National Voices' Long Covid Project

Learning and Reflection Report



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Chief Executive Foreword

National Voices has almost 200 members, working with diverse communities living with a wide range of conditions. We don't tend to work on a specific diagnosis – our members are best placed to do this. However, we found ourselves in discussions about the emerging need to set up Long Covid services, as part of our wider work on pandemic recovery, and the urgent needs of people who were most heavily impacted by Covid.

We could bring two assets to this work: First, by providing examples of progressive practice from our members for the people they advocate for. These members support people with long term conditions, and acknowledge the emotional, social and practical impacts of ill health and disability.

Secondly, we were in the process of building and deepening our relationships with organisations who tackle not just ill health, but stigma, discrimination and marginalisation. And the emerging picture around Long Covid was that its burden on communities, and the structural barriers to equal access and outcomes were exacerbating existing inequalities.

So, we embarked on a journey of exploration. What could happen if we combined the deep and authentic insight from organisations who support people 'at the margins' with our connections to decision makers at the centre, and our networks of partners and members?

We are so grateful for the contributions and commitment of our project partners. Your listening, advocacy and practice is what we truly need to tackle the inverse care law. Thank you to PPL for pulling together our learning, and to Aleyah Babb-Benjamin for holding with grace and resilience the inevitable tensions that arise from work that surfaces issues of power and injustice. And thank you for the many people with Long Covid and their organisations who spoke with us, for teaching us about the devastation this virus continues to cause, but also about hope and solidarity. You should be so proud of how far this movement has travelled in such a short time.

Charlotte Augst.

Chief Executive, National Voices



National Voices' Long Covid Project summary

Long Covid is a relatively new condition, and it refers to the persistence of symptoms attributed to COVID-19 more than twelve weeks after initial infection. These symptoms typically include extreme fatigue, breathlessness, and muscle weakness, amongst many other things.

One of the current gaps in information is understanding the lived experience of people from communities at risk of exclusion living with Long Covid. This includes understanding and awareness of the condition itself, and experiences of accessing care.

To address this information gap, the National Voices' Long Covid project brought together six organisations who serve different community groups. These organisations are inequalities-focused voluntary and charity sector partner organisations (VCSEs) who aim to develop community-focused support to support existing clinical Long Covid pathways.

The project had three aims:

- 1) To harness the crucial role of VCSEs in providing Long Covid support;
- 2) To co-produce solutions with those affected by Long Covid;
- 3) To create an open-circuit peer support group with the six key organisations.

Over the past twelve months, the six partner organisations have carried out individual pieces of work with different communities at risk of exclusion to:

- find out the current awareness and experiences of people living with Long Covid,
- · increase awareness of Long Covid; and

 create personalised support materials for signposting self-management of Long Covid symptoms. 	and

Purpose and approach of this report

This report serves as a post-project learning and reflection of the National Voices Long Covid project. This report has four purposes, to:

- 1) Summarise the positive learnings and challenges the organisations faced throughout the year;
- 2) Provide recommendations for multiple stakeholders on how to build on the learnings and challenges for future work;
- 3) Summarise the activities undertaken by partner organisations through this project, including what they chose to do and their process; and
- 4) Explore the role of network and partnership working in partner organisations' work during this project.

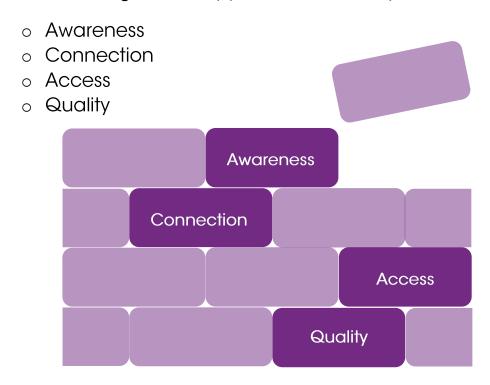
The findings and recommendations in this report used the following **methods** to gather information in March and April 2022:

- One-to-one conversations with project leads from partner organisations;
- Desk review of insight reports and project updates from partner organisations and National Voices;
- Conversations with external partners of National Voices working in the Long Covid space, including Self Help UK, Long Covid Support, and Long Covid SOS.

