

A guide for Patient Participation Groups (PPGs)

Working with their Primary Care Networks
to involve people and communities



April 2024



● PPGs working in partnership with GP practices and Primary Care Networks	4
● Formal Patient Participation Groups: what they are and how they work	5
● Patient Participation Groups: Different Ways of Working	6
● How PPGs can work together across their PCN	9
● Recruitment and retention of members	13
● Key principles to involving people and communities in an effective way	14
● Hearing diverse voices including ethnically diverse people, young people, and working age people	16
● How PPGs can work with Healthwatch effectively	18
● Additional training	20
● Other useful materials and resources	21



This guide is for Patient Participation Groups (PPGs) that are supporting their GP Practice but want to expand and diversify their membership and reach, hear from local people and communities, and work with other PPGs in their Primary Care Network (PCN) area.

This guide has been designed to provide advice on:

- Different models of PPGs with examples from across Sussex
- Good practice to have a high functioning PPGs
- How PPGs can adapt successfully to working with PCNs
- How PPGs can involve more young people, working-age people and other diverse groups including ethnically diverse communities
- How PPGs and Healthwatch can work together collaboratively
- Additional training and tools to support PPG volunteers



PPGs working in partnership with GP practices and Primary Care Networks



All GP practices in Sussex work together in their local areas in groups known as Primary Care Networks which are usually known as PCNs.

Primary Care Networks bring together existing primary care services to provide proactive, personalised, coordinated and more integrated health and social care for people close to home.

Each of the 1,250 PCNs across England are based on GP registered patient lists, typically serving natural communities of between 30,000 to 50,000 people (with some flexibility). They are small enough to provide the personal care valued by both people and GPs, but large enough to have impact and economies of scale through better collaboration between GP practices and others in the local health and social care system.

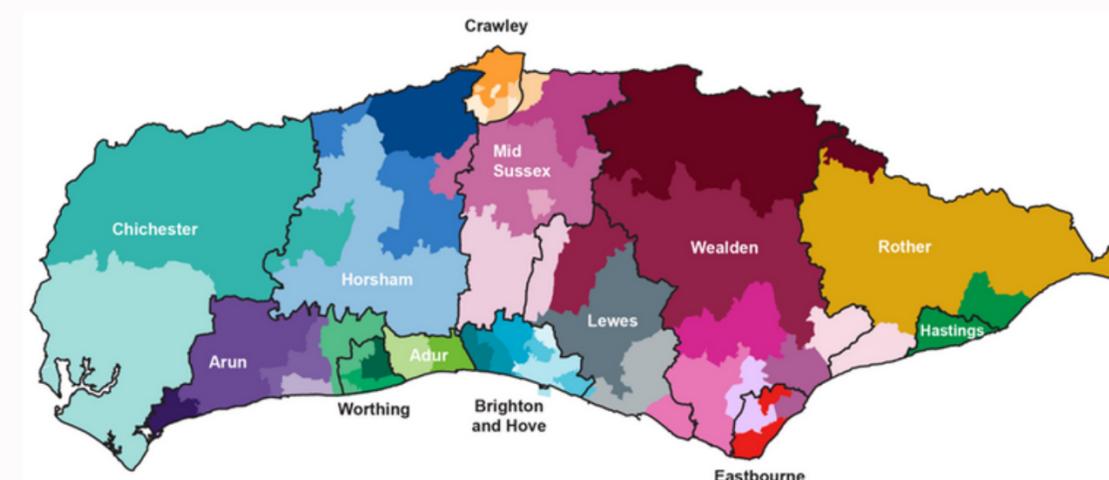
There are 38 PCNs across Sussex; 19 in West Sussex, 12 in East Sussex, and 6 in Brighton and Hove. When practices work together, they can offer a broader range of services to patients than individual practices can provide. These services can include pharmacists, first contact physiotherapists, first contact paramedics, physician associates, health coaches, care coordinator roles, GP assistant roles and social prescribing. These roles within the network of practices provides patients with a broader range of appointment options.

As PCNs have developed, **the role of PPGs has become more important.** These networks need to understand the people and communities they serve and identify how the PCNs can develop services that improve the health of the population. Individual GP Practices must contractually have a PPG in some form. This can be one formal committee, a series of smaller focus groups, or another way of working such as gathering patient feedback be email or surveys.

While Primary Care Networks don't need to have a PPG in addition to this, some choose to have a PCN-wide PPG in place.

This guide aims to share ideas on how individual Practice PPGs can collaborate to improve services and involve people across the PCN area.

Below is a map illustrating the 38 footprints of the Sussex PCNs. You can view an interactive version of the map [Census 2021 - Sussex PH \(census-2021-sussex-ph-overview.netlify.app\)](https://census-2021-sussex-ph-overview.netlify.app).



Formal Patient Participation Groups: what they are and how they work



Formal committee-based Patient Participation Groups (PPGs) are often started by GP practices asking patients to volunteer. Patients eventually take over management of the PPG with a committee meeting regularly to provide leadership and direction.

This type of PPG works closely with the practice, and members can include volunteer patients who are registered with the practice, GPs, Practice Managers, and other practice staff. Anyone over the age of 16 who is registered at the practice can join their PPG.

