

National Voices' Long Covid project

Preface & Case studies

In the summer of 2021, National Voices commenced an NHS England & Improvement funded Long Covid project, that brings together **six small inequality focused partner organisations** to explore how Long Covid services can better support people at risk of exclusion, tackle the inverse care law, and build on the strength of communities. We received a small grant to carry out this work and thought it appropriate to properly remunerate the important contributions of the VCSE organisations involved in this project. To reflect this, **we gave away more than half of the grant to these groups, with each receiving £10k (bar Self Help UK, who received slightly more for their peer support consultancy contribution)**. These groups have been resourceful and have used this small amount of money to build relationships, develop key insight and pioneer community-focused solutions to the Long Covid issue.

Over the course of this project, our partners have met three times in roundtable meetings to share insight, expand networks and forge forward with an intersectional way of working. At meeting number two, we were able to recognise mutual barriers to health and care, and established **awareness, connection, access and quality** as four key priority themes within this work. There is now shared action underway from these groups in gathering insight whilst co-producing solutions to understand the impact of this work and the crucial role of the VCSE within the Long Covid agenda.

The groups have managed to reach **over 150+ people** living with Long Covid and have conducted **over 25+ focused interviews** with members of their communities. We saw that:

- Only 27% of respondents said they had received medical support following their Covid infection.
- 72% had had no medical support at all.
- A smaller number of respondents (18%) said they had had a CT scan of their lungs following infection.
- 40% were being cared for by a family member and in 60% of cases, this care was being given by a spouse or partner.
- In 60% cases, the respondent believed that giving them care had impacted on the lives of their carers.
- The vast majority (75%) of respondents had received the Covid-19 vaccine with a mix of the Pfizer and AstraZeneca vaccines being evenly spread.

- The most reported Long Covid symptoms were fatigue, headaches and abnormal breathing.
- Most (60%) respondents had no long-term health issues before contracting Covid-19.

Considering the time and budget constraints within this project, National Voices are proud to have gathered this insight and modelled an **inclusive and intersectional approach**. We have also extended to NHSEI the opportunity to lead on the **multi-agency support network**, with our Long Covid project clearly highlighting that the VCSE – and wider community more generally – is central to people’s recovery. **Formal services need to work in partnership with these communities and their groups. We stand ready to bring the power of this partnership to the challenge of getting ICSs to adopt this multi-agency approach.**

The following case studies are a glimpse at some of the experiences of Long Covid from those who are supported by our project partner organisations, and speak to the vital role of the VCSE in providing a voice and bridging the gap. With more time and more money, there will be much further opportunity and scope to gain depth of insight within communities who remain seldom heard in the conversation of Long Covid.

Case studies

ET, 18-29, West African, woman, Living in the South East

“I had COVID-19 in January 2021 but spoke to a doctor during an appointment for a separate issue in November, when asking for an inhaler because my breathing was becoming severely affected every time I came down with a cough or sore throat. He suggested that I might have Long Covid, but it honestly hadn’t occurred to me before that. I just thought that working from home during Covid had had an impact on my fitness and so my asthma was playing up. I am Constantly tired, and I have been ill with flu like symptoms since having Covid 4 times. What starts off as a cough or a sore throat leads to me being unable to breath properly, aching body, lethargic, feverish and loss of appetite. Above all, it is draining physically, mentally, and emotionally. **There needs to be more information about this condition so that people know what to look out for. I don’t know why there isn’t a follow up interview with all Covid sufferers so that any persisting symptoms can be identified. I appreciate opportunities like this to share my experiences with others.**”

DA, 28 Caribbean man, from London

"When I got Covid, I wasn't particularly worried. Lots of my friends have had it and most of them were only very slightly affected. I caught Covid last autumn and was badly hit with it. I didn't need hospital though and assumed I just needed a few days of duvet time. After about a week, my systems had improved enough for me to resume my life to some extent, but I have had cold like symptoms, a headache and general feeling of tiredness since. I didn't even think of Long Covid, and just thought I was a bit depressed. I read some stuff about Long Covid, and this prompted me to ask my GP. He said I may well have Long Covid but didn't really offer much help other than that. I would have hoped he would have directed me to a support group or some way of me getting help with what was going on. He gave me the impression that I just needed to 'man up' and get on with it. Feeling like this makes me feel like I'm only half myself. **Some of the information out there that has been circulated by groups like ROTA has helped me to understand what I'm going through. It's also good to speak with other people who genuinely understand. Friends can sometimes think I'm milking it or being lazy.**"

MF, 44 Northern Ireland, Caribbean

"I first got Covid last spring. I treated myself at home and didn't think much of it. Since then, I have experienced headaches, pain, heart palpitations, difficulty breathing, tinnitus and fatigue. My children have been helping look after me, but it is taking a toll on them. They have to dedicate time to doing chores I would have undertaken, and it has impacted on our ability to share family experiences together due to the pain and fatigue that I routinely experience. I feel like I'm being a burden to them. I was diagnosed by the doctor at work 6 weeks after my initial infection. Other than that, I've had no medical support. I've been buying drugs from the pharmacy but have had nothing on prescription. **I feel like I've been left to just get on with it.**"

