

# HEARING FROM THE **UNHEARD:**

## Impact of Long Covid in Black and minority-ethnic groups in the UK (HI-COVE)

ENGAGEMENT EVENT PROGRAMME

18<sup>th</sup> January 2023

Welcome to today's event – thank you for joining us.

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

Study email: [HI-COVestudy@westminster.ac.uk](mailto:HI-COVestudy@westminster.ac.uk)



### HI-COVE

HEARING THE UNHEARD  
VOICES OF LONG COVID

UNIVERSITY OF  
WESTMINSTER

 Queen Mary  
University of London

 University of  
Southampton

 Keele  
UNIVERSITY

 NHS  
Midlands Partnership  
NHS Foundation Trust  
A Keele University Teaching Trust

FUNDED BY

 NIHR | National Institute for  
Health and Care Research

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

## AIMS

- What are the experience and perceptions about Long Covid, impact on daily lives, and role of support like family, friends and religion?
- What are health care experiences like, and the extent to which the care offered matches needs?
- How can support needs be better addressed to encourage better outcomes for patients?

(Funded by NIHR: Research for Patient Benefit)



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# HI-COVE study approach



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One-to-one **semi-structured interviews** with Black and minority ethnic participants.

## Aims:

- What are the experience and perceptions about Long Covid, impact on daily lives, and role of support like family, friends and religion?
- What are health care experiences like, and the extent to which the care offered matches needs?
- How can support needs be better addressed to encourage better outcomes for patients?

**Purposive sampling** to ensure diverse sample (see socio-demographics slide)

Analysis using constant comparison - managed in NVivo

Use of **workshops, publications and art-work** development to improve awareness and advocate for more appropriate services.

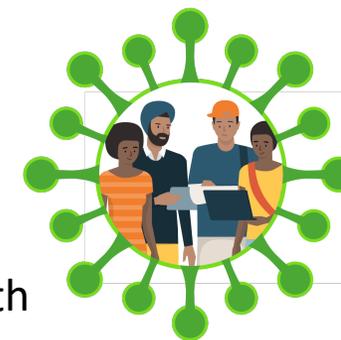
Study Protocol:

Link [here](#)

Smyth et al., (2022), Plos one,  
17(10), e0275166.

# *Patient Advisory Group (PAG)*

Our **Patient Advisory Group (PAG)** is made up of individuals from ethnic minority backgrounds from across the UK, living with long Covid or who care for someone with Long Covid.



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PAG meetings are regularly **held online** to allow people from across the country to participate on a flexible basis, from the comfort of their home.

PAG members are involved in **each stage of the research process** to ensure that our project is in line with the needs of patients and the public, and to maximize its patient benefit.

So far, they've been involved in:

- Grant development
- Recruitment
- Interview questions
- Feedback on preliminary results
- Website
- (and to assist with outputs, art work and dissemination soon)



# *The HI-COVE study – Preliminary findings*

Interviews completed (n=29)

## **Age:**

- 7 - aged 20-29
- 11 – aged 30-39
- 3 – aged 40-49
- 5 – aged 50-59
- 1 – aged 60-69
- N/A – 2

## **Gender :**

- 14 – male
- 15 – female

## **Ethnicity\*:**

- 1 – Arabic background
- 12 – Black background
- 11 – South Asian background
- 4 – mixed
- 1 – other