Formal PPGs should be clear about what they are there to do and how they hope to achieve their ambitions. The PPG should have well thought out core objectives so that if someone asks what the group does, there is a clear answer.

It is important for members of formal PPGs should think about the wider patient interest and not their personal concerns when serving on the PPG.

Formal PPGs should meet a minimum of four times a year to stay active and functioning but many meet more frequently especially when planning events and activities.

PPGs can support their practice in a range of ways. Some examples include:

- Collecting feedback on patient experience through surveys, discussions in waiting rooms and at events
- Suggesting improvements to the practice based on patient feedback
- Letting patients know about other services in the local area
- Working with the practice or PCN to organise health promotion open days and events, allowing people to find out more about local health care, self-care, and the PPG.
- Volunteering to support vaccination clinics and health promotion days
- Contribute if the practice is inspected by the Care Quality Commission (CQC – a national inspection agency) – usually, the CQC will want to talk to the PPG Chair, and possibly some other members too, to seek their views
- Represent practice views at the local PPG Network where all PPG representatives share best practice and learning

Top tip:

[NHS England](#) and the [National Association for Patient Participation](#) have more information about what a PPG is and ideas for how they can work with Practices.



Patient Participation Groups: Different Ways of Working



The formal PPG model is just one way of reaching and hearing from people and communities. There is scope for innovation and creativity in the way in which PPGs work and some people would like to get involved in other ways.

If a Practice is hearing and acting where possible on the voices of people and communities, **patients can be involved anytime in any way.** The GP contract does require GP Practices to establish a group, but it is not prescriptive on how that takes place other than it being representative of local patients. The Care Quality Commission (CQC) will also expect to see practices engage and involve people and will consider PPGs as being one way this can be achieved.

Practices may find they can have more effective conversations through engaging with **different community groups at different times and in different places.** Groups don't need to be called a PPG – they can work with the community to come up with a name that makes sense for everyone. Friends of (name) Medical Centre is an increasingly popular alternative name for a PPG.

Be creative – the main thing is to give people a voice and work together to improve services and deliver quality improvements. Having a network of people and communities, connecting via social media, or attending a range of community-led sessions to hear from your local population can be a good way of hearing from them.

By using a range of flexible approaches, **PPGs are more likely to be able to hear a diverse range of voices.** There are many ways in which you could get people involved: social media, community meetings, targeting particular communities who experience health inequalities, or working in partnership with local voluntary sector organisations.

Examples of alternatives to a committee style PPG might include smaller groups that come together for specific tasks or activities i.e., a health event or support the practice with communications. They may hold coffee mornings or information evenings inviting people to come and hear about specific health conditions or support their PCN at vaccination clinics.

Alternatively, if there are volunteers with more availability you could develop a PPG or **PCN Ambassador role** to build relationships with communities and the VCSE sector and identify groups to attend and share information with.



Good practice:

Make a record of what has been done to hear the voices of patients and demonstrate how you have responded to what has been said.

Patient Participation Groups: Different Ways of Working (cont.)



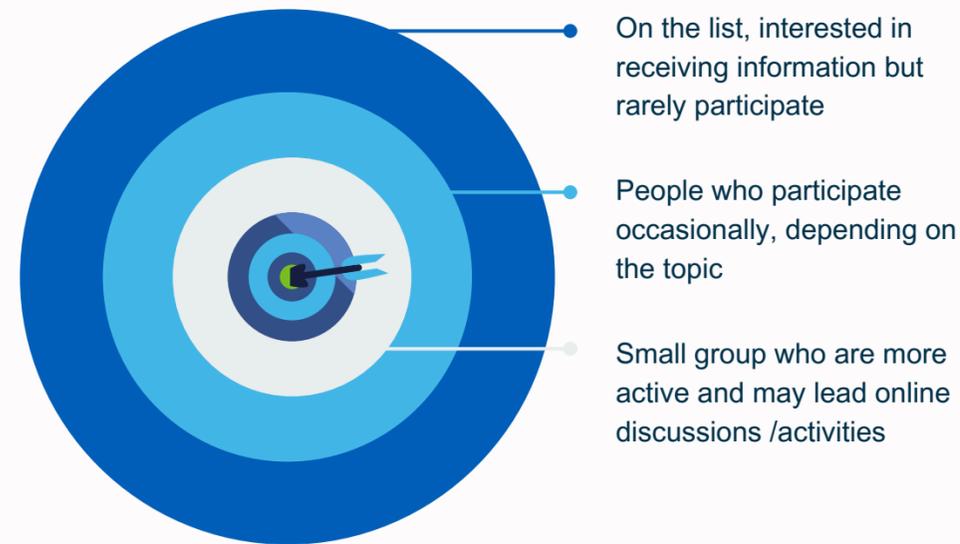
Virtual PPGs (VPPG)

Virtual PPGs can be a good way to involve people who cannot offer a lot of time due other commitments such as studies, work, or family commitments.

A Virtual PPG doesn't just mean meeting online but includes a variety of ways for people to share their experiences and influence how primary care in their area is run.

