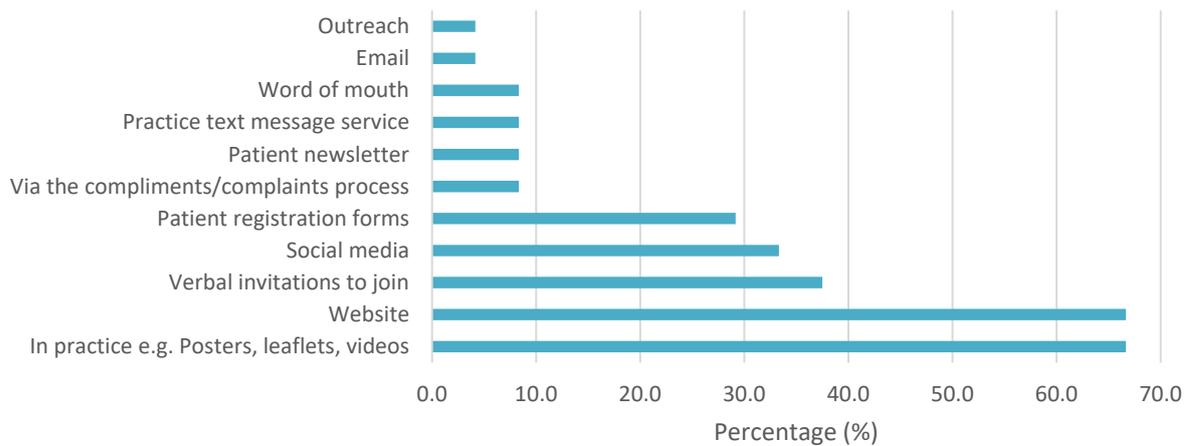


- Pre-COVID PPG meetings occurred over a range of time periods with quarterly most common.
- Of the seven active PPGs, three are continuing their quarterly frequency whilst others have changed to a six-weekly or ad-hoc basis.
  - Post-COVID-19 all but one plan to revert back to their pre-COVID frequency, whilst one is considering a more structured approach to previous ad-hoc arrangements.

## PPG membership

- Recruitment

### How do you recruit patients to your PPG?

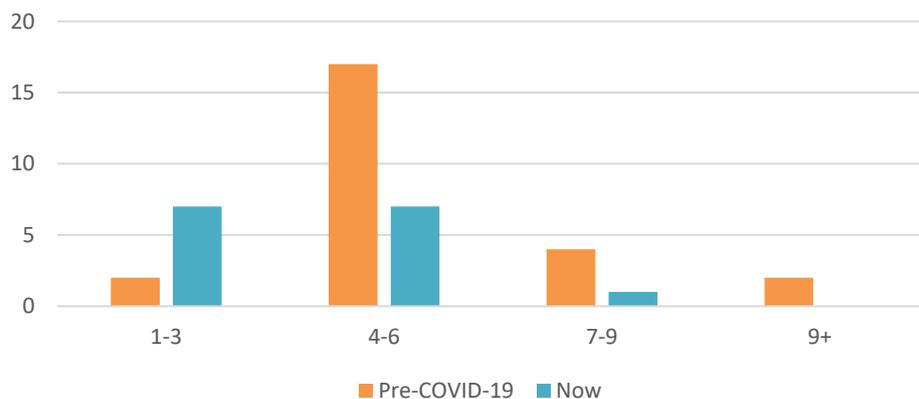


(24 practices answered this question)  
(Practices could give more than one answer)

- Practices employ a range of methods to try and recruit patients to join their PPG with information displayed within the practice building and on their website most commonly used.
- Verbal invitations to join by reception and clinical staff are also employed by over one third of practices.