\* Summary groups presented



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# Preliminary findings

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Living with Long Covid

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Help- seeking

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Racism and healthcare

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Impact on mental health

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Broader discrimination

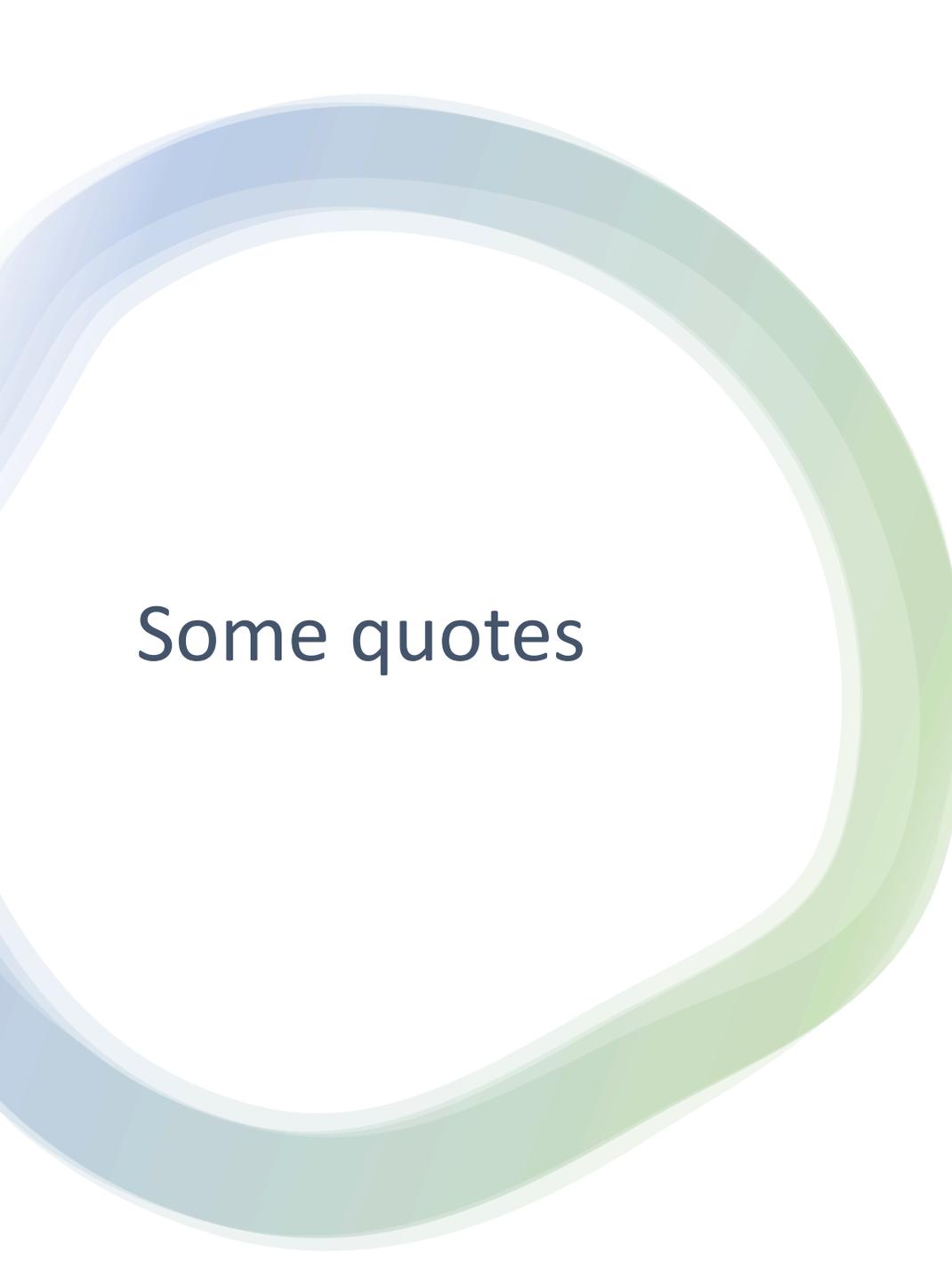
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Stigma

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Experiences of Primary care

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## Some quotes

*'So, I had an advocate, I had a white advocate, and she does all the speaking for me....whatever she's saying is what I told her to say, and for some reason the [doctor] reaction is different.'* P-001 (Black female)

*'...of course racism and sexism would have been a part of the way they would have treated me, but I can't put my finger on a specific incident that was obviously race-impacted, you know.'* P-011 (Black female)

