



# Engaged or Ignored?

**Reflections from patient participation groups about  
practice during Covid-19**

**December 2020**

**Author: Joanna Matthews**

## Foreword

In June this year, Shaping Our Lives was awarded a grant by the National Lottery Community Fund to carry out and complete research into the impacts of COVID-19 and national and regional lockdowns on d/Deaf and Disabled people, Deaf and Disabled People's Organisations (DDPOs) and patient groups.

This report reflects on experiences of five people who before lockdown started were members of patient groups. We carried out these interviews online in October and November 2020 and the report is an edit of transcripts and recordings. The interviewees were given the opportunity to review and amend the draft report.

We knew the identity of the interviewees but have kept their identities anonymous. We have not identified the health authorities they come from. Quotes used in this report were made by one of the five interviewees (unless otherwise indicated).

Thank you to our five interviewees for their time and insight. Interviews were carried out by Joanna Matthews (member of Shaping Our Live's National User Group) and Ann Nutt (Co-Chair Shaping Our Lives).

The report also includes some findings from Locked In or Locked Out? a survey about the use of remote technology by d/Deaf and Disabled people during, and beyond, the first national COVID-19 lockdown, which lasted from March 20 until early July. There were 90 survey respondents.

The other two in this series are:  
Behind Closed Doors :The longer-term impacts of COVID-19 on independent living for d/Deaf and Disabled people.  
Crisis, Challenge and Change: Reflections from Deaf and Disabled people's user-led organisations about the impact of COVID-19 on their work in 2020.



## Glossary

CCG	Clinical Commissioning Group
CQC	Care Quality Commission
IC	Infection Control
ICS	Integrated Care Systems
NAPP	National Association of Patient Participants
PPG	Patient Participation Group
SEP	Strategic Estate Partnerships
STP	Sustainability and Transformation Partnership

## Involvement

In this report we use the terms involvement, involvement activity and engagement. An involvement activity is an event, series of activities or group set up by an organisation to engage and involve service users in designing, overseeing and/or evaluating one of the organisations services or processes. These activities are often grouped as one and called co-production. Patient engagement and patient involvement are also commonly used terms.

In the health and social care sector this means patients and service users working alongside clinicians and professional practitioners. Other terms commonly used to describe individuals who get involved are, patients with lived experience, experts by experience, and lay members.

It may help to consider involvement in the context of other familiar activities which are used when describing relationships between clinicians and other NHS staff and patients. Often these activities are described in a hierarchy (with involvement at the top):

Involving  
    Engaging  
        Consulting  
            Informing.



## Introduction

The role of patient groups in primary and secondary health care in England is to contribute to good clinical practice and help decide how services are delivered, leading to improvements in patient care. Their remit is to be involved, not as end recipients of consultations, but as partners in co-producing good quality health services which meet patient needs.

“The genuine engagement of patients, communities and NHS staff is crucial to the success of STPs and ICSs, as is clinical leadership.”

### [STP Governor Briefing, NHS Providers](#)

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

### [Patient participation groups in general practice: building better partnerships \(British Journal of General Practice, November 2016\)](#)

“The importance of giving patients and those making complaints support and practical ways to raise concerns and provide important insight to inform improvements in care is a prominent theme in the Francis Report and subsequent reviews. In the context of a doctor’s practice, not only are patients key to raising concerns about care but also play an instrumental role in assisting doctors to improving their own practice through positive and critical feedback aiding in reflection.”

### [An update on the GMC’s work to address the Francis Recommendations, General Medical Council](#)

We interviewed five people (lay members of patient groups) in October and November 2020 using semi-structured interviews. Between them they have many years’ experience, not only on their groups (which generally cover a defined locality), but also as patients, as committee members of not-for-profit organisations and hospital trusts, and respected commentators. They are connected to and understand the communities they represent and are well-placed to judge what is good and bad practice in public involvement. They are experts by experience.

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For context, Shaping Our Lives asked Disabled people in a quantitative survey conducted in June to August 2020 about whether they had taken part in involvement activities before and during lockdown. Just over one half of those surveyed said that they had been part of an involvement activity pre-lockdown. Nearly one third said that the activity had carried on in lockdown through remote meetings (read the full report [Locked In or Locked Out?](#)).

This report is a snapshot of how five localities (and one national body) involved patients during 2020, as the COVID-19 pandemic took hold in the UK. It gives a flavour of what went well and what was more challenging from the patient perspective. We did not interview any of the staff teams which service these groups. We have provided examples which could help other patient participation bodies and NHS engagement teams.

