



LIVED EXPERIENCE OF LONG COVID

Session 1
09:00 – 10:30

**Hosted by: Nisreen Alwan (University of Southampton)
and Sarah Baz (University of York) on behalf of the Long
Covid and Health Inequalities Academic Group (part of
the Qualitative Long Covid Network)**

#PatExp

#LongCovid



RUTH EVANS

Managing Director

Patient Experience Network





LOUISE BLUNT

Head of Operations

Patient Experience Network





Helen Brady

Event Manager

Patient Experience Network





**WHO WE ARE AND
WHAT WE DO**



Patient
Experience
Network



DR NEIL CHURCHILL

**Director for Experience, Participation
& Equalities
NHS England**



Our Vision

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

- Providing peer support.
For people with Long Covid and their carers
- **61k** members >100 countries
- <https://www.facebook.com/groups/longcovid>

Long Covid Support
Group



- For knowledge exchange
about Long Covid
research.
- **5.5k** members
- > 90 countries
- <https://www.facebook.com/groups/2590602557864509>

Covid-19 Research
Involvement Group



- **23k** followers
- <https://www.facebook.com/LongCovidPage/>

Long Covid
Support Page



- **30k** followers
- @long_covid

Twitter



- **12k** followers
- @long_covid

Instagram



Inequalities and stigmas - themes

Social Isolation

Disability

Politicisation

Age

Parents

**Economic
underprivilege**

**Social
underprivilege**

Isolation and Disability

Social Isolation

Those living alone have no help to access care either physically or having someone to advocate

Disability

Accessing care is difficult for those who are physically disabled or have learning difficulties.

You're the wrong age to have Long Covid

Youth

'You're too young to be ill, just go out and be active'

Seniors

"It's just your age, you're not as young as you used to be"

Healthcare poverty

Economic underprivilege

Effective treatment isn't available on the NHS, and alternative or private treatments can be expensive

Social underprivilege

Accessing care is difficult for those who struggle to take time off work due to poor workplace rights or loss of earnings

A political disease

Politicisation

Vaccine and/or lockdown scepticism leads to Covid minimisation and LC scepticism

Masking viewed as a radical and provocative act

Friends and family who view Long Covid as not a real illness can regard the sufferer as delusional or a troublemaker

We hear of family breakdown ranging from choosing to avoid family events up to full estrangement with relatives

Case study - a gaslighting spiral

John

Middle aged professional married man with young children

Perfectly health until Covid in summer 2022

Doctors told him his pain was 'impossible' so family also believed this

His attempts to cope with, and get treatment for, severe pain, led to family calling in mental health services

Detained in a mental health hospital for 40 days. Pressured to take medication for psychosis but refused

Got out by arranging for another trust to review case and obtain physical examination

Now going through divorce and banned from seeing his children

A tale of two mothers

Sonya and Emma

Educated professionals

Have LC as well has a child with LC

Struggling to navigate a maze of services and referrals

Exhausted from doing battle with healthcare services

Sonya

“[The doctor] Kept looking at me to see if I was looking at [child] and I got so worried based on previous appts with the paediatrician (who has been talking to him) so I just looked at the floor. Once I accidentally interrupted him and said "sorry, carry on" he REALLY didn't like it and gave me a dirty look which my child commented on afterwards. [Child] said afterwards "I felt like he was saying its all in my head- if I could think or distract myself better I would have been better years ago".

“I've even started questioning myself like have I brainwashed him, am I the problem?”

“Sometimes I get really worried I'm going to be accused of making this up

Emma

“I am absolutely aware of my privilege in these situations. I know that I have an army behind me; I'd receive huge support and outrage if I posted about it on social media, and I have a family who could afford legal action if it ever came to that.”

“[I want to] ensure that everyone has that army behind them regardless of their social, financial, cultural background. I will not stand for the injustice of it all - everyone should be treated equally and deserves as much support and assistance as they need. I can feel my blood pressure rising already.”

Injustice and harm

Children are under threat of removal from families

Parents are being accused of fabricating illnesses in their children

Healthcare professionals collude with schools and social services in gaslighting families and threatening action

Long Covid Kids are aware of live cases in the UK

Double injustice that children are taken away from caring parents and they will not get the healthcare they need

Peer support – a safe haven

[Long Covid Support group] is my safe place to go to if I have a LC issue. I don't post how I am and how I feel anywhere else. Basically I have learned over the last few years that nobody outside this group wants to know! I avoid bad comments by coming home to here.