*'For ethnic minority people, their symptoms are not taken as seriously, and it takes a greater level of suffering for a GP to recognize that something's happening.'* P-007 (South Asian female)

*'Some people [in community] are less helpful because they think you should be better by now. And I've had some comments of, you know "I think you're in the long COVID mindset"'* P-008 (South Asian female)

## *What does our study add?*

- Importance of intersectionality runs through narratives, e.g. role of gender, education, ethnicity, access to resources
- Healthcare not necessarily safe or easy to negotiate for racially minoritised patients
- Double whammy: Of all the usual problems with Long Covid + negotiating difference and systemic racism
- Building better relationships with racially minoritised patients would go some way as a first step





# Alexa Wright's art-based approach

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# *The HI-COVE study – art based approach*

- *Alexa Wright,*
- *After Image RD 2 (1997)*

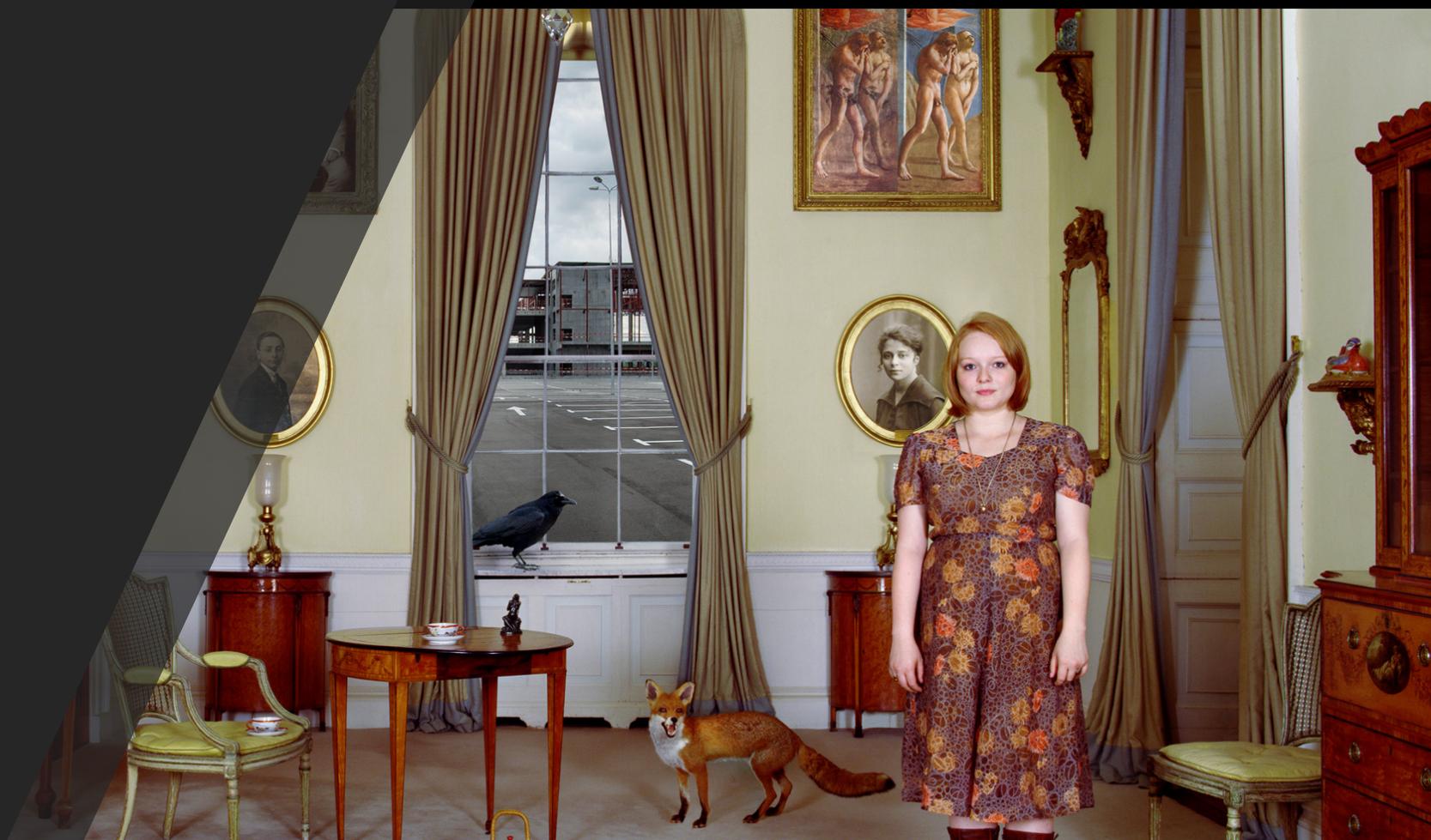


# *The HI-COVE study – art based approach*



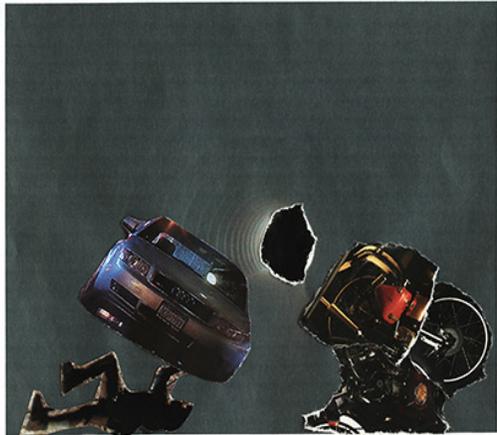
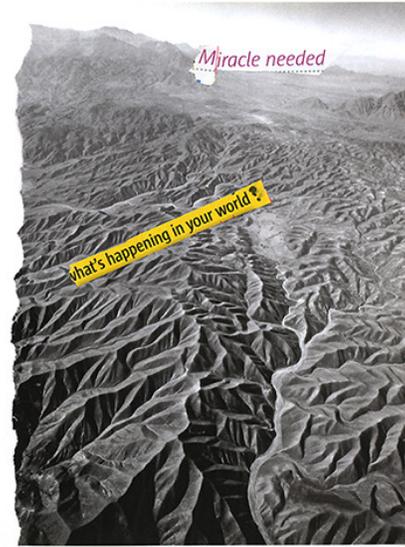