Practices can reach a significant number of people through a fully established VPPG. Insight on access and experiences of NHS services can be sought through surveys, feedback forms, online focus groups and quick polls. Practices can send out information about local NHS services and share opportunities for people to get involved in the operational running of the practice or PCN, such as helping at vaccination clinics or planning and attending health events.

Similar to PPGs, there will be a range of people with different interests and opportunities to get involved so a thriving VPPG will be engaged through a wide range of mechanisms.

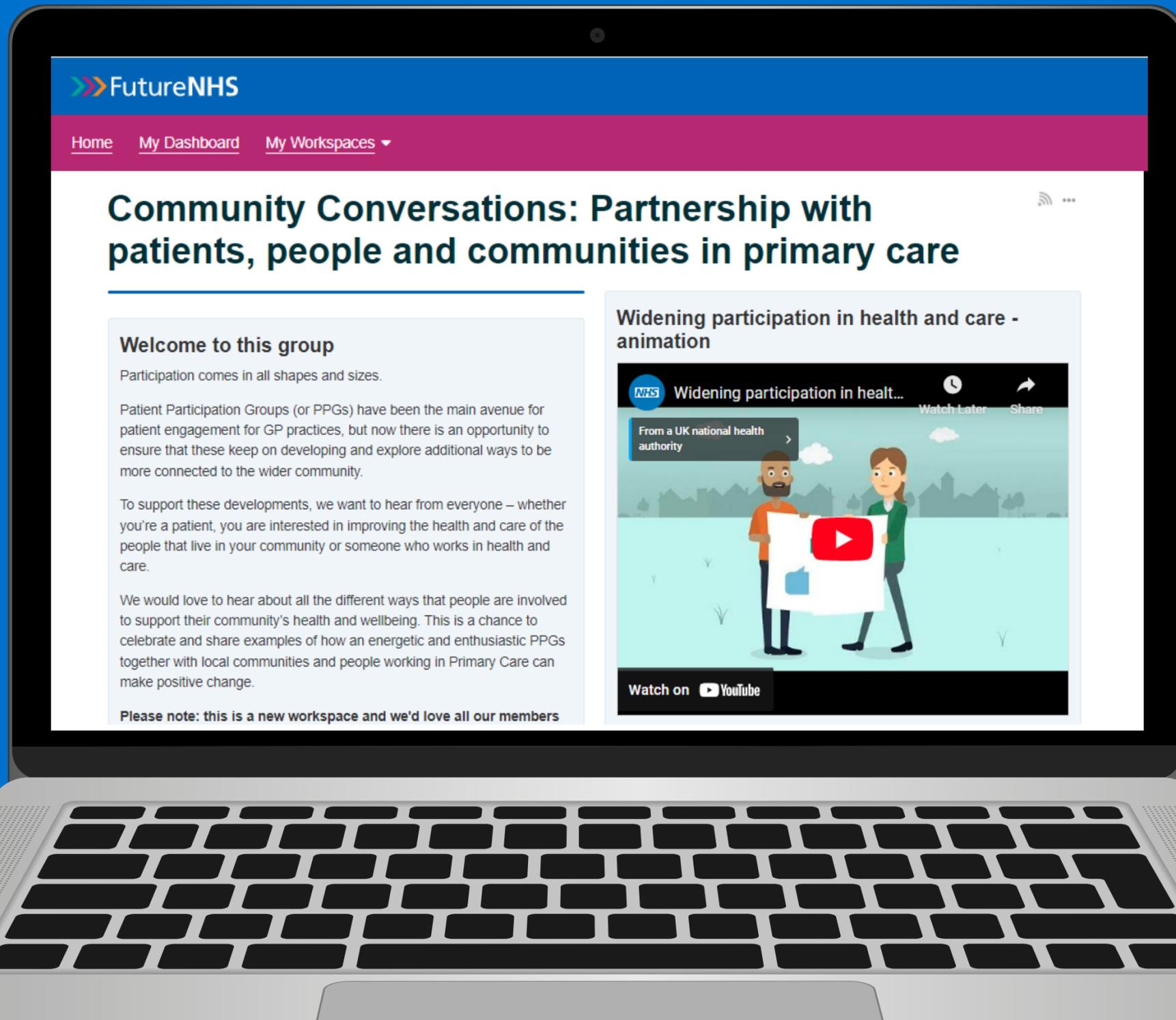


VPPGs are only accessible to people who have adequate digital skills and access to the internet, so it is important to not solely rely on virtual participation but offer a range of ways to get involved. VPPGs should complement rather than replace in-person PPGs.

VPPGs are administered by Practice staff and must be GDPR-compliant. Volunteer PPG members are not able to access patient email addresses or other contact details but by working closely with the administrator, they can link in and promote communications, engagement opportunities and share insight and action with the VPPG. There may also be opportunities to recruit to the PPG through the VPPG.

To build up membership of a VPPG, a membership form should be included in the GP registration pack to describe the group and encourage sign up (including a GDPR statement). Once the VPPG is established, ongoing recruitment can be targeted to ensure they are a diverse representative group.