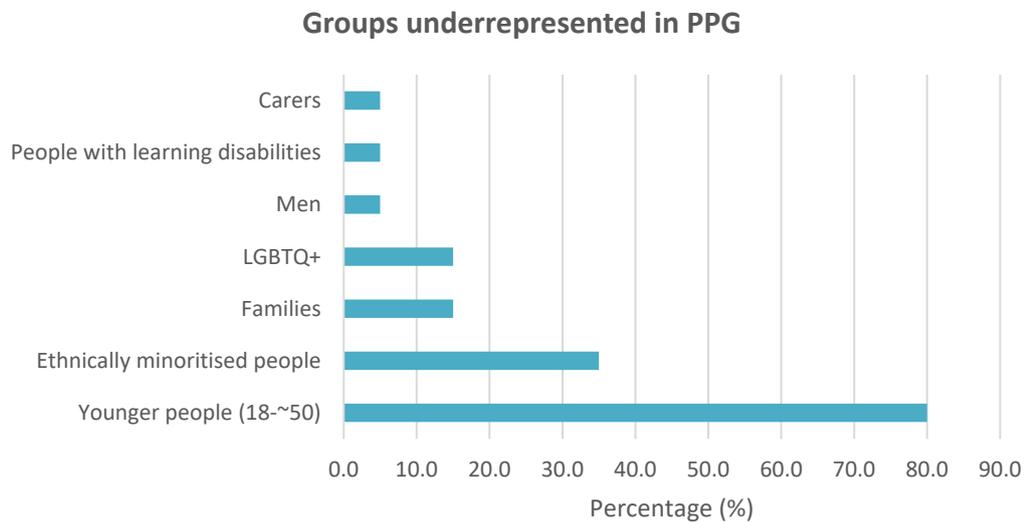
- Number of members

### How many members does your PPG have?



(No. of practices - 27)

- Pre-COVID-19 PPGs had greater number of members than now.
- Pre-COVID-19 more practices had PPGs with seven or more members.
- Representation
  - Of the 25 practices who responded to this question, only 4 (16.0%) felt that the membership of their PPG was reflective of their patient population.

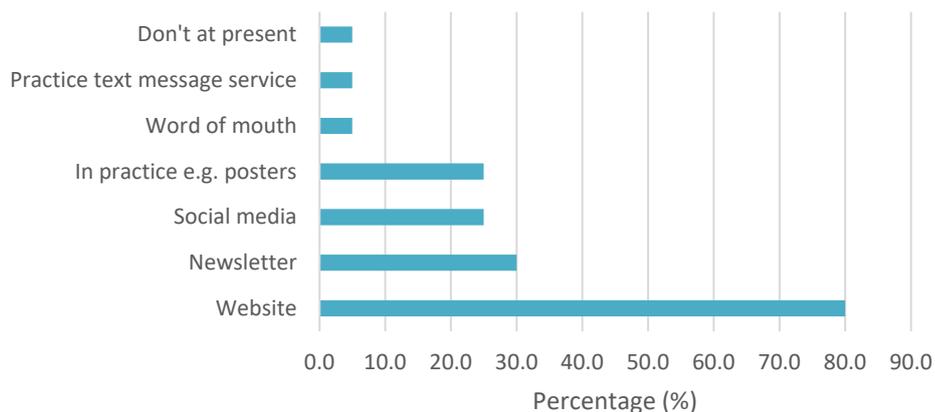


(No. of practices – 20)  
(Practices could give more than one answer)

- The majority of practices reported a lack of representation from people aged under 50 years of age.
- For over one-third of practices ethnically-minoritised representation was lacking.

### Sharing PPG activity

**How do you keep your wider patient population informed of the actions of the PPG?**



(No. of practices – 20)  
(Practices could give more than one answer)

- Sharing information about the work the PPG has been undertaking is primarily communicated through practice websites.
- Nearly one-third of practices share information via their practice newsletters.

## PPG links

- Practices were asked whether their PPG was engaged in any wider networks or meetings such as the NGCCG's Patient, Public and Carer Engagement Forum (PPCEF).
  - Six practices reported that PPG members attend the following meetings:
    - PPCEF (x3)
    - ACORN
    - Elders Council
    - Healthwatch
    - PCN

## Things that have worked well

- 16 practices identified at least one thing that has worked well within their PPG.

	No. of practices	Percentage (%)
Patients providing feedback	9	56.3
Face-to-face meetings	2	12.5
GP attending meetings	2	12.5
Patient-led	2	12.5
Practice sharing information	2	12.5
Supportive members	1	6.3
Recruitment process	1	6.3
Flexibility	1	6.3
Supportive practice staff	1	6.3

(Practices could give more than one answer)

- The opportunity to gain valuable feedback from patients around services provided by the practice was mentioned most frequently.
- Having face-to-face meetings and GPs attending the meeting also worked well.
- A patient-led group rather than one managed by the practice as well as the opportunity to share practice information with patients was also mentioned.
- A further two practices however stated that they could not identify any good practice.