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- *Alexa Wright,*
- *A View From Inside, 2012*





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*The HI-COVE study – art based approach*  
*Piecing It Together, 2015*

A close-up photograph of a glowing green traffic light lens. The lens is circular and features a grid pattern of small, bright green lights. The background is dark and out of focus, with a blurred red light visible on the left side. A white horizontal bar is overlaid at the bottom of the image, containing the text "Spotlight" on key work on Long Covid.

“Spotlight” on key work on Long Covid

# Long COVID research platform for GM *consent for approach model*

- Prof. Nawar Bakerly
- *Consultant Respiratory Physician*
- *Salford Royal NHS Foundation Trust*
- [Nawar.bakerly@nca.nhs.uk](mailto:Nawar.bakerly@nca.nhs.uk)



Help BEAT Coronavirus

**NIHR** | National Institute for  
Health and Care Research

# Long COVID research platform for GM *consent for approach model*

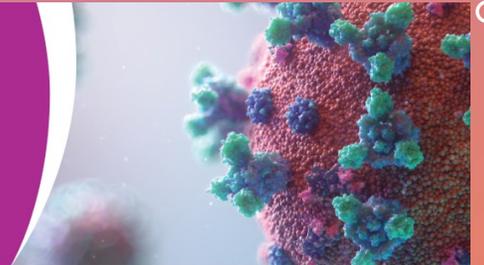
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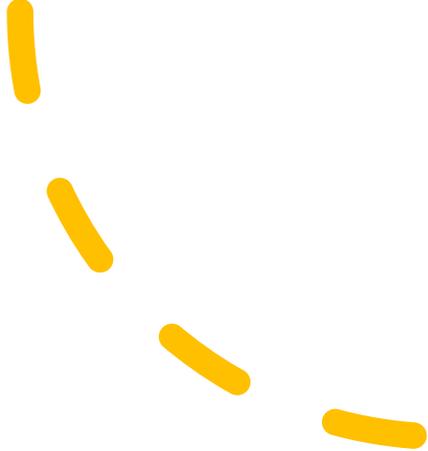
Help BEAT Coronavirus