This report has been created in partnership between National Voices and PPL, a social enterprise and B-Corp that exists to promote better health, wellbeing and economic outcomes across the UK working with individuals, communities and the organisations that support them.

What we heard

Throughout this project, four themes emerged around which the foundations of Long Covid support should ideally be built:



Participants and our project partners recognised that without each of these elements, we will continue to leave behind those most in need of support and repeat prevailing and pre-existing failings within health and care. With this in mind, supporting those living with Long Covid is an opportunity to get things right. Through our work, we heard that:

The knowledge and expertise already exist in the community: Our work shows us that the people on the ground are best placed to understand what is needed for themselves and their communities. Even then, their understanding may need to adapt to new and changing circumstances. Time and space should be given to allow this expertise to evolve.

Traditional peer support frameworks don't always work: For some individuals e.g. for some Gypsy and Traveller people, we heard that peer support models don't always work, as there can be a cultural hesitancy around sharing information about personal health in a group setting. Alternatives to traditional support models e.g. targeted 1:1 support or peer support working within families should be explored.

Trust must be earned and sustained: We cannot assume trust, but should earn and maintain trust through networks of connection and support which are properly resourced. Systems should be challenged to consider trust as a measurable outcome of any community engagement project and think critically about how individual projects fit into the wider picture.

We must serve the unheard Long Covid voices: Groups such as children and young people are thought to have been thoroughly underserved by governments and systems in the Long Covid crisis. Other groups, including those living with myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS), have recognised stark similarities in symptoms and experiences relating to Long Covid, with much more work needing to be done to join up care across particular groups and conditions for a more holistic approach to managing Long Covid.

"We need help finding help": We must start where people are, not where we expect them to be. We need to work with communities to understand how they like to communicate, find and process information rather than assuming we know what works for them. Systems can often opt for the easy way out by using written English in traditional communications, when in fact most people don't take in information in that way. Experimenting with alternatives to traditional communication routes will begin to help those who need help finding help, to find it.

Our Recommendations

Three key recommendations have emerged:

1. Inclusive and accessible communication

Ensure patient choice, personalisation and considerations around equality and accessibility are at the heart of all communication.

One of the findings of the partner organisations was that often information about Long Covid did not meet the communications needs of people with a disability, impairment or sensory loss, people who have low or no literacy, people who do not speak English fluently and more. Thus, it is recommended that:

- i. Health and care organisations follow the <u>Accessible Information Standard</u> which sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.
- ii. VCSE organisations, health and care commissioners and providers consider and respond to the needs of people who have low or no literacy and people who do not speak English fluently when delivering communications around Long Covid. This may need to involve staff training provided by VCSE organisations and those with lived experience.
- iii. Written and verbal methods of communication should account for disabilities, both physical (deafness, blindness, etc.) and hidden (mental, psychosocial, learning disability etc.)

2. Stronger as a collective

Increase the use of network working as a method for conducting community-based research and improve community engagement with public health interventions.

Project partners agreed that the creation of a network of VCSE organisations to co-produce best practice methods for engaging communities at risk of exclusion with Long Covid has been one of the most productive and rewarding facets of the project. Thus, it is recommended that:

- iv. The partner organisations and the wider voluntary sector continue to use their networks to share best practice, challenges, and resources towards a common goal.
- v. National Voices continue to explore network working as a co-production tool, either in the context of different illnesses or research areas, or in the context of stakeholders in a different sector.

3. Next steps for Long Covid

Provide further funding and resources towards researching the effect, impact, and management of Long Covid.

Partner organisations have primarily used this project to investigate the extent of awareness around the condition of Long Covid within communities at risk of exclusion, as well as to test engagement and support methods with them. This has been a small-scale piece of work, and given that Long Covid is relatively new , it has been challenging to engage with communities. To build on this crucial piece of work, it is recommended that:

- vi. Further research, both community-based and clinical, is commissioned and conducted to best support people living with Long Covid across the UK, especially people from communities at risk of exclusion.
- vii. A more thorough inequalities agenda is taken when addressing the condition and necessary support measures, looking especially at communities at the sharp end of the inverse care law, as well as children and young people.