Usually, practices will set up a designated email address to use for VPPG correspondence. This keeps correspondence separate from other practice emails and makes it easier to record the engagement undertaken and keep track of responses.



Top tip:

You can find out more about the support available to you from NHS England by joining and exploring our NHS Futures PPG space:

future.nhs.uk/PPGnetwork/grouphome

How PPGs can work together across their PCN



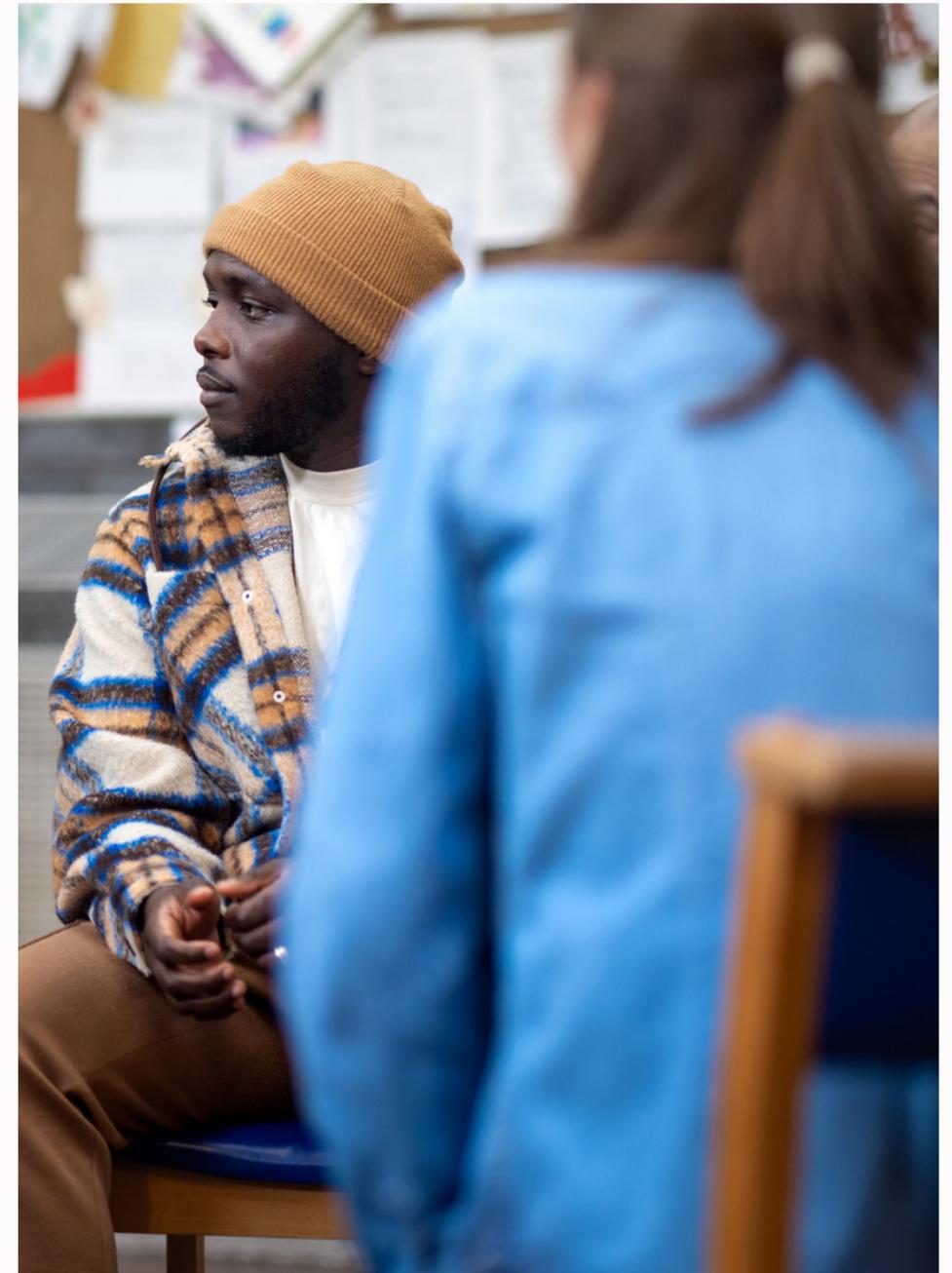
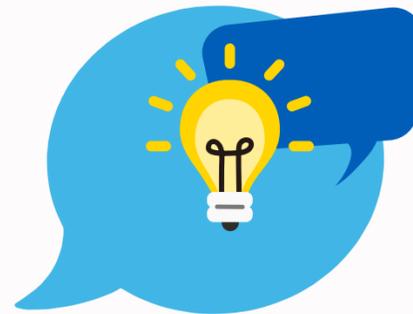
While the main focus of an individual PPG is on making improvements to its local practice, their insight and experiences can be relevant to all the Practices in its PCN, making it beneficial to everyone to work more collaboratively.

All PCNs have a Network Manager or Operational Manager. A good first step to working with other PPGs in your PCN would be to contact the person in these roles and ask for their support with bringing practice PPGs together to discuss how they could collaborate effectively. Your Practice Manager should be able to give you contact details for the people in these roles, or may prefer to get in touch with them on your behalf.