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Health and Care Research



The aim of this project is to create the infrastructure needed to enable the conduct of future Long-COVID research projects across GM enabling recruitment at speed



REGISTER NOW TO  
TAKE PART IN RESEARCH



RESEARCH WILL CHANGE THE FUTURE

**Help BEAT Coronavirus** is part of Research for the Future, an NHS-supported campaign that helps people find out about and take part in health and care research. Taking part in research helps to discover new ways to prevent, diagnose and manage coronavirus (COVID-19).

Registering to take part means we will inform you about research opportunities. The process is easy, we will ask you for your contact details as well as some questions about your general health and whether you have had coronavirus (COVID-19). Everyone over the age of 18 is welcome to register.

There are lots of different types of research you can take part in, including questionnaires, joining discussion groups or taking part in trials to find new treatments. It is always your decision whether to take part in anything we tell you about. If at any time you change your mind and no longer want to take part, let us know.

Any information you provide is stored on a secure NHS database. It will never be shared with anyone else. For further details about how we protect your personal information, see our privacy notice [www.researchforthefuture.org/privacy](http://www.researchforthefuture.org/privacy)

## Register now

 [www.researchforthefuture.org](http://www.researchforthefuture.org)

 0161 206 3636

# REGISTER NOW

TO TAKE PART IN HEALTH RESEARCH

SCAN ME



research  
FOR THE **future**

Long Covid Support  
Vision, Mission and Values

Dr Margaret O'Hara  
Founding Trustee, Long Covid Support



Long Covid Support

[www.longcovid.org](http://www.longcovid.org)

@long\_covid

@Know\_HG



# Long Covid Support Vision, Mission and Values

**Dr Margaret O'Hara**  
Founding Trustee, Long Covid Support

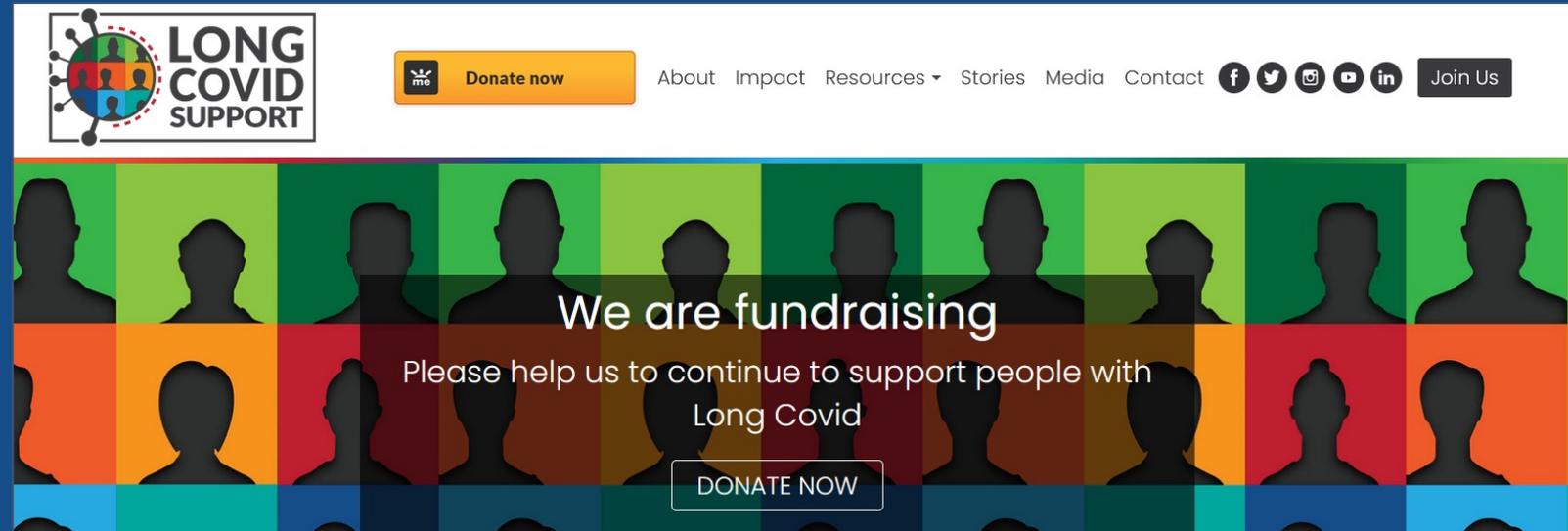
Long Covid Support  
[www.longcovid.org](http://www.longcovid.org)