## Report

Victoria (as Vice-Chair) and Sam (as Chair) both sit on the patient participation groups of hospital trusts in the same region of England, one serving a largely rural population, another with a more suburban catchment area. At the start of 2020 both trusts were committed to significant change; one merging with another trust to double the size of their catchment across two counties, the other commissioning purpose-built premises in a new location. When the pandemic hit both trusts provided acute and intensive care to COVID-19 patients alongside serving an existing patient group and continuing with their transformation plans. Victoria and Sam had different experiences of patient involvement.



## Victoria

### A possible blueprint for good practice

The patient panel which Victoria helps lead has been established for about seven years. She is the first to admit that it took a while to find its feet and its value to be acknowledged by the hospital trust.

“Looking at a scale of 1-10, with 10 being the most valued, it’s taken us about five years to move from about a 2 or 3 to where we are now which is a 9 to 10, and in the last couple of years it’s snowballed – the more we’ve done, the more we’ve been appreciated.”

The panel meet regularly with the head of patient experience in attendance, and a staff minute taker. Each meeting they have staff attendees, asking for help, updating or thanking the panel for an input. The panel’s role is wide ranging, they now: oversee the trust’s response to complaints (sampling three per month and with access to all); initiate the design and production of official patient facing communications (almost all hospital leaflets etc are run by them); and have had a key role in the new build process.

Most panel members are on subcommittees (of clinical specialisms) and volunteer within the hospital to further assist, for example conducting a biannual survey of patients and carers on the hospital’s end-of-life care. They write their own Annual Report reporting on how and why they have been involved in a hospital activity and host an annual conference focusing on a specific issue; in the past this has been cancer, end of life, and discharge procedures. For 2021 they have chosen diabetes because of its comorbidity with COVID-19 (and prevalence rates in their community) and have secured a talk from one of the global leads on a specific treatment. Victoria is confident their conference recommendations on future patient pathways will be reviewed seriously by the trust.



Before 2020 the panel had been involved in the trust's Ebola planning attending Infection Control (IC) meetings and feeding back on the level of patient confidence in the plan. Their relationship with IC has continued so that when COVID-19 came they had a lot of confidence in the team's function. However, they were not specifically consulted about any of the hospital's lockdown measures; Victoria's view is that the trust had to respond to the emergency.

"in fairness they needed to make decisions hour by hour, I don't think we had a role in that."

The panel did not meet in March and April but then their offer of support (condolence letters to families, talking to staff) was taken up and by the end of lockdown they were back on track with meetings, planning for the building project. They have been proactive in asking for plans for tackling the routine treatment backlogs, with specific concern for cancer patients, and in October the Chair of the Executive Board asked to meet the panel to discuss how to encourage patients to come back for routine treatments, many being too scared of COVID-19 infection to attend. In partnership the panel and the trust agreed a communications strategy.

Meetings were online in lockdown and Victoria is aware this caused problems for visually impaired members of the panel. Members were not offered equipment or training to get online. From August onwards they held blended meetings, in person with social distancing and remote attendees too. This was helpful for a panel member with caring responsibilities who could stay at home.

Victoria acknowledges that the panel is not diverse and attracts about one new member a year. However, when the hospital moves to its new location it will be in the middle of housing development with the opportunities for enhanced recruitment that brings. Victoria sums up the patient panel's current relationship with the hospital:



"We're in a unique position with the hospital board and staff where now they almost bow to our superiority as a free resource – a change from previous position where we were on the periphery and rarely engaged."

## **Sam**

### **Some thoughts about missed opportunities**

Sam's experience is very different. Sam had been a very active member of a hospital group for many years. Following merging with another trust, the group was no longer required by the new trust and was disbanded during the summer, during lockdown.

Prior to being disbanded the one COVID-19 related activity Sam's group had been asked to comment on was a draft of 'letters to loved ones' which the group did, but as they did not see the final version they do not know if any of their feedback was taken onboard.

Sam feels that a lot of expertise and knowledge has been lost by disbanding the group and that the impact on members was felt so much harder due to the fact all communications were via email or on a couple of occasions by Microsoft Teams.

"It's not so much what has happened, as each organisation is free to do as they see fit, it's the way it was done and that due to the COVID-19 restrictions we didn't have the opportunity of asking questions or expressing our sadness face to face"

Having had a limited experienced of MS Teams, Sam acknowledges that for some people this method can work quite well as a means of communication. Although Sam fears that there will be a move to keeping most meetings online within organisations the concern is that this will disadvantage those with a poor internet connection, which is often an issue in rural areas.





