

**HI-COVE**  
HEARING THE UNHEARD  
VOICES OF LONG COVID

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## Hearing from the unheard: Impact of Long Covid in black and minority ethnic groups in the UK (HI-COVE)

### Stakeholder Engagement Event

Date: 18<sup>th</sup> January 2023

Location: online

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#### Aims

- Share initial findings of the HI-COVE study
- Discuss findings with a range of stakeholders
- Discuss ideas sharing the results

#### Attendees

- 66 participants
  - 9 study team members
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#### Study Details

**Project Website:** <https://blog.westminster.ac.uk/hicovestudy/>

**Project Team:** <https://blog.westminster.ac.uk/hicovestudy/test-page/>

**Principal Investigators:** Dr Nina Smyth; Prof. Damien Ridge

**Co-applicants:** Prof. Nisreen Alwan; Dr Rebecca Band; Prof. Carolyn Chew-Graham; Dr Dipesh Gopal; Dr Tom Kingstone; and Alexa Wright

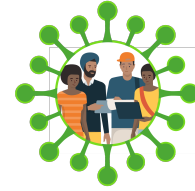
**Project funders:** National Institute for Health Research (NIHR 203106) and hosted by Midlands Partnership NHS Foundation Trust

**Ethics approval:** University of Westminster (ETH2122-1074)

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#### Structure of Engagement Event

- Introductions
- Overview of HI-COVE qualitative study findings
- Discussion / reflections from participant attendees
- Talks from three guest speakers
- Discussion / reflections from participant attendees

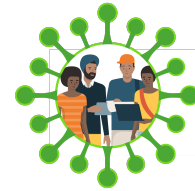


**Details of Engagement Event:**

Prof. Carolyn Chew-Graham introduced the event and welcomed participants. Prof. Damien Ridge described the aims of the HI-COVE qualitative study and presented initial findings which resonated with other studies reporting narratives of people with Long Covid. Dr. Nina Smyth give an overview of the patient involvement aspect of the study. Prof. Nisreen Alwan and Dr. Dipesh Ghopal described the findings particularly pertinent to the study population (minority ethnic groups in the UK).

**Reflections**

Aspect of webinar / theme	Comments	Comment from
Qualitative study – participant characteristics	<ul style="list-style-type: none"> <li>• Use of the broad term ‘Black’ questioned, more granular identification suggested.</li> <li>• It was suggested that gender, age, nationality and accent will impact on experiences of Long Covid and help-seeking – including dismissal of symptoms.</li> <li>• Were all participants long-term residents in UK?</li> </ul>	Discussion
Qualitative study – findings  Living with Long Covid	<ul style="list-style-type: none"> <li>• Webinar participants identified with findings and felt our findings reflected their experiences.</li> <li>• Some people reported challenges at work due to their Long Covid, e.g., having their symptoms dismissed and questioning their illness, co-workers thinking they are just being a difficult employee.</li> <li>• Worries about comparisons of Long Covid to CFS/ME because of the lack of progress made in treating CFS/ME.</li> <li>• <i>“These testimonies are so powerful. I think of what I have been through with Long Covid, how I’ll I have been, the constant fight to be believed and get medical care, and I am a white woman. Reading the testimonies of your participants, it is utterly heartbreaking when you hear the additional struggles.”</i></li> </ul>	Discussion  Discussion  Discussion  Qualtrics
Qualitative study – findings  Experiences of healthcare	<ul style="list-style-type: none"> <li>• Long Covid symptoms not taken seriously, being dismissed by the healthcare professionals. Webinar participants reported this is more likely on their ‘good days’, especially if the doctors are not aware of how</li> </ul>	Discussion



	<p>much the symptoms can vary from person to person, or day to day.</p> <ul style="list-style-type: none"> <li>• Lack of knowledge and understanding of Long Covid amongst healthcare professionals. Some recalled being asked by their GP about the latest developments in Long Covid research.</li> <li>• Webinar participants described having had to become 'experts' in the area of Long Covid, keeping up with the available treatment, to be able to fight for treatment for themselves. However, people admitted that it can be exhausting while dealing with ongoing Long Covid symptoms.</li> <li>• Difficulties accessing GP appointments frustrations of having to see different GPs each time, having to recount story (which can be hard to do when symptomatic) – being able to see the same GP would be helpful.</li> <li>• <i>"We shouldn't have to become experts, find energy to educate everyone around us including healthcare."</i></li> </ul>	<p>Discussion</p> <p>Discussion</p> <p>Discussion</p> <p>Qualtrics</p>
<p><b>Qualitative study – findings</b></p> <p><b>Intersectionality</b></p>	<ul style="list-style-type: none"> <li>• Some reflections on whether poor care is due to Long-Covid being poorly understood or because of individual characteristics – this is hard to disentangle and so an intersectional approach is important for framing these results.</li> <li>• Numerous people highlighted the extra burden of trying to figure out if one or more of their identity dimensions contributed to their negative experiences in healthcare. Additionally, the constant cycle of questioning oneself due to that can be made worse by the additional Long Covid diagnosis and how it is perceived as 'vague' and 'non-specific', giving more room for discrimination.</li> <li>• <i>"Some white participants, who also live with Long-Covid, were struck by the additional struggles in healthcare faced by the people from ethnic minority backgrounds (there is another layer here potentially which makes it even harder)."</i></li> <li>• <i>"There seemed to be some discussion regarding whether the findings are exclusive to [ethnic minority] groups, or whether similar can apply to other marginalised groups, or even white Long covid sufferers. Further correlation with health inequalities prior to covid pandemic may show that the pandemic</i></li> </ul>	<p>Discussion</p> <p>Discussion</p> <p>Qualtrics</p> <p>Qualtrics</p>