You can work with the PCN to decide whether they would like to establish a formal network of practice PPGs or if you would prefer to work together more informally for specific projects.

It may be that PPGs across a Primary Care Network could commit to a quarterly or annual event to share information and hear from community partners such as Healthwatch and the Integrated Care Board (ICB).

Many PCNs hold monthly meetings and it may be possible for Chairs of individual Practice PPGs to take turns to attend and report back to other PPG Chairs in the Network.



How PPGs can work together across their PCN (cont.)



Having individual PPGs join together to work at PCN level allows:

- Patients and PCN staff to meet and discuss constructive suggestions for improving the PCN, and share concerns that could affect the local population
- Increase knowledge and understanding of the local PCN
- Raising broader issues happening within the member practices that the PCN can support on a wider scale
- Engaging and working together with local communities to ensure PPGs are truly reflective of the area and help the PCN to provide the best possible care for the population



Ideas for PCN-wide working

PPGs in each Practice within the PCN may choose to produce a PCN-wide Patient Participation newsletter for patients, either in addition to or instead of, a practice newsletter. As GP Practices start to work more closely together, some of the services they offer may be offered at different sites, meaning patients need to travel to new places. A PCN-wide newsletter may be able to share this information. Alternatively, PPGs may choose to work together to plan a health event to address a specific concern in their area.



Example of PPGs across a PCN Planning a health event

In Brighton and Hove, a group of practices (now recognised as a PCN) came together with their PPGs, members of the public, local Voluntary Community Social Enterprise (VCSE) organisations, Public Health, and Social Care to develop a forum over a number of years. The forum meets quarterly and through the lead VCSE, runs a range of events, groups and drop-ins.

Most recently a small number of people in the forum came together to plan a health hub event, bringing together the PCN, members of the public, social prescribers, providers of NHS Health Checks and other services. 184 people attended and as a result:

- **24 people** received a GP referral for a range of health care needs including blood pressure, blood glucose levels and hypertension
- **6 people** were referred to social prescribing for support to access other services
- **32 people** engaged around bowel cancer screening
- **85 people** were given information around cancer screening including 70 completed quizzes
- **14 people** signed up to find out more about their local PPG



It was great to see people engaged in understanding what matters to them and how to support their health... In the health hub, we had a great uptake of over 48 people for blood pressure and blood glucose checks and associated education. We picked up 5 potential hypertensives and two people with high glucose readings, all of which were signposted to their GP for further investigations



Thanks, and congratulations to you for organising a delivering such a fantastic and well attended community event. You definitely engaged with the local community and offered support to help improve their health and well-being. The West Hove PCN were delighted to work in partnership with you as part of the event.



How PPGs can work together across their PCN (cont.)



Sharing best practice

Individual Practice PPGs may wish to link with others in their PCN to share ideas and learning from patients. For instance, if a PPG has undertaken a survey or held interviews with patients, sharing the outcomes of these activities across the PCN ensures they have a wider impact.

Because they are so local, individual PPGs often know, and are representative of, their local communities. It may be helpful for PCNs to call upon this knowledge when planning services to ensure any changes are as effective as possible. Working collaboratively means PCNs can also learn from individual practice PPGs about how different ways of working can effectively engage diverse groups of patients. For example, an individual PPG may have had success engaging with younger patients by visiting a youth club or with their Muslim patients by distributing posters to a local Mosque.

As well as sharing best practice within your PCN there are opportunities to meet with PPGs in your local area through local PPG Networks. In Sussex there are three networks; Brighton and Hove, East Sussex and West Sussex. The networks meet quarterly, with NHS Sussex representatives, to share ideas, best practice and hear from the ICB about latest developments. If your PPG is not currently part of your local Network, get in touch with NHS Sussex by emailing sxicb.involvement@nhs.net.



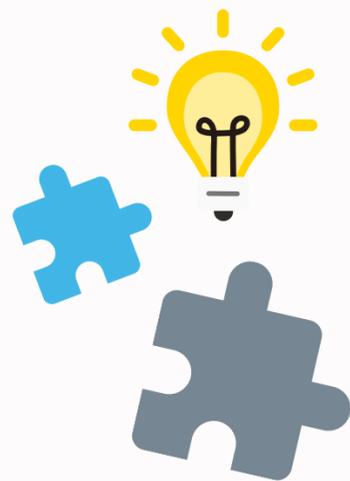
Developing a health information video with an ethnically diverse community

A PCN area in Sussex had a high number of people with dementia in their area. Analysis of the data suggested dementia is prevalent in the Asian community. Clinicians, local VCSEs, including Carers organisation and community members came together and developed a video to engage the community around dementia, increase the understanding of the disease and how to live well with dementia. The video was filmed in several languages and shared widely with the community.



Every practice and PPG are different, as are the diverse local patient populations they exist to serve and represent.