Sam went on to say:

"It was a sharp lesson to learn that we weren't actually in charge of our group and in fact very much at the mercy of the staff making decisions about us, but without us and ones which affected us hugely and that definitely exacerbated anxieties among some of the members who were already struggling with the effects of the pandemic."

As more trusts merge Sam has a genuine concern that many hospital groups will slowly but surely disappear.

"This would be soul destroying for the many patients who have given up hours and hours of their time for their local hospital."

## Laura

### Some insights into meeting diverse needs

Laura works with adults living with mental health issues. She is also an expert by experience as a user of mental health services. She knows from experience this is a community that can find online meetings challenging. We interviewed Laura because she was recruited as the service user advisor to a large quality improvement project, focusing on the issue of violence and aggression in acute care settings, which is sponsored by a group of NHS mental health trusts. Her role is to ensure that service users' perspective inform the project and that they become meaningfully involved. Laura therefore has insight liaising both with patients and trust patient engagement staff. The project which began in September 2019 was paused during lockdown and the completion date has been extended by 3 months.

Pre-lockdown Laura would have co-facilitated the focus groups face to face to capture the views of service users on violence and aggression and their suggestions for improving safety on NHS inpatient wards. But in lockdown she could only include those who had access to online meeting platforms. There was a practical challenge in trying to get access to technology for some participants.



Aside from practical access issues Laura knows online environments excludes some participants who find the setting challenging because they can't interpret important verbal and non-verbal clues, they cannot judge how someone they don't know is responding and conversations become stilted.

"These online focus groups require different skills for everyone, thinking 'can I come in now?'. Harder to facilitate as well, spotting who wants to say something on that point. As a facilitator I can't make good eye contact which is so important for empathy, and I can't tell if someone might not be coping."

Laura gave a good example of alternative arrangement provided by one service user engagement lead at an NHS trust for participants to come into their offices to use the IT equipment at a safe social distance. However, she is concerned that in a rush into our new virtual world people who don't cope with online interaction will be excluded from engagement and treatment.

Laura is a lay member of a NICE guidelines committee and speaks from experience about participating in those meetings. She has experienced both good practice and some challenges. This national committee was convened to review a specific set of guidelines before lockdown, but its activity was paused for 6 months. Laura thinks this was inevitable as the professional members were called back to NHS front line duties and NICE prioritised producing Covid-19 guidelines. Now meetings have re-started and at an increased volume so that its work can still be completed.

Laura highlighted the good practice she had encountered, in particular the imaginative use of Zoom to create an excellent lay committee training day. Other good practice included; a note of participant access requirements was made; training was offered to committee members on use of online meeting platforms; the patient engagement team have been 'dropping in' to meetings to check that lay people are fully involved; each agenda has a section for lay person concerns (in the middle of



the meeting so all are present); the Chair was welcoming and inclusive.

The challenges Laura highlighted (in addition to those she noted when she was a facilitator) were how difficult it is to challenge, particularly in a meeting with different hierarchies (senior medical staff and lay people), sometimes with an inherent doctor/patient imbalance still present. This is a situation that arises in many different 'mixed' engagement meetings anyway but heightened in an online environment. Laura gave an example of challenging the use of language being proposed for the guidelines and reflected it would have been much easier face to face.

"Sometimes it is hard to even see the person you are talking to in an online meeting, to know how they are reacting."

Laura thinks it is too early to say whether NICE (and other committees she is involved in) will return to face-to-face meetings. Laura highlighted a concern, shared by Sam, of online meetings which is the lack of important informal networking in and around a formal meeting, and a desire to return to the past practice of face-to-face meetings:

"Masses of knowledge is passed on in this way, informally face to face. Or discussions about what works and doesn't work from spontaneous conversations sharing work. For lay people that getting to know you opportunity is not there, building links and understanding shared views, unless you work at finding ways online. It derails organisations, and people contributing, the time taken time to get technology sorted and put new processes in place. Organisations have been thrown off balance [by lockdown working] like people, although we are getting to grips with it now."

One challenge for all committees is the production of printed papers for ease of review by members –offices closed by lockdown mean members are expected to organising printing their own papers (often lengthy reports) which has a cost and is an access issue.



Laura belongs to a third committee, a regional forum of experts by experience in the health service. They are organising a Christmas social so that new members can be welcomed informally, and all members get to know each other better. This is in recognition that in knowing each other better helps working together.