	<i>increased challenges for [ethnic minority] Long Covid patients.”</i>	
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### **Guest Speakers**

We welcomed three guest speakers:

- Margaret O’Hara founder of [Long Covid Support Group](#)
- Prof. Nawar Bakerly, Consultant Respiratory Physician (*Salford Royal NHS Foundation Trust*)
- [Brendan Delaney](#), GP and Professor of General Practice (Imperial College London)

Margaret O’Hara described how the Long Covid Support group was established and described results of a recent survey the group had conducted, and illustrated the array of resources available.

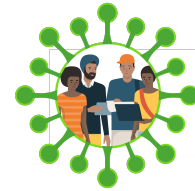
A quote in Qualtrics highlighted the value of the support group: “Finding information and sharing information via Long Covid Support has helped me...”.

Prof. Bakerly described the Greater Manchester Long Covid cohort he has established – this will be a resource for researchers to recruit for research studies.

Prof. Delaney described his experiences of developing and living with Long Covid, and highlighted research he is conducting into Long Covid.

### **Reflections**

<b>Aspect of webinar / theme</b>	<b>Comments</b>	<b>Comment from</b>
<b>Spotlight</b>	• <i>“Finding information and sharing information via Covid Support has helped me. It is a frustrating illness for medical staff and patients. I sincerely hope that a higher profile can be achieved.”</i>	Qualtrics
	• <i>“I appreciated Dr Bakerly’s presentation about research and Dr Delaney’s sharing of his experience. I didn’t know doctors with Long Covid had created their own Facebook group.”</i>	Qualtrics
	• Discussion around differences in treatments available in UK compared to other European countries.	Discussion



Dr. Alexa Wright presented her ideas for the **Artwork** to illustrate findings from the HI-COVE study.

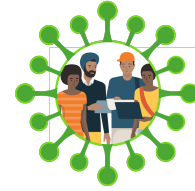
**Reflections**

Aspect of webinar / theme	Comments	Comment from
<b>Artwork</b>	<ul style="list-style-type: none"> <li>• Very positive comments about Alexa’s artwork.</li> <li>• Participants offered own ideas of what artwork might contain.</li> <li>• There were comments about the tension between making artwork reflect an individual experience but also making it reflect the range of experiences.</li> <li>• Exhibition could be virtual (online) or real-life.</li> <li>• <i>“Loved the idea of creative expression of experiences”.</i></li> <li>• <i>“I don't think art is used enough to disseminate science finding, it's a way to humanize results and get to people on an emotional level.”</i></li> </ul>	<p>Discussion Discussion Discussion Discussion Qualtrics Qualtrics</p>

Finally, discussion about ways of **sharing findings** of the HI-COVE study was chaired by Prof. Chew-Graham.

**Reflections**

Aspect of webinar / theme	Comments	Comment from
<b>Dissemination activities</b>	<ul style="list-style-type: none"> <li>• A need for wider public dissemination of findings and shining the government and media spotlight was noted, as many see it as a way of keeping the research into Long Covid treatment going.</li> <li>• Suggestions to write to local MPs with findings.</li> <li>• Importance of sharing findings with GPs – perhaps a conference? Importance of ensuring that GPs are aware of the struggles that people with Long Covid face.</li> <li>• <i>“Ads on Instagram”</i></li> <li>• <i>“I hope you can post research findings on FB and Twitter as soon as possible.”</i></li> </ul>	<p>Discussion Discussion Discussion Qualtrics Qualtrics</p>
<b>Future Collaborations</b>		Discussion



	<ul style="list-style-type: none"> <li>• Several <b>academic</b> researchers expressed their interest in the HI-COVE study and suggested future collaboration – analysis of data or learning event.</li> <li>• Potential formation of a working group with a joint impact strategy campaigning for reduction of inequalities in accessing healthcare for Long Covid amongst people from ethnic minorities, and to increase awareness of long Covid amongst both medical professionals and the public.</li> </ul>	Discussion
<b>General</b>	<ul style="list-style-type: none"> <li>• <i>“Very interesting and consistent with comments from participants in my groups.”</i></li> <li>• Feedback was positive: <i>“very useful”</i> and <i>“extremely useful”</i></li> </ul>	Qualtrics  Qualtrics

Prof. Damien Ridge closed the webinar by thanking everyone for their contributions.

Link to summary slide set presented at event: [https://blog.westminster.ac.uk/hicovestudy/wp-content/uploads/sites/101/2023/03/Hi-COVE-Engagement-Event-One\\_summary-slides.pdf](https://blog.westminster.ac.uk/hicovestudy/wp-content/uploads/sites/101/2023/03/Hi-COVE-Engagement-Event-One_summary-slides.pdf)