## Things that have not worked well

- 14 practices identified at least one thing that has not worked well within their PPG.

	No. of practices	Percentage (%)
Recruitment	4	28.6
Representative recruitment	4	28.6
Lack of capacity to carry out all PPG requests	2	14.3
Patients use platform to highlight personal issues	2	14.3
Members won't engage	2	14.3
Drop-in style meeting	1	7.1
Too much on agenda	1	7.1
Whole PPG	1	7.1
Members lack understanding of how the NHS operates	1	7.1

(Practices could give more than one answer)

- General recruitment and also recruitment of specific groups to make the PPG more representative of the patient population, were the most frequently highlighted areas where things have not worked.
- Two practices noted that it had been difficult to get members to engage and take part in activities.
- For two PPGs a lack of time and resources to carry out the activities requested by the PPG has been a problem.
- Two practices also highlighted an issue with PPG members using the forum to highlight their own personal issues rather than those of the practice population.
- A further two practices however stated that they could not identify anything that had not worked well.

### PPG support needs

- Practices were asked what support they would like with their PPG in the future. Seventeen practices identified the following:

	No. of practices	Percentage (%)
Recruitment of members	3	17.6
Recruitment of representative members	3	17.6
Additional resources to support running PPG	3	17.6
Outside support to organise/manage the PPG	3	17.6
Any available support	2	11.8
Developing a PCN-wide PPG	2	11.8
Getting PPG back up and running	1	5.9
More internal staff support	1	5.9
Engaging patients more effectively	1	5.9
Patients taking the lead/managing PPG	1	5.9
Community outreach for recruitment	1	5.9

(Practices could give more than one answer)

- Unsurprisingly recruitment of members either in general or to make the current membership more representative was identified. One practice felt that support to carry out recruitment in the community in order to try and get better representation of the patient population would be useful.
- Several practices asked for additional resources to help support the running of the PPG; they would like good practice and tools such as surveys to be shared, help with running in-house events and more time to dedicate to the PPG.
- Three practices felt that they would benefit from support from outside of the practice to actually run their PPG on their behalf and feedback to them or to develop relationships with the wider community and also voluntary and community sector organisations.
- Two practices felt that greater integration with their PCN and the PPGs within it would be beneficial, this would facilitate discussions around the wider area/community and enable PPGs to share ideas and work together.

# Gateshead practices

- We received feedback from 26 GP practices operating across Gateshead, 24 have PPGs. The key themes were:

**Value of patient involvement** - Practices in Gateshead understand the value of patient involvement in the running of their practices and highlighted positive aspects of their PPG; it offers a platform to gather patient feedback and communicate practice developments and actions to patients. However, a lack of time and resources pose a barrier for many in terms of being able to run an effective PPG. Many asked for support to improve or redevelop their PPG.

**Impact of COVID-19** - COVID-19 has changed the way in which many PPGs operate. A large number have had to pause meetings due to COVID-19. Those who are still operating have adopted new formats and structures with many now meeting virtually. Whilst this way of operating has suited some, others are looking to revert back to face-to-face meetings. Many practices are considering new ways of working when their PPG starts up again. The frequency of meetings has also been impacted by COVID-19, with practices moving to a less frequent quarterly or bi-annual format. The number of members within PPGs across Gateshead has also declined from pre-COVID-19 numbers.

**Recruitment and engagement** - Many practices struggle to recruit members to their PPGs despite employing a number of different recruitment techniques. Member numbers have also declined over the pandemic for those who have an active PPG. Practices have identified this as an area where they are currently under-resourced. A number of practices also stated that their PPG was not representative of their population and noted that one of the main things which does not work well is recruitment of younger patients. Again practices have identified the need for more resources to be targeted at this issue. For several practices, once members have been recruited, there are difficulties around keeping them engaged and interested and again some would like support around this.

**PPG links** – Only one PPG in Gateshead indicated that they attended PCN meetings currently, and most respondents did not provide information to suggest that they regularly worked with PCNs or other structures. This has been identified as an issue that requires further work.