Outlined below are practical pointers to help you succeed in increasing the number and diversity of patients involved in your PPG. It's useful to know and apply some basic principles of good practice when planning and acting to widen participation in your PPG whether this is for your practice or across your PCN:



- make it easy for people to participate, remove any barriers i.e., lengthy bureaucratic Terms of References, create an open and transparent process for people to connect with the practice and share views
- only ask people to participate if you're able, and prepared, to take their views into account
- be clear about who you are asking to participate and why you are asking them to participate so that you can tailor and publicise participation opportunities widely and appropriately (e.g., if you want to encourage young /and or working people to participate in PPG meetings then hold them outside of working hours and/or offer online opportunities to get involved)
- offer more than one option for participation (e.g., both on-line and face to face options)
- if you're not sure about the most appropriate way to engage people (e.g., people with a specific health condition or people identifying as belonging to a particular community) then ask them what would work best for them
- include knowledge and experience that exists in your community from VCSEs and Healthwatch
- make it enjoyable to participate (e.g., provide space and time for people to chat to and learn from each other; use informal as well as formal formats to elicit people's views online and face to face; use accessible language; *provide translators and/or advocacy support if required?)
- demonstrate that participants' views and experience are valued (e.g., listen to and acknowledge diverse points of view; give professional and patient views equal respect and weight)
- communicate and celebrate the positive outcomes of participation, whether big or small as this will help encourage more people to participate in future
- feedback to participants and to the wider community on what difference participation has made (e.g., to patients, to your practice) so that people can see that their participation is meaningful

Key principles to involving people and communities in an effective way



Personalise and tailor involvement – one size does not fit all. Use a range of ways to involve people including events, attending pre-arranged events, coffee mornings and information sessions



Be inclusive and seek the diverse voice of people in your Primary Care Network

To reach those who don't often access primary care services or aren't linked into your social media and newsletters there may be opportunities to use:

- **community noticeboards** at leisure centres, community halls, libraries, and cafes
- **local community publications** such as parish newsletters and magazines; these are often free publications sent directly to mailboxes in your community
- **canvassing or leaflet drops** in local residential areas
- **local Voluntary and Community Sector newsletters** such as Healthwatch, Voluntary Action groups – these are often sent out monthly to a large distribution list of people who are interested in local services
- **District and Borough Council publications** (where applicable)
- **media opportunities** to share good news stories about your PPG activities and what you have achieved, with local radio and newspapers to reach a wider audience
- **attendance at local events** such as school summer fayres, Christmas markets and voluntary and community sector events



Be flexible in your approach and try out new ideas. Seek feedback to learn and improve the planning and delivery of the involvement method.

Key principles to involving people and communities in an effective way (cont.)



Find support within the practice— agree a lead representative from your practice and/or PCN to support your PPG to plan activities.



Use the strengths in your team – people in your PPG and people in your local community will have different strengths. Identify the strengths and utilise them i.e., you may have a member who is good at social media content, or a local faith leader who has a congregation of hundreds and can support promotion and education around NHS services and health care needs.



Map all the places where people come together in your local community to see what strengths and skills are available including:

- Local schools
- Leisure and community centres
- Libraries
- Places of worship



Share feedback and action taken— people are more likely to engage again if they are informed of how their feedback has made a difference. You may want to create a page on the PCN website to share findings and outputs from events, surveys, and activities. Include a “You Said, We Did” so people understand how their contribution has had an impact.

Hearing diverse voices including ethnically diverse people, young people, and working age people



Your PCN will hold a lot of data to help you understand more about your local population. You may have a large ageing population or live in an area with pockets of deprivation. Think about people and communities who often don't have their voice heard such as:

- Ethnically diverse communities
- Unpaid carers
- Those who are homeless or temporarily housed
- Children and young people
- Refugees and migrants
- LGBTQIA+

People in some communities may be less interested in joining a committee style PPG, which is why taking an innovative approach to the structure of your PPG is so important. PPGs may need to take a proactive approach and reach out to the wider community to seek their views.

Build links with local voluntary and community sector organisations who work with communities that you feel may not have their voice heard. For example, an organisation working closely with people with learning disabilities could support some of their members to come to an event or offer an opportunity for clinicians and PPG members to attend a forum or group.

Unpaid carers are often members of local Carer organisations and may provide a useful link to their events and networks to share information. Some carers may be unable to join a face to face PPG due to their caring responsibilities but may be willing to join a virtual group.

Build relationships with local community groups to both share information and hear from people in your local community, for example:

- Parent and baby groups
- Youth groups
- Community centres where people access exercise classes, educational classes, and support groups
- Explore working with housing associations and residents' groups

Be prepared that not everyone will be able to commit a lot of time. Consider inviting representatives to attend for a specific purpose or as a one-time event to ensure that their voices are heard. Some people may prefer to get involved in the planning and running of activities rather than formal meetings.

Consider the accessibility of communications – certain font colours on pages can be difficult to read, patients may need translations, including braille, easy read, and British Sign Language clips to understand the communications.

THE NHS YOUTH FORUM'S
TOP TIPS to INVOLVE
YOUNG PEOPLE in
PATIENT PARTICIPATION
GROUPS (PPGs)



PPGs are often keen to recruit young people but can find this difficult. See the British Youth Council's Top Tips for Involving Young People in PPG's:

[NHS-Youth-Forum-Brochure-for-PPGs.pdf \(byc.org.uk\)](#)

How PPGs can work with Healthwatch effectively



Healthwatch is the health and social care champion, gathering public and patient views and experiences, and sharing these with NHS leaders, decision makers and service providers to improve standards of care. They seek to learn what is working well and what needs to change.