What went well

During conversations with partner organisations we gathered positive feedback about National Voices' Long Covid project, as well as their individual work within the project. The following areas were mentioned by partner organisations as elements of the project which worked well, and which had a positive influence on their experience, and those of the communities they are involved in:



Being able to reach those in the community in most need of support.

Through this project, the VCSE partners have been able to reach over 150 people living with Long Covid and have conducted over 25 focused interviews with members of their communities. The VCSE partners have been able to reach individuals and groups from communities at risk of exclusion due to their ability to build trust and communicate effectively with them. One individual stated that:

"...the information out there that has been circulated by [VCSE] groups has helped me to understand what I'm going through. It's also good to speak with other people who genuinely understand."



Those who engaged with the work had a really positive response to the project.

The individuals and groups that partners have engaged with appreciated the opportunity to learn more about Long Covid, the symptoms, and how to manage them. They valued being able to speak openly about their experience in living with Long Covid, and

meeting others who have experienced living with Long Covid. One individual noted in their interview with a partner organisation:

"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."



Communication works best through the use of 'plain English' language.

Individuals and communities supported by the partner organisations found that co-produced information and resources about Long Covid are particularly helpful when technical and medical jargon are removed, and instead replaced by plain, universal and easy to understand language and imagery.



Developing a network of organisations supporting communities at risk of exclusion in the Long Covid space.

Partners appreciated the opportunity to work with other organisations and learn about different communities. This project provided opportunities for organisations to explore similarities with other organisations in terms of engagement approaches, challenges, and findings from individual activities. For example, the <u>questionnaire</u> developed by National Voices' project partner – Asthma + Lung UK – was used and adapted by another organisation to broaden outreach and capture insight.



Having dedicated touch points for peer support within the network.

Partners agreed that having regular touch points with the other organisations, particularly the network meetings led by Self Help UK, have been helpful in their individual journeys throughout the project, and a good opportunity to understand how other organisations are taking this work forward.



The project was well managed by National Voices.

Partners mentioned that it was encouraging to see National Voices prioritise and provide funding for Long Covid research in a timely manner. Some partners also mentioned that the project's reporting structure was simple and easy to follow. The project's management was accommodative and appropriate to the sensitivity of the work.



Learnings for future programmes

During our conversations with partner organisations, we gathered feedback about some of the challenges associated with this project, which should be considered as learnings for future programmes.



Similar projects can be even more impactful with more time and resources.

Some partner organisations felt that a longer timeline would have allowed them to have a larger impact within their respective communities. More funding would have meant more research and understanding around the new and emerging condition of Long Covid. Funding is always a challenge, however the more resource that is available, the more impactful this type of work with communities at risk of exclusion can be.



The 'newness' of Long Covid means future work in this area should draw on the growing body of research to best provide holistic support.

Most partners agreed that addressing Long Covid as a condition was challenging because it is relatively new. It took more time than anticipated to get widespread engagement from communities, with many continuing to debate whether Long Covid is indeed real or not. Some partner organisations highlighted that the lack of known cure for Long Covid means that signposting and self-management tips brought about a question of ethics, as they could only provide support for symptom management. Another challenge is that existing literature and research on Long Covid does not prioritise the emotional and mental health impact of the condition, even though partners found through community

engagement that these are some of the main symptoms that individuals can experience. As the body of research on Long Covid continues to grow, future projects on the condition would benefit from taking new findings into account in order to provide up-to-date, holistic guidance and research to individuals and communities who need it most.



Communication methods have a huge impact on the success of engagement.

A few partners mentioned having had difficulty in engaging with communities at risk of exclusion due to a lack of awareness of Long Covid, limited access to information, and medical scepticism. Most partners were wary of the fact that their individual reach within their communities has been quite limited and felt that the work had inadvertently excluded certain groups with limited digital literacy, non-English speakers, and people with disabilities. For future similar projects, more work can be done to further identify specific methods of communication which are evidenced to be most effective in engaging particular groups.



There is a trade-off between flexibility of a project's brief, and specificity and clarity.