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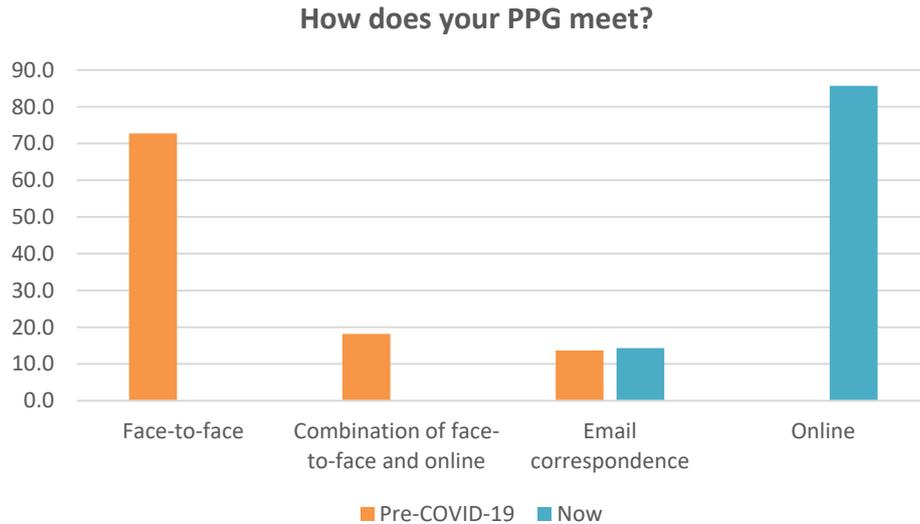
## Active PPGs

- Of the 26 practices operating in Gateshead, all but two (92.3%) have a PPG.
  - The majority (17, 65.4%) have however paused their activities due to COVID-19.
  - Seven (7.7%) are active.
- The two practices without a PPG cited reasons for this:
  - Pressures on the practice which meant they were unable to organise meetings.
    - The GP who was in the process of starting a PPG left the practice and this was never followed up due to the pressures within the practice.
  - Failed recruitment activities.

## Chair

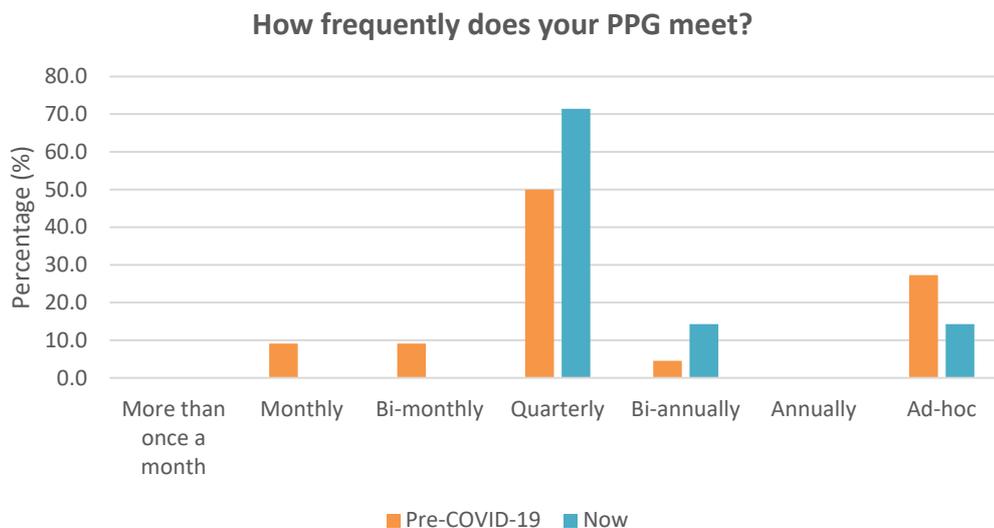
- 13 (50%) practices have a dedicated PPG Chair; seven are patients of the practice, the others are practice staff.
  - One practice noted that at the next PPG they will be looking to appoint a chair.

## How the PPG meets



(Pre-COVID active PPGs – 24, PPGs active now – 7)  
(Practices could give more than one answer)

- Pre-COVID nearly three quarters of practices held face-to-face meetings with their PPG, currently no meetings take place in this way.
- Instead, the seven practices with active PPGs are using online and email communication methods to interact with patients.
  - Post COVID-19 two of these practices said that they would revert back to their face-to-face only meetings, whilst three will use a combination of pre-COVID-19 methods and methods they are currently using. One practice will continue to use the new format.
- Additionally, although 17 practices have paused activities, more than half have been in contact with their PPG, primarily by email.
- Post COVID-19, of those who have paused their PPG:
  - Four said that they would revert back to face-to-face meetings.
  - Ten said that they are considering new ways of working with the PPG.