Find us



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



Long Covid Support

Observations on stigmas and inequalities from the front lines of peer support

Dr Margaret O'Hara
Founding Trustee, Long Covid Support

Long Covid Support
www.longcovid.org



@long_covid
@Know_HG



Long Covid Support

- Registered charity (England and Wales) since May 2022
- Founded by people with Long Covid
- 9 Trustees
- Approx 50 active volunteers



Peer Support



Research
Involvement



Advocacy

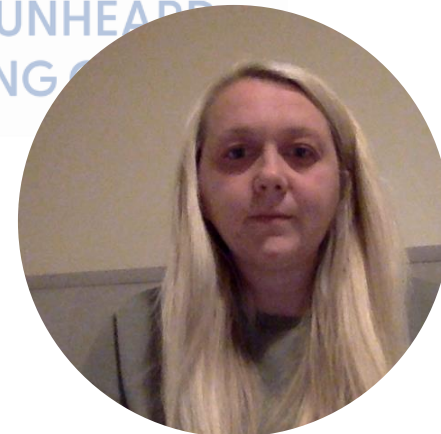
'You can be in hell and they still refuse to help': Racially minoritised people with Long Covid reflect on care & support

Nina Smyth*, Damien Ridge*, Nisreen A Alwan, Carolyn A. Chew-Graham, Rebecca Band, Dipesh Gopal, Tom Kingstone, Alexa Wright



HI-COVE

HEARING THE UNHEARD
VOICES OF LONG COVID





HI-COVE

HEARING THE UNHEARD
VOICES OF LONG COVID

- **Long Covid experiences**, the 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?

Study Aims

Study Protocol:



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

Approved by University of Westminster ethics: ETH2122-1074





HI-COVE
HEARING THE UNHEARD
VOICES OF LONG COVID

Qualitative study

Workshops, website and art-work

Patient Advisory group

Study Protocol:



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

Funded by NIHR: Research for Patient Benefit

Approved by University of Westminster ethics: ETH2122-1074





Interview Participant Socio- Demographics (n=30)

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

- Gender:**
- 15 – males
 - 15 – female

- Ethnicity:**
- 2 - Arabic background
 - 12 – Black background
 - 11 – South Asian background
 - 4 – mixed
 - 1 – other

Occupations: Unemployed, student, higher ed, tradesperson, retail, health professional, IT/information, transport, self-employed

**Ladder for
community
standing
(higher =
better)**

1 = 1
2-3 = 2
4-5 = 10
6-7 = 9
9-10 = 3
n/a = 5





Experiences of Primary Care

'...it's kind of amazing that you can be in hell and they still refuse to help. So, it's kind of amazing how much power they have over you...'

Male, 30-39, Mixed Latino

'...I think everyone has the right to a doctor that listens as brilliantly as my doctors, because if...you know that your body is very different from the way it was before COVID, you shouldn't have to justify to anybody what you're experiencing'

Female, age group 40-49, Black African



Experiences of Secondary Care



'...She referred me to the Long Covid clinic, but nothing came of it... they said they were over capacity, and they'll text me again, and I never heard anything again. I just gave up; I think they forgot about me...'

**Male, age group 30-39,
Bangladeshi**



'...He [respiratory physician] basically laughed in my face, said 'I don't think any of this is going on...and you should consider seeing a clinical psychologist'...I was just so shocked...'

Male, 30-39, Mixed



Emotional Distress



‘...dying slowly, it was a grip of death, it was worse and that is still my worst nightmare. Just a drip around my neck that stopped me from breathing...’

Female, age group 50-59, British Black Caribbean

‘...they made me lie about having a cough so I could get some help. I had to lie about a cough...’

Female, age group 50-59, British Black Caribbean

‘...I had nightmares every night for 18 months...do you think you should see somebody...so I actually did...Uh, self, refer...’