With the changing landscape of Long Covid as information and resources evolve, there were moments in the work where aims and goals needed further clarity and distinction. This is somewhat expected with this type of work, and in fact allowed for some flexibility in how organisations could meet the objectives of the project. It will be important that future projects keep in mind the careful balance between specificity and flexibility.

Activities of partner organisations for the Long Covid project

We have summarised below some of the work that partner organisations undertook as part of this Long Covid project.

Activities of project partners



Asthma + Lung UK

Who are they?

Asthma + Lung UK's mission is to help create a world where good lung health and the ability to breathe freely are a basic right enjoyed by all. They conduct research, campaigning, and provide advice and support as the UK's leading lung charity.

Their work in this project

As part of this project, National Voices submitted a joint proposal with Asthma + Lung UK for a joined-up VCSE approach to Long Covid. Asthma + Lung developed an online post-Covid Hub for people living with Long Covid. The hub provides sign-posted information and opportunities for further support. Asthma + Lung UK also created a Long Covid Needs self-assessment tool, which produces a self-assessment summary report that can be taken to the GP to discuss Long Covid symptoms and treatment options.



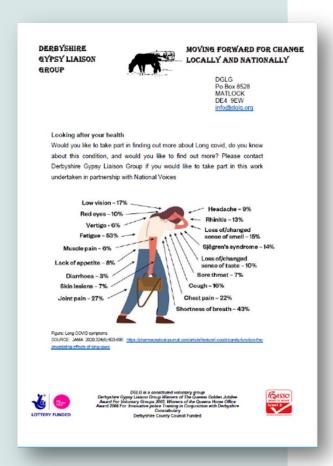
Derbyshire Gypsy Liaison Group

Who are they?

Derbyshire Gypsy Liaison Group (DGLG) provides valuable assistance and information to the Gypsy community in Derbyshire. One of DGLG's primary activities include providing health care guidance.

Their work in this project

conducted DGIG twelve one-to-one in-depth interviews and wider community engagement to gather the experiences of those from Gypsy and Traveller a background living with Long Covid. As a project output for the work, DGLG co-produced information film with an Romany Gypsies and Irish Travellers who have been badly affected by the COVID 19 pandemic. In the short film, Romany **Journalist** Jake Bowers meets three Gypsy and Traveller men for whom the pandemic is far from over.





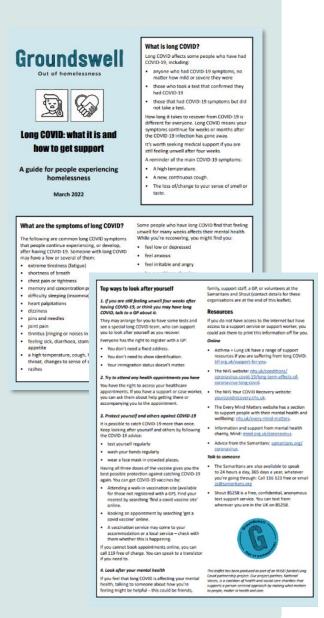
Groundswell

Who are they?

Groundswell works with people with experience of homelessness and create solutions to homelessness. Their mission is to enable people who have experience of homelessness to create solutions and move themselves out of homelessness.

Their work in this project

Groundswell engaged with their peer network and conducted a sector-wide survey to understand the awareness, prevalence, and needs of people experiencing homelessness with regards Covid. to Long Following this research. Groundswell developed an information leaflet which provides an overview of Covid symptoms, Long management tips, and signposts to other resources and sources of support for people experiencing homelessness. This Long Covid distributed has been guide through social media channels, newsletters. the handout printed copies, and shared with Groundswell's network Homeless Health Partners.





People First

Who are they?

People First is a national self-advocacy organisation run by and for people with learning difficulties. The organisation aims to speak up and campaign for the rights of people with learning difficulties. They work across the country, giving support, information, advice and training to people with learning difficulties and user-led self-advocacy groups.

Their work in this project

People First have created easy read, accessible <u>support</u> resources for people with learning disabilities living with Long Covid. This included a self-diagnosis questionnaire and other educational materials. People First have also launched a learning disability COVID-19 support and action group within their organisation. One of this group's activities include hosting peer-led support groups and workshops to increase understanding of Long Covid symptoms and self-management techniques for people with learning disabilities.