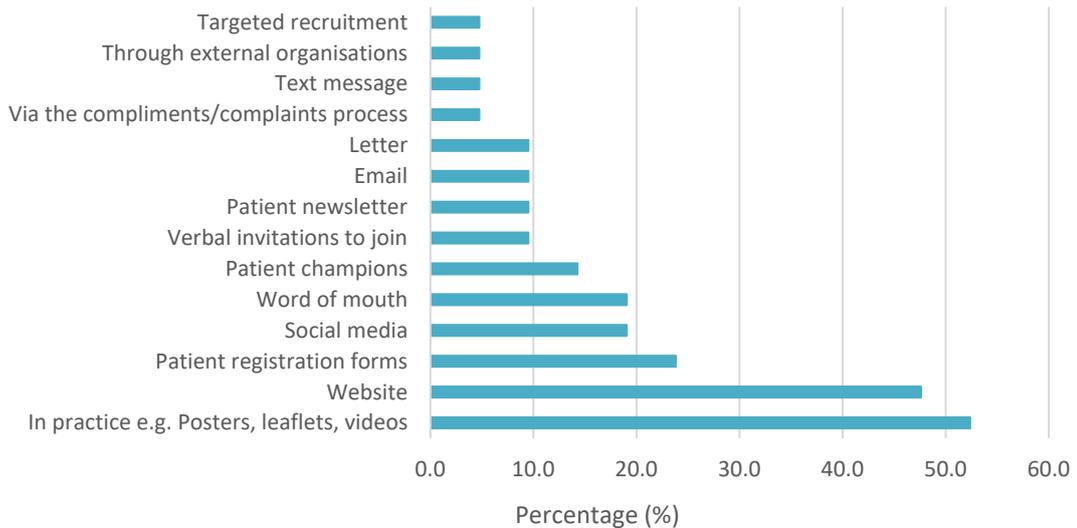
(Pre-COVID active PPGs – 22, PPGs active now – 7)

- Pre-COVID, PPG meetings occurred over a range of time periods with quarterly most common.
- Of the seven active PPGs, four are continuing their quarterly frequency whilst others have changed to a bi-annually or ad-hoc basis.
  - Post-COVID-19 five out of the seven practices are going to keep their new frequency.

### PPG membership

- Recruitment

#### How do you recruit patients to your PPG?

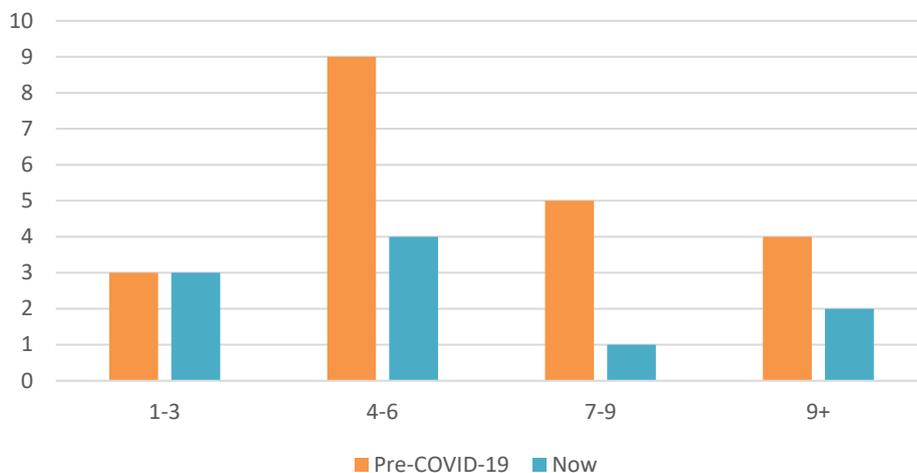


(21 practices answered this question)  
(Practices could give more than one answer)

- Practices employ a range of methods to try and recruit patients to join their PPG with information displayed within the practice building and on their website most commonly used.