@long\_covid  
@Know\_HG

# Long Covid Support

- May 2021
  - Incorporated as a not-for-profit company
- May 2022
  - Received registered charity status
- Founded by people with Long Covid
- 7 Trustees
- Approx 50 active volunteers



Peer Support



Research  
Involvement



Advocacy

# Our Vision

For everyone affected by  
Long Covid to have  
access to appropriate  
treatment and support.

# Our Mission

## Support

- To connect people living with Long Covid globally to share learnings and perspectives and provide support to improve their quality of life.

## Advocacy

- To engage with key policy makers so that patients' rights and needs are heard and they are equal partners in all decisions about their health, employment and welfare.

## Research

- To support research into effective treatments, innovations and services and to ensure that research priorities are informed by lived experience.

## Education

- To raise awareness and improve understanding so that Long Covid is well defined, with high quality information, support and health services in place throughout the UK.

# Our Values

## Peer-led

Warm, genuine,  
compassionate,  
empathetic and  
approachable

## Inclusive

Diverse, equity-oriented  
and open-minded

## Expert

Professional, lived-  
experience  
informed, evidence based  
and knowledgeable

## Driven

Motivated, tenacious,  
passionate and  
determined

## Collaborative

People-centred, partner-  
oriented, open, fair and  
holistic

## Dependable

Trustworthy, safe and  
respected

- Providing peer support. For people with Long Covid and their carers
- **55k** members >100 countries
- <https://www.facebook.com/groups/longcovid>

Long Covid Support Group 

- For knowledge exchange about Long Covid research.
- **5k** members
- > 90 countries
- <https://www.facebook.com/groups/2590602557864509>

Covid-19 Research Involvement Group 

- **17k** followers
- <https://www.facebook.com/LongCovidPage/>

Long Covid Support Page 

- **>25k** followers
- @long\_covid

Twitter 

- **>10k** followers
- @long\_covid

Instagram 

# Supporting people with Long Covid:

#1YrOfLongCovidSupport

"This group has not only been a reference point through Long Covid it has also given me hope and encouragement at my lowest times. Thank you to all involved, I will be forever grateful."

a member of the Long Covid Support Group

#1YrOfLongCovidSupport

*"Thank you so much for setting the page up. It's been an absolute life saver. I think I'd be in a very bad place if I hadn't have found you all."*

a member of the Long Covid Support Group

#1YrOfLongCovidSupport

*"Thank you so much. I don't feel alone anymore. I feel heard and understood."*

a member of the Long Covid Support Group



If you or your child have had new symptoms for a month or more and think you might have had Covid-19, support is available.

After a Coronavirus infection, many people make a full recovery. For some, the illness can last longer. This is known as Long Covid. You can have Long Covid after a mild or even symptom-free initial illness. Symptoms can affect any part of the body, can come and go, or new ones can appear weeks or months later.