People First have been vocal about the barriers that exist within VCSE partnership working for the people who they support, and have been instrumental in shaping National Voices' approach to such themes as meeting accessibility, inclusive partnerships and how to meet people where they are.



Race On the Agenda (ROTA)

Who are they?

Race On the Agenda (ROTA) is a social policy and research organisation that focuses on issues impacting Black, Asian and Minority Ethnic (BAME) communities. ROTA's work is based on the principle that those with direct experience of inequality should be central to solutions to address it, and their work is actively informed by the lived experiences of BAME communities.

Their work in this project

ROTA engaged with experts in the field of health inequalities to do an initial assessment of awareness and understanding around Long Covid within black African and Caribbean communities in London. They also conducted a co-designed survey to gather the experiences of those from a black African or black Caribbean background living with Long Covid, which unveiled stark disparities in access and experience. ROTA have worked closely with Caribbean African Health Network (CAHN), also a National Voices member, to raise awareness of Long Covid and symptom management within their black African Caribbean communities in London Manchester, particularly through working with publications such as The Voice.

TOUCATE - EMPONER

South Asian Health Action

Who are they?

South Asian Health Action (SAHA) seek to engage with, educate and empower the South Asian community on health challenges facing the community. SAHA's mission is to empower the South Asian communities to make better health choices that could lead to better lifestyles.

Their work in this project

SAHA have conducted community engagement to raise awareness of Long Covid and its associated symptoms within South Asian communities in Leicester and London. They created and distributed <u>printed leaflets</u>, <u>social media posts</u>, articles in local and regional newsletters, and a radio advertisement on EAVA FM. SAHA have also conducted survey research and six one-to-one in-depth interviews to gather the experiences of those from a South Asian background living with Long Covid.







Self Help UK

Who are they?

Self Help UK is the leading specialist organisation in promoting, supporting and encouraging Self Help Groups, both locally in Nottinghamshire and nationwide. Self Help groups enable people to take better control of their circumstances or conditions, gain strength and support from others, and improve their self-care.

Their work in this project

Self Help UK worked with us in two capacities; they have created and continue to host a Long Covid Deaf Cancer peer support group. This Covid-19 survivors group provides an online platform and opportunity to empower through shared experiences, with regular meetings to stay connected within the changing landscape of Long Covid.

Self Help UK also worked with us in a consultancy capacity, holding three peer support workshops with the project's six partner organisations to provide guidance around how to develop and deliver peer support sessions to their own members. The workshops covered the following topics: Understanding different Peer Support Groups; Reflection on the impact of Covid and Long Covid; and future planning for the network. The discussions revealed huge similarities in the communities involved in the project, and generated key learnings around the importance of empowering voices by sharing similarities in experience. Our project partners will have access to an inclusive resource centre hub once live, and access to online drop-in consultation sessions around enabling and progressing peer support within their communities.

Our Long Covid Members

The organisations below are three other charities not explicitly part of the National Voices Long Covid Project, but who belong to our growing membership and have supported our work as those at the forefront of change within the Long Covid space.



Long Covid SOS

Long Covid SOS began as a social media campaign raising awareness of Long Covid. Since then, Long Covid SOS have partnered with the WHO, and others in awareness raising. They continue to conduct research on Long Covid, including its impact on both BAME and underserved communities



Long Covid Support

Long Covid Support began as a Facebook group for people living with Long Covid to share their experiences and support each other. This group currently has over 50,000 members globally. Long Covid Support are now working on Long Covid advocacy with partners such as Taskwatch and the WHO. They were critical partners in the development of the Long Covid NICE Guidelines.



Long Covid Kids

Long Covid Kids provide grassroots support, connection and advocacy for families, children and young people living with Long Covid and believes all children should be able to thrive and look forward to a positive future.

Special Thank Yous

Project Partners

Asthma + Lung UK

Derbyshire Gypsy Liaison Group

Groundswell

People First

Race On The Agenda

Self Help UK

South Asian Health Action

Long Covid member charities

Long Covid Support

Long Covid SOS

Long Covid Kids

COVID-19 focused member charity

Covid:aid



National Voices

National Voices is the leading coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have almost 200 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.

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