English Gypsy Traveller woman, 64 years old

Alisha had a lot of underlying health issues when she went down with Covid. Alisha went down with Covid 19 during early lockdown, it was immensely stressful, and she was very ill. An ambulance had to be called to her home as her breathing was almost non-existent, this happened suddenly after she was out of isolation from others, she was very frightened of dying, one of the things on her mind was that she had lost close friends with the same thing *"They wanted to put me to sleep but I was frightened of dying so I said no"*. **She reports that the hospital was kind but that there was no follow up appointment except for a chest Xray, she can't remember if she was given any information for support or if anyone spoke to her about after care, she**

reported that she had lost eight days, which were all a blur. Alisha doesn't feel that she has fully recovered.

"Since having covid... I say all the time, I came out half a woman. I've had some bad times, but nothing like this, my breathing is a lot worse, I suffer with depression more, but we have had a lot on in our family, so I can't blame just Covid for that. I get very, very tired. My hair comes out in handfuls, and I lost my taste for months. I struggle with my strength and my mind can't seem to keep anything in it. My sleep is all over the place. I'm up at stupid hours in the night."

It has been 11 months now, and Alisha did not realise that vision can be affected, and she reported to the interviewer that her eyesight had worsened. Worryingly Alisha feels that she cannot go back to the Dr with her concern, she told the interviewer how hard it is to get an appointment and did not have the energy to pursue it. We asked about support, and she stated that she did not want to sit *moaning and groaning* to health services but did feel that there should be more information about Long Covid. She talks to her family and other members of her community but doesn't like the idea of a support group. **Alisha says that information made by and tailored to members of her community can help her to feel less alone.**

AJ, 53-year-old, British Bengali Asian

AJ first contracted Covid on 5th January 2021. Her partner was the first to contract covid and followed by AJ then catching it. She conducted a lateral flow test which was negative. Her PCR results were inconclusive. On day 6 she then received a positive PCR result. Three weeks after contracting Covid, AJ returned to work but didn't feel right at all. She still suffered from extreme exhaustion and body aches and ibuprofen had no effect or relief. She also suffered extreme brain fog for a long while and was unable to fulfil the simplest of tasks, which led to her feeling low in self-esteem and confidence. This was discussed with her line manager, who thought she was suffering Long Covid symptoms and referred her to occupational health. Via a telephone consultation with the Occupational Therapist she was then advised to see her GP. AJ had several GP telephone consultations during April – November 2021. She felt annoyed that she could not see a medical professional in person as they refused a face-to-face consultation. She felt fobbed off and disregarded. In October 2021 she was prescribed HRT medication after a number of on-going tests but has no follow-up support for her Long Covid. **AJ feels there should be more support and advice both in the workplace and in the health community that's specifically Long Covid focused.**

"The right messages of how Long Covid affects the BAME community have not been made publicly available. I feel this type of information would be beneficial to communicate to my community. There should be more information available about the risks of Long Covid and how this affects different age groups. Projects like these are ideal to create support based on personal and individual cases."

YS, 18-29, Indian Asian

First contracted Covid in June 2021. YS was double vaccinated yet still caught Covid. She was the first family member to bring it into the household. Her husband tested positive shortly afterwards. Her other three children were lucky not to catch it. Her lateral flow was positive, and her PCR test results showed two different outcomes. For the first two weeks both YS and her husband were bed ridden, she felt so nauseous and lethargic. One month after contracting Covid she still couldn't taste or smell anything. Her husband seemed to recover a lot quicker than herself. As YS is diabetic and has high cholesterol levels, she feels this may have contributed towards her slow recovery. YS feels she's still not 100% - she still has brain fog and experiences breathing difficulty. However, she's learnt to control this by learning various breathing techniques and exercises through Long Covid support group chats and meetings. Meditation and yoga have also been a form of exercise that YS has turned to and does with other members of the community. Covid has impacted every aspect of her life from an emotional well-being, social and a professional and educational perspective. YS has many, what she calls "blank canvas moments" where she cannot remember what she has done or what she's doing next - this has massively impacted her work and university life. This has resulted in YS suffering a lot of anxiety and having several panic attacks which triggers her migraines. When she's in a heightened state it can result in vomiting, depression and being bed ridden for several days. She has sought medical advice about this which has resulted in receiving talking therapy and attending a crisis help centre. No specialist Long Covid support has been offered. **YS is passionate about sharing her experiences of Long Covid with others in her community, especially brown women, to empower them and show visibility.** She believes we need to ensure the right support is in place for people suffering both pre- and post-Covid. Educating the older South Asian generation (e.g. YS's parents) is vital, so that they are aware of the symptoms and the support available.

"There are only positives in speaking to and working with organisations like SAHA. These organisations are a vital link to both patients and carers. They help to deliver better services within the community and help create strategic approaches to health services. Community organisations help get the important messages across to service users. Was good to meet Kirit Mistry - SAHA Chair through my volunteering in health research at NIHR

where we connected and shared contact details which he followed up and shared the Long Covid Survey."