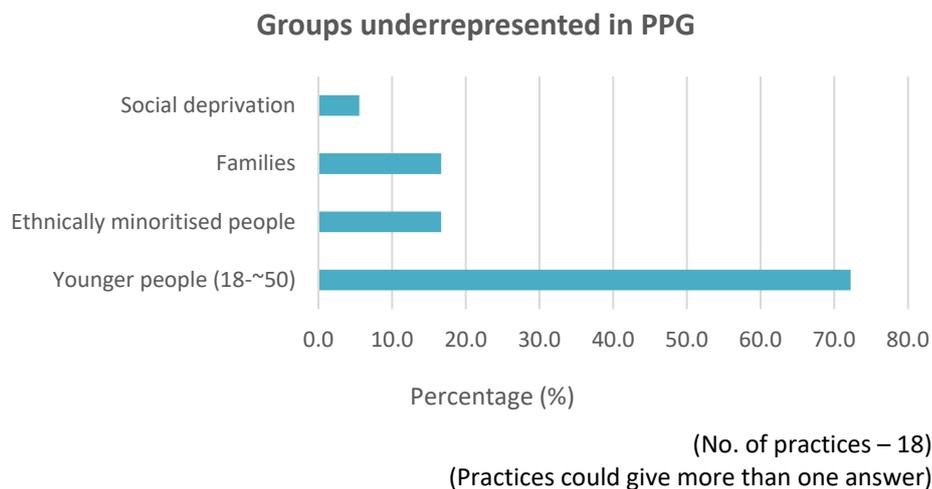
- Number of members

#### How many members does your PPG have?



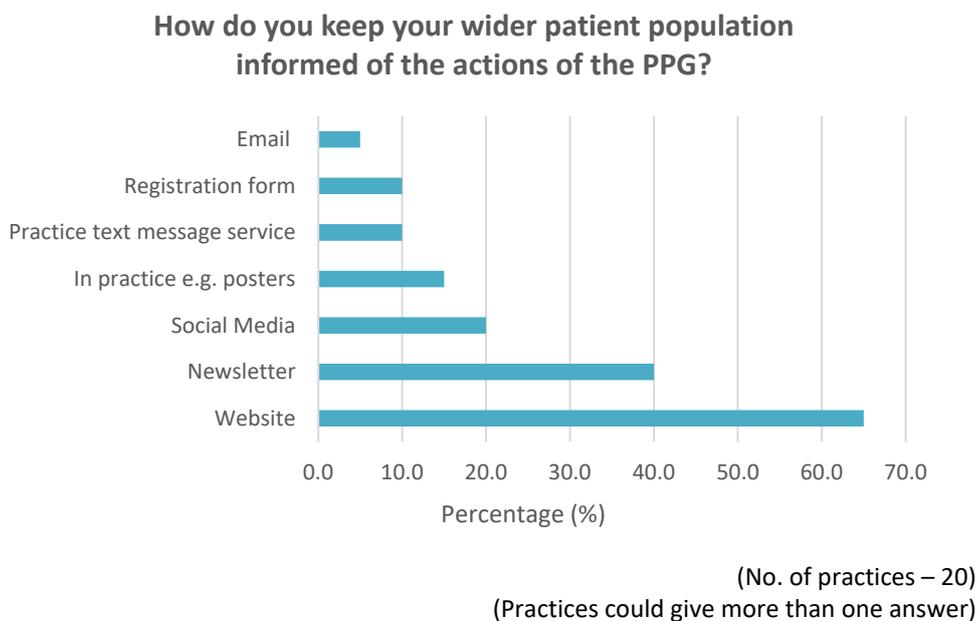
(No. of practices - 26)

- Pre-COVID-19 PPGs had greater number of members than now.
  - One practice stated that all their PPG members had taken on caring duties during the pandemic which left them with little time to engage with the PPG.
- Pre-COVID-19 more practices had PPGs with four or more members.
- Representation
  - Of the 21 practices who responded to this question, 6 (28.6%) felt that the membership of their PPG was reflective of their patient population.



- The majority of practices reported a lack of representation from people aged under 50 years of age.

### Sharing PPG activity



- 65% of practices use their website to keep their wider patient population informed of the PPGs actions.
- Whilst 40% also use newsletters to promote PPG actions.

## PPG links

- Practices were asked whether their PPG was engaged in any wider networks or meetings such as NGCCG's Patient, Public and Carer Engagement Forum (PPCEF).
  - Only one practice reported that their PPG engaged in PCN meetings.

## Things that have worked well

- Seventeen practices identified at least one thing that has worked well within their PPG.