**Common Long Covid Symptoms**

ADULTS	CHILDREN
<ul style="list-style-type: none"> <li>• Extreme tiredness</li> <li>• Shortness of breath</li> <li>• Chest pain or tightness</li> <li>• Memory or concentration problems</li> <li>• Difficulty sleeping</li> <li>• Fast heart rate or palpitations</li> <li>• Joint or muscle pain</li> <li>• Upset stomach or pain</li> <li>• Changes to smell or taste</li> <li>• Headaches or dizziness</li> <li>• Anxiety or depression</li> </ul>	<ul style="list-style-type: none"> <li>• Extreme tiredness</li> <li>• Dizziness</li> <li>• Rashes</li> <li>• Brain fog</li> <li>• Headaches</li> <li>• Chest pain</li> <li>• Stomach pain or upset</li> <li>• Sore throat</li> <li>• Mood changes</li> <li>• Joint or muscle pain or swelling</li> <li>• Sickness or nausea</li> </ul>

Source: NHS  
Centers for Disease Control and Prevention

For information and support visit [LongCovid.org](https://LongCovid.org) or [LongCovidKids.org](https://LongCovidKids.org)






**Seek medical help if you are worried.**

Long Covid Support registered company limited by guarantee (England and Wales) 13422248  
Long Covid Kids and Friends registered charity (England and Wales) 1196170  
© 2021 Long Covid Support © 2021 Long Covid Kids Published: November 2021

# Associated groups

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Long Covid Work



# Stakeholder networks:

- Regional ICSs/Health Boards
- NHSEI Long Covid Task Force
- NICE
- NIHR
- DHSC Roundtable
- WHO
- ISARIC/GLOPIDR
- Employers
- Healthcare professionals





# Find us

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LongCovid.org



Long Covid Support Group <https://www.facebook.com/groups/longcovid>

Covid-19 Research Involvement group <https://www.facebook.com/groups/2590602557864509>

Long Covid Support <https://www.facebook.com/LongCovidPage/>



@long\_covid



@longcovid



info@longcovid.org

# Professor Brendan Delaney

- **Chair in Medical Informatics and Decision Making**
- **Imperial College London**
- [brendan.delaney@imperial.ac.uk](mailto:brendan.delaney@imperial.ac.uk)

Brendan talked about his experiences living with Long Covid and his current research on Long Covid.

Do see this important paper:

[Recommendations for the recognition, diagnosis, and management of long COVID: a Delphi study. British Journal of General Practice 2021; 71 \(712\): e815-e825. DOI: <https://doi.org/10.3399/BJGP.2021.0265>](#)





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## *The HI-COVE study reflections*

- How should we disseminate our findings?
- What are the next research steps?
- Raise your hand or add to comments in chat, or use Qualtrics link with our questions in the Teams chat:  
[https://westminsterpsych.az1.qualtrics.com/jfe/form/SV\\_0jomqJWfMCNISC6](https://westminsterpsych.az1.qualtrics.com/jfe/form/SV_0jomqJWfMCNISC6)



- Please use this optional link to leave your email and name if you want to be contacted in the future about HI-COVE or other Long-Covid projects:  
[https://westminsterpsych.az1.qualtrics.com/jfe/form/SV\\_9F5Qu1oHN0rdufk](https://westminsterpsych.az1.qualtrics.com/jfe/form/SV_9F5Qu1oHN0rdufk)





# *Thank you for participating!*

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Your views and comments are valuable to us – if you have further comments, please do submit them using the Qualtrics link in the Teams chat

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Thanks to all our participants who told their stories, despite the difficulties of Long Covid. Also thanks to those who contributed to the results, workshop and presentation, including co-chief investigator (Nina Smyth), our Patient Advisory Group, Patrycia Gaszczyk (research fellow), Claudia Knowles (intern), and our co-investigators (Nisreen A Alwan, Rebecca Band, Carolyn A Chew-Graham, Dipesh Gopal, Tom Kingstone, Alexa Wright).

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

Study email: [HI-COVEstudy@westminster.ac.uk](mailto:HI-COVEstudy@westminster.ac.uk)

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