## Malcolm

### The bigger picture

Malcolm is the chair of Laura's regional forum. Leading an independent body that provides insight and feedback to help shape health services, he is well placed to give an overview of how patient engagement is responding both to lockdown and also to the pace of change in the primary and secondary health service in the move towards Healthcare Partnerships.

"It is more important now to consult patients because of this scale of change. However, in all four areas [patient panels, CCG commission forums, STP service user groups and PPGs], we see patient engagement is not a priority."

In lockdown Malcolm experienced some good practice at a strategic level:

"The Academic Health Science Network involved us all the way through; the only delay was when they were diverted to other NHS duties. There was about a month with no public consultation, but we were warned before that."

However, he is concerned about a shift from good engagement because of virtual meetings. Pre COVID-19, patient groups attended face to face meetings to participate and co-produce changes to services or new services.

"When you had face-to-face meetings and they wanted to change something, we would sit round a table and thrash out what was good for patients and the public."

In response to lockdown alternative procedures are in place but are Malcolm experiences them as ineffective:



“With the virtual meetings where discussion is impossible: they field your questions in the chat box then come back to you in three-four weeks with an answer. It doesn’t work.”

Malcolm can envisage engagement working well on a virtual platform:

“but more time should be allowed, or dedicated meetings should be in place to allow patient reps to have a voice.”

He is experiencing CCGs reverting to a model of one-way communication to the public. Malcolm, and his colleagues in the forum, have a real concern that effective patient and public engagement will become a casualty of COVID-19.

Malcolm has a solution to offer membership organisations (such as healthcare partnerships and hospital trusts) who find that large scale surveys are getting low percentage responses. He suggests dedicated virtual sessions around a particular topic, inviting service user reps to have that discussion. Although this might mean additional meetings the quality of the output would benefit.

Like Victoria and Sam, Malcolm is concerned with the lack of diversity in voices being heard during lockdown and how that impacts on service priorities. He acknowledges that with seldom heard groups, those traditional excluded like asylum seekers, it takes time (and therefore funding) to engage them without alienating them and causing them more stress..

## **Felicity**

### **Patient participation - a long list of don'ts**

Our final interviewee is Felicity and we wanted to talk to her about her experience in patient participation. She is also someone with a good overview as a trustee of her local HealthWatch. She is both Chair of her GP surgery’s PPG and Councillor for her local Parish Council. She lives in the large village which both institutions serve and therefore not only has



a formal route to monitor her GP's performance but many soft indicators from friends and neighbours' anecdotes. Luckily her local MP is a patient at the surgery so when the relationship between the practice and the community deteriorated this spring, the community had a valuable ally with first-hand experience.

Felicity gave us some background to her PPG and then told us what went wrong.

"The PPG has been going for seven years (I have been Chair for four). It doesn't report to the CCG – which covers the county - only to the practice but is part of a network of PPGs in the area who meet to share experiences.

Originally the PPG was chaired by the practice manager but now it's been taken over by patients. Before lockdown we met in alternate practices every three months with the Practice manager. Our remit is to be a conduit for information flow from patients to practice and practice to patients. The surgery has two sites in adjacent villages. Historically the practice funded the meetings of the PPG in terms of paying for a hall for the meetings. We had lots of speakers come to give health related talks. They raise money through cake sales and bits of fundraising to give speakers a small thank you gift. We would like to use the money to make improvements to the patients' waiting area.

The previous manager wouldn't deal with any complaint without names, dates and specifics and as patients understandably didn't want to be so upfront she never answered any complaints. However, the relationship was reasonable – she would come to every PPG meeting, give a report of what was happening in the practice. The CQC was very damning about the reception area and communication. The practice came one from bottom in an NHS survey of practices in the whole county.

At the start of the pandemic the NHS sent a letter to all GPs saying they didn't have to meet with PPGs. They meant 'don't have a physical meeting', but our practice took this as they didn't have to meet at all, the PPG so had no communication with the practice from the start of lockdown. Then the village surgery became a COVID-19 testing centre, so all patients had to go to the next village instead, a journey with two buses which isn't easy. I found out on 26th March when I got a message from a local who found



signs on the practice door saying it was closed. I got a text on 27th March saying it was closed –and I’m the PPG Chair! But no one else got anything, not a letter. If they had told us we’d have circulated the information through our networks – letting patients know where they were meant to go.”

The PPG decided to meet anyway without the practice. Some things needed to be fed back.

“During the pandemic we decided to meet every month – people were very concerned, and we needed to support people, so we met through Zoom. It was good to support the patients even though the practice didn’t attend. We are members of NAPP, the National Association of Patient Participants (which the practice does pay for) and we get good information from them.

