



involvement insights: PATIENT GROUPS

WHY HAVE THEM?

'The NHS belongs to the people' – The NHS is founded on a common set of principles and values that bind together the communities and people it serves – patients and public – and the staff who work for it.

NHS Constitution

The patient – undoubtedly should be the most important stakeholder in decision making about their healthcare, if the principles of the NHS Constitution is upheld.

The Health and Social Care Act 2012 makes clear the duties on the NHS Commissioning Board and the clinical commissioning groups to promote the involvement of patients and carers in decisions about their care and treatment, and to enable patient choice. Clinical Commissioning Groups have patient structures the roles of which are to encourage patient participation at various levels to help shape better health services for the population.

THE DIFFERENT LEVELS OF PARTICIPATION

Patient participation is mainly two kinds – Individual and Group participation.

- **Individual participation** – when an individual have something specific that they would like to get involved in and comment on e.g. commenting on a consultation like IVF or audiology. This is ad-hoc and representative only of those individuals' views. In some cases participation may be on behalf of another individual e.g. a parent filling in a survey related to children's services, a carer of elderly person who suffers with dementia etc.
- **Group participation** – Patient groups are set up to encourage patient voice. Some patients may want continuous involvement and chose to join a patient group; these are set up depending on what they have set out to do i.e. their remit. Groups tend to be more structured and have longer term involvement opportunities. E.g. a diabetes group who meet to discuss how to manage their long term condition, [a patient participation group \(PPG\)](#) etc.

SO WHY IS IT IMPORTANT TO INVOLVE PATIENTS?

The benefits of participation are important both for the patient and professional. Besides a statutory obligation to involve patients it also makes logical sense to involve those on behalf of whom services are being bought. This should ultimately lead an improved health and experience for the patient.

Many people are looking to influence some kind of change through their participation – The big question is - If there is no scope to influence anything is participation really worth anything? Perhaps the thoughts below will help you choose what level of participation is right for you.

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Midlands and Lancashire CSU commissioned by NHS England to help build expertise and capability in support of the participation agenda



THERE ARE SO MANY WAYS TO GET INVOLVED – HOW DO I CHOOSE?

Some steps to help you identify your level of involvement:

- Do you want individual or group participation?
- How much scope does the group have to influence change?
- Feedback – will your contribution be valuable? Professionals should be offering regular feedback
- Frequency of meetings, virtual involvement – are you able to attend face to face meetings or perhaps contribute via email, webinars?
- Are you looking for a condition specific group?

We must remember patients / public are also qualified professionals with an array of skills and expertise to offer. It is not uncommon to find patients who are now chairs of patient participation groups chairing really effective meetings or sitting on procurement committees to ensure the process is fair and transparent, some have been involved in mystery shopper exercises to determine the quality of services / care received by a patient.

There is no shortage of opportunities to get involved; a CCG website will have details of how patients can get involved and sign up to receive newsletters and updates of what is happening locally, visit the Involvement website to find out about events and consultations, ask one of our navigators – we are here to help.

PATIENT PARTICIPATION – HOW CAN IT BE ENCOURAGED?

For organisations seeking to involve patients – clearly demonstrating how patient voice is being heard will encourage participation; if people can see benefit in how their opinion or voice has helped shape an influence some level of change they will be encouraged to stay involved.

There are many ways that dialogue with patients can be encouraged; honesty, transparency, and accountability and feedback are crucial.

Watch this short, two-minute video on from one of the directors at the Consultation Institute, Elizabeth Gammell on the [feedback](#) during a consultation.

CO-PRODUCTION – WHAT IS IT?

Like with most things in life, if change is imposed, there is a greater level of resistance but where joint decision making is encouraged it leads to shared ownership and better results. It's our NHS – and we must work together to shape it.

The benefits of clinicians and patients working together to design health services produces some real benefits. Joint working leads to better patient pathways – that means the route to accessing services is simplified because patients affected by the condition have contributed to a solution that should help them and others use the service with ease. Unnecessary delays are avoided in the system and the patient receives the right care at the right time and the right place.

So, [Involvement](#) is here...start your journey with us today, get involved and help shape a better health service for the future. Good luck!

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