	No. of practices	Percentage (%)
Patients providing feedback	6	35.3
Face-to-face	2	11.8
Patient-led	2	11.8
Practice sharing information	2	11.8
GP attending meeting	1	5.9
Supportive members	1	5.9
Having a combination of different formats	1	5.9
You said we did - acting on feedback	1	5.9
Having two PPGs for different patient groups	1	5.9

(Practices could give more than one answer)

- One third of practices (35.3%) felt that the PPG was a useful platform for gathering patient feedback.
- Two practices felt that face-to-face meetings work well and made the point that they were more effective than virtual meetings.
- Another two practices stated that having a patient-led PPG worked well.
- One practice found that having two different PPGs, one for the general population and one for their Jewish population worked well.
- Five practices who responded to this question noted they could not think of any areas of good practice.

## Things that have not worked well

- Fifteen practices identified areas which do not work as well within their PPG.

	No. of Practices	Percentage (%)
Recruitment	5	33.3
Representative recruitment	4	26.7
Patients taking ownership of the PPG	2	13.3
Patients use platform to highlight personal issues	1	6.7
Formal face-to-face meetings	1	6.7
Online format	1	6.7
Members not engaging	1	6.7

(Practices could give more than one answer)

- One third of practices highlighted that recruiting patients to join the PPG was an area where they struggled.
  - One felt that this was because there was little incentive for them to give up their free time.
- Over a quarter struggled to recruit members who were representative of the practice population, younger people were mentioned specifically here.
- Two practices highlighted difficulties in persuading PPG members to take greater ownership of the group in terms of its direction and recruitment of a patient Chair.

### PPG support needs

- Practices were asked what support they would like with their PPG in the future. Sixteen practices identified the following:

	No. of Practices	Percentage (%)
Recruitment of members	6	37.5
Recruitment of representative members	3	18.8
Engaging members more effectively	3	18.8
Outside support to organise/manage the PPG	3	18.8
Additional resources to support running PPG	2	12.5
New meeting format	2	12.5
Joint working with other PPGs/PCN	2	12.5
Meeting content/structure	2	12.5
Patients take the lead/manage the PPG	1	6.3
Getting PPG back up and running	1	6.3

(Practices could give more than one answer)

- Over one third of practices stated that they would like support with recruiting PPG members.
  - 18.8% of practices would like support with recruiting more diverse members to ensure that their PPG is more representative of their patient population.
- 18.8% of practices would like support on engaging PPG members more effectively.
- Another 18.8% suggested bringing in a third party to organise and manage their PPG.
- Support to develop a new format of PPG such as a virtual group was also highlighted.
- Two practices felt more joined-up working would be useful, working more closely with other PPGs or as a PCN.
  - One practice reported that a PCN-wide meeting had been trialled but was poorly represented and requested help to make it more successful.

# Final thoughts and recommendations

- GP practices across Newcastle and Gateshead paint a similar picture of their PPGs with key themes replicated:
  - GP practices appreciate the value patient involvement in the form of a PPG can bring, providing a two-way communication between practice and patient and are keen to see them succeed. A lack of time and resources however impact upon the effectiveness of their PPGs, many do not have a dedicated Chair, and few are patient-led. The majority of practices identified areas where they would appreciate some support to help improve or redesign their PPGs.
  - COVID-19 has had a huge impact on PPGs, the majority of which are currently paused. However this impact is not entirely negative. The minority of practices who have kept their PPGs running have tried out new communication tools, online meetings have replaced face-to-face, but email and telephone are also now being used more frequently. Those whose PPG is not currently operating have used email and telephone to keep communication channels open. It is also encouraging to hear that post-COVID-19, the majority of practices are considering maintaining these new ways of working or offering different ways to get involved, or are planning a review of the way they operate, which will hopefully make it easier for patients to take part.
  - Recruiting patients into PPGs is the main issue for practices. Despite advertising in various ways and carrying out direct targeting of patients, numbers remain low and have fallen since COVID-19. Moreover, the majority of practices do not feel that their PPGs reflect the general patient population with younger people under 50 and ethnically minoritised groups least likely to be represented. Once members have been recruited some practices struggled with retaining their membership.
  - Very few PPGs have any interaction with other PPGs, even those within their PCN, with the PCN in general or with other patient forums. Several asked for more joined-up working in this respect, to share resources or best practice for example.
- The following recommendations are made whilst acknowledging that COVID-19 and social distancing is currently still in place. Some of these recommendations may not be possible at the current time.