Healthwatch has statutory powers to ensure that these ‘voices’ are heard by commissioners (NHS England and Sussex Integrated Care Board), providers (GP practices, Hospital Trusts etc.) and regulators (Care Quality Commission).

Sussex has three local Healthwatch. They cover Brighton & Hove, East Sussex and West Sussex, listening to people in each of these areas, but also collaborating to understand trends and issues at a Sussex level. They also support patients, services users and partners by pro-actively sharing advice and information on health and care.

How can Healthwatch support PPGs?

Your local Healthwatch (contact details listed below) may be able to support your PPG through their core services, including:

- helping people find health and social care services through their free Information and Signposting services
- providing information and resources to support practices through Healthwatch newsletters and on their websites
- offering channels for patients and carers to praise or raise concerns about local services

How can PPGs and Healthwatch collaborate?

There are wide-ranging opportunities for PPGs and Healthwatch to collaborate in areas such as:

- planning events, focus groups and engagement activities
- reaching and hearing from local people
- analysing and reporting insight gained from engagement activities
- recruiting volunteers and increasing PPG membership

Please note, local Healthwatch are social enterprises, which means that resources may need to be provided or obtained where activities sit outside of their core role.





For further information please contact:



Healthwatch Brighton and Hove

-  info@healthwatchbrightonandhove.co.uk
-  01273 234040

Healthwatch West Sussex

-  helpdesk@healthwatchwestsussex.co.uk
-  0300 012 0122

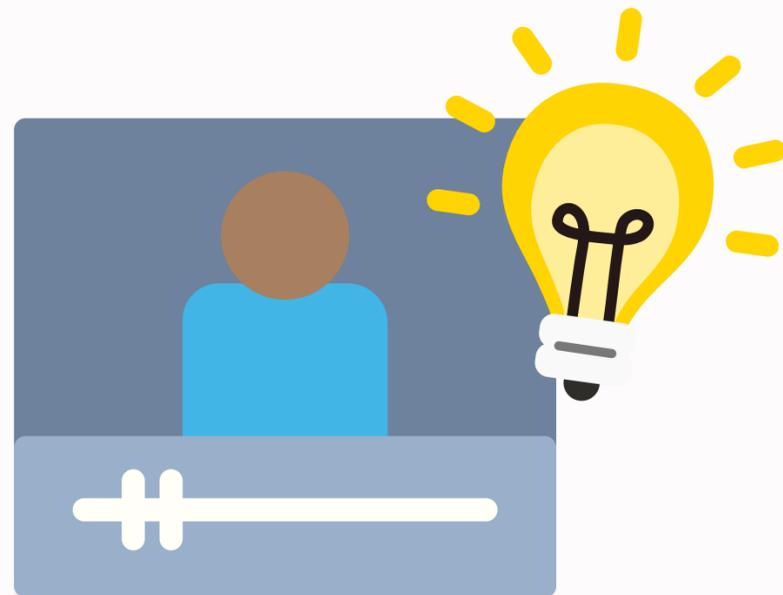


East Sussex Community Voice

-  info@escv.org.uk
-  01323 403590



To support you in volunteering as part of your PPG there are opportunities to gain more knowledge and upskill in key areas of NHS healthcare:



The NHS Explained: How the Health System in England Really Works - The Kings Fund has a popular course that is ideal for anyone wanting to understand how the NHS works. It is eight hours of learning, usually over four weeks and is free to access (there is a subscription for people who would like unlimited access).

Volunteer passport - This is a suite of free online courses from Health Education England, designed for anyone who is volunteering in health and care. Topics include:

- Equality
- Diversity
- Human rights
- Safeguarding
- Mental health awareness
- Disability awareness.

You must register with an email address first, then you can select any of the courses that are of interest. [Find out more](#).

Introducing the voluntary sector

The Open University has a course that provides a detailed overview of the voluntary sector, giving you knowledge and skills that you can apply to your own work or volunteering, as well as your everyday life. The course should take three hours a week, over eight weeks to complete. Take the course

Diversity and difference in communication -

The Open University has a short online course to help you understand the impact of diversity and difference on communication within health and care services

Other useful materials and resources



NHS Sussex has developed a Working with People and Communities strategy that highlights:

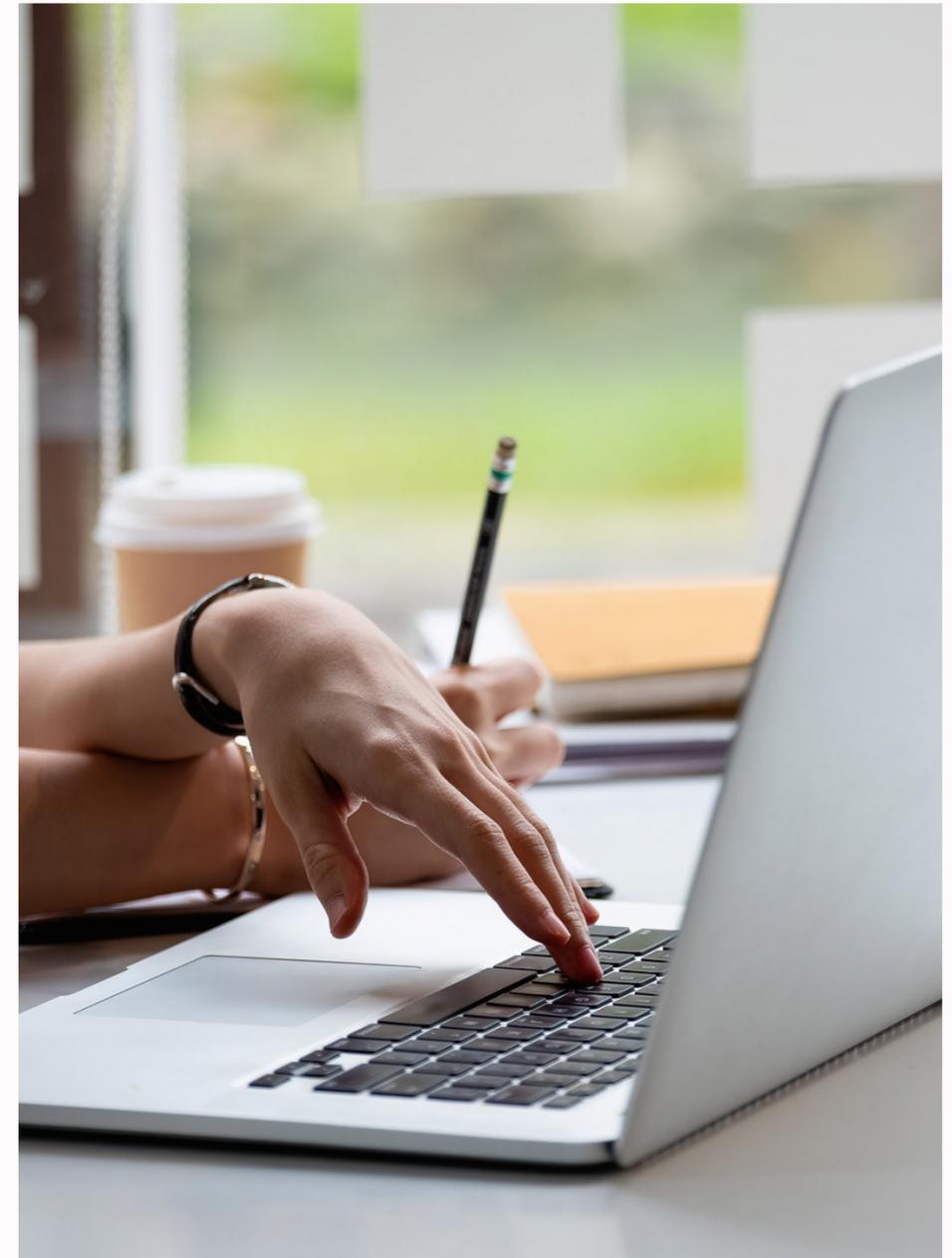
- Key principles to support involving people and communities
- The range of methods of involvement
- How the views and experiences of local people and communities will help shape and improve local health and care services

'NHS Sussex hosts an online portal for PPGs where they can:

- View notes from PPG Network meetings
- Share good practice around involving people and communities
- Share any key themes and insights and receive feedback from NHS Sussex about actions and impact as a result
- Access training information, toolkits, and information
- Chat to other PPG members
- Ask NHS Sussex questions

To access the portal please contact

 sxicb.involvement@nhs.net



Other useful materials and resources (cont.)



NHS England has come together with Healthwatch, the National Association for Patient Participation, and The Patients Association to change the way services are delivered.

The '[Partnerships with patients, people and communities in primary care](#)' online discussion space will give you an opportunity for peer support, the chance to discover and share involvement examples and engage in meaningful conversations with other members. You will need to register to access the platform.

The [video](#) will also support you in understanding the benefits of partnership working and offers you ten recommendations to improve involvement in primary care.

Resources from National Association of Patient Participation (NAPP) who have more than 40 years' experience in facilitating and fostering patient participation, to ensure the patient voice remains at the heart of local, regional and national decision making.

NAPP has some free resources for [patients](#) and details further information about PPGs including a Step by Step guide to PPGs. Some content requires paid membership.

PPG Champions support through the NHS Futures PPG Champions Group. This group meets every two months to bring together inspiring speakers and members of the public interested in primary care level engagement with people and communities. There are also opportunities to influence NHS England policy.



Email england.ppgchampions@nhs.net to get involved.

Joining the online group is free and easy – click on the [Future NHS page](#) and 'request access' to create an account. Once your account is created, request to join the group. Alternatively, you can also email england.ppgchampions@nhs.net.

Resources from the Patients Association: a variety of resources and videos on Patient Participation Groups and videos as listed below:

- [Developing PPG's](#)
- [Effectively working together in partnership](#)
- [Recruitment, increasing diversity and communicating](#)



NHS
Sussex