In September practices were told they had to resume relationships with the PPGs. Our practice said as they use to only meet us every three months that is all they would commit to, and they will only meet us for one hour. I’m allowed to email them once a fortnight – but I get nothing back. The new manager is reluctant to tell us anything. For example, a GP left and the patients didn’t know until after. Although a letter was supposedly sent, nobody got it.

With the local surgery villagers can walk in to make appointments and then take prescriptions to the chemist next door. With the only option being in the next village we now have to phone to make an appointment and sometimes wait 20 minutes to be answered, if you do have access you can make a booking online but otherwise your only option is the phone which is hopeless for deaf patients. We discovered they have a speech to text service but wouldn’t publicise it until we leant on them to do so.

After we got our local MP involved HealthWatch, the Parish Council and the CCG met with someone from the practice. The village surgery opened on 12th October, but we are concerned it will become a vaccine centre and close again.

I offer help to the practice (for example on flu vaccination days) but they never reply. I ask them if we can communicate with patients but get nothing.



What upsets us is we want to help support the practice and help develop good practice and support patients and patients. We initiated a questionnaire, paper and online, which highlighted problems – hard to get appointments, long telephone response time, shut at lunch times etc. We sent the results to the GPs and heard nothing back. We keep trying to feed-back but they don't listen or change anything. All we want to do is work with them to develop a good patient experience.”

We know that many PPGs have kept meeting during lockdown and continued meeting medical staff but to put Felicity's experience into some context, in our quantitative survey (Locked In or Locked Out?) we asked that if involvement activity had stopped in lockdown were people able to share any reasons as to why that happened? For some this was personal choice but amongst those others who gave a reason several had been involved in PPGs; all said that their surgery had stopped having meetings of any sort and they were either given no explanation or told that the staff were too busy.

## Some conclusions

### Good relationships matter

The COVID-19 pandemic meant that health services were delivered very differently in 2020. Anecdotally there have been positive and negative consequences on patient health and well-being. Patient participation forums are a valuable resource for primary and secondary health care staff to work out what isn't working and what works well. However, this resource is not always tapped into. It seems that where there was established good practice (characterised by mutual trust and respect between staff and patient representatives) then this continued during lockdown, even though how engagement happened had to change. Where relationships were not good at the start of the year then, not surprisingly, patient engagement continued to be poor to the frustration of the patient representatives and possibly to the detriment of delivery.





## **A blended approach**

There has been some specific learning about engagement online in 2020. When activities are designed for an online environment they can work well. It is essential to offer training in the platform being used to create equality for participations and reduce uncertainty; everyone can focus on the meeting content. It is important for engagement leads to recognise that issues for patients and service users attending can be amplified in an online setting and the opportunities to implement a range of support measures reduced.

## **Maintain Involvement**

There is a concern that COVID-19 has been an excuse to terminate patient engagement altogether, implement planned changes badly or revert to simple consultations as a substitute. Although there are benefits to individual participants in meeting virtually there is a general acknowledgement that these do not outweigh the losses from not meeting face-to-face. The losses include informal information exchange and networking.

## **Efficient and Effective**

NHS England has stated publicly that patient engagement is a crucial part of how it does and will operate. There is published evidence that patient engagement is of benefit to the effective and efficient delivery of health services, and following the Francis Inquiry Report, 2013, an acknowledgement that patient feedback is vital for patient safety.

## **Future role of the user-led sector**

The user-led sector is well placed to understand the patient perspective and the challenges faced by individuals who take part in patient groups. We recognise the importance of involving patient groups as primary and secondary care is undergoing change. The user-led sector can support clinicians and other senior leads reflect on what works well and what could be improved. We can also be a resource for engagement teams in hospital trusts and primary care, supporting the



development of best practice, particularly as new models of care are rolled out across England.



# Shaping Our Lives

**[www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)**

**Email: [information@shapingourlives.org.uk](mailto:information@shapingourlives.org.uk)**

**Telephone: 0845 241 0383**

**Facebook: [@shapingourlives](https://www.facebook.com/shapingourlives)**

**Twitter: [@Solnetwork1](https://twitter.com/Solnetwork1)**

**YouTube: [shapingourlives1](https://www.youtube.com/shapingourlives1)**

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Shaping Our Lives National User Network Limited

Company No. 04382606 (Company registered in England and Wales)

Company registered address: Figurefox, The old Estate Office, Farley Lane, Farley Wollop, Basingstoke RG25 2HR