## NGCCG

- INE's 'Patient Participation Group Toolkit: Guidance to help you set up and get the most out of your Patient Participation Group' should be recirculated to all GP practices. This covers the basics of how to set up a PPG but also includes ideas around extending the scope of a PPG to PCN level and beyond.
- INE could also run a session at the GP Timeouts to go through the Toolkit with practice staff.
- Explore ways to build relationships with practices around patient and public involvement.
  - Consider sharing related NGCCG activities with practices via a monthly bulletin or a page on GP TeamNet.
- Consider working with Practice Managers to explore their role in patient engagement and what they could offer (mindful of current pressures).
- Consider conducting a mapping exercise with PCNs to establish what their aims and objectives around patient and public involvement are, who has responsibility for it and any activities they have undertaken.

## Practices

- Review:
  - As many practices have currently paused their PPGs, it would be sensible, ahead of relaunch, to review:
    - Membership – is it representative of your patient population?
    - Recruitment methods – what is the reach? What improvements could be made? Consideration should be given to the most appropriate methods for engaging ethnically marginalised groups and younger people.
    - The number of ways patients can engage.
    - Effectiveness – what is the track record of the current PPG?
    - Read or revisit INE's 'Patient Participation Group Toolkit: Guidance to help you set up and get the most out of your Patient Participation Group'.
- Management:
  - All PPGs should have a Chair and one who is a patient representative rather than a member of practice staff. This gives ownership to the group and encourages co-production between patients and the practice. Practices should make plans to recruit patient Chairs to their PPGs.
- Recruitment:
  - Think about carrying out a survey with patients to understand the barriers to them becoming PPG members.
  - Review the demographic profile of your patient population. Where there are particular groups of people not represented in your PPG, consider how you will target these groups including the method and message. A targeted plan for each group will be most effective.
    - For tips on encouraging young people to get involved have a look at The NHS Youth Forum's 'Top tips to involve young people in Patient Participation Groups: <http://www.byc.org.uk/wp-content/uploads/2017/07/NHS-Youth-Forum-Brochure-for-PPGs.pdf>
    - For patients who do not have English as a first language, they may prefer to see something in their first language.
  - Consider working with local voluntary and community organisations, particularly those who work with younger people and ethnically minoritised groups to understand how best to reach these groups. They may also be able to advertise the opportunity to join your PPG.
  - Make your PPG more accessible to patients by offering more than one way to get involved; a face-to-face meeting should not be the only format; consider virtual groups, online surveys etc.
  - Consider offering 'rewards' for taking part in the PPG, for example taking the time to thank members for their volunteering commitments publicly, or by awarding a certificate. The opportunity to become a member of a PPG could also be advertised on local volunteering websites.
- Member retention:
  - Consider developing a programme of topic areas to be addressed at regular intervals. Ensure patients know the value of their involvement and use a variety of tools to engage patients.
  - Give patients the opportunity to get involved in PCN related activities too.
- Joined-up working
  - Encourage PPG Chairs to attend their respective place-based PPCEFs.
  - Communicate with other practices to share best practice, tools, and ideas.

- Approach your PCN to develop a PPG involvement network to share best practice amongst member practices and the PCN itself.
- Consider how your PPG could feed into the patient involvement and engagement activities of the PCN.
  - Consider whether your PPG could also become part of a larger PCN PPG to support and also influence the operations of the PCN. Discuss with PPG members support for this and potential ways it could operate.

## PCNs

- Explore how to communicate your patient and public involvement plans to your PPGs and how they can get involved in the PCN's activities.
- Develop a PCN PPG involvement network where PPG members can come together to share best practice and also influence the operations of the PCN.
- Consider how patients could be involved in your PCN:
  - A PCN PPG would enable patients to influence activities. Members could be drawn from practice PPGs.
  - The PCN PPG Chair could become a patient representative/lay board member.
- To help practices recruit patients to their individual PPGs, PCNs should consider developing an advertising campaign which all practices within their network could access. Key messages would include the role of a PPG and the benefits of joining in particular.
  - Materials and messages should focus on younger patients (aged under 50) and ethnically minoritised groups in the first instance.
    - Practices should however be instructed to ensure that the materials and messages they use are appropriate for their patient population and target the groups which are underrepresented within their PPG.
- Explore the opportunities to offer patient leadership training to PPG members to provide them with the skills to take on a chairing role.