Female, age group 50-59, Asian



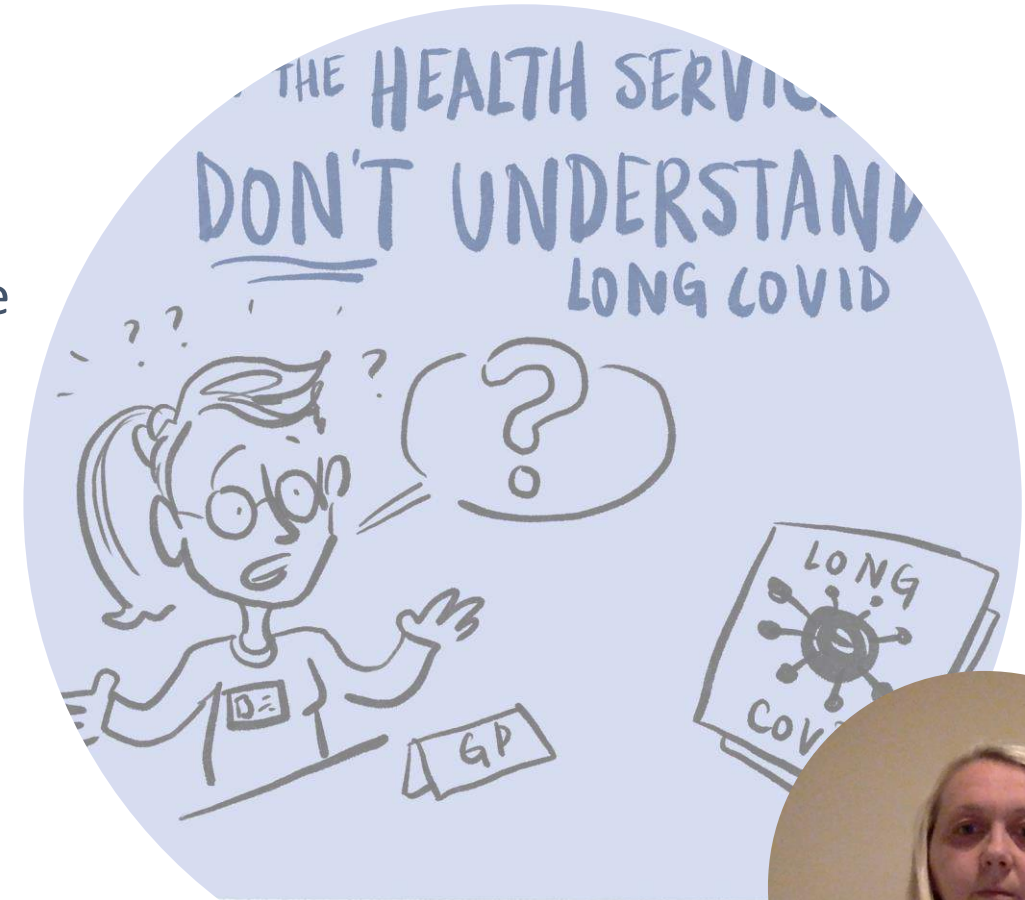
Lack of understanding

‘... I always got believed. But it was always we can't do anything...’

Female, age group 54, Asian

‘...talking to my GP about mental health because like they've been really hostile and they just don't really get it...’

Female, age group 20-29, Bangladeshi



The value of good care and support



Limits to family & community understandings/ stigma

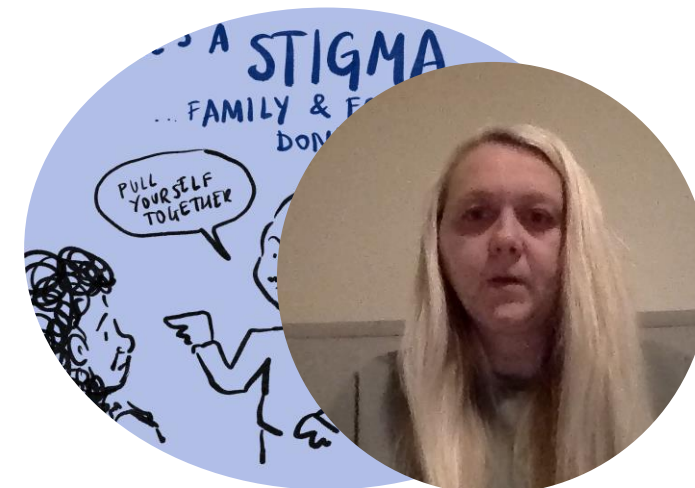


‘...My sister got me through the darkest times...you're in the dark hole and there's a shining light shining on you, and that kind of like pulled me through...’ **Male, 30-39, Mixed Latino.**



‘...In our culture and community, people don't understand. You always have to pretend...They would make nasty remarks about me...’ **Female, age group 50-59, South Asian**

‘...I don't want to believe it still because of COVID-19 that I'm still having these symptoms or could it be...’ **Female, age group 20-29, Black African**



Experiences of healthcare



Overall, most report challenges getting healthcare (e.g. getting appointments)



Participants frequently experience professionals as uninterested, unknowledgeable, gaslighting, dismissive, annoyed with them, and/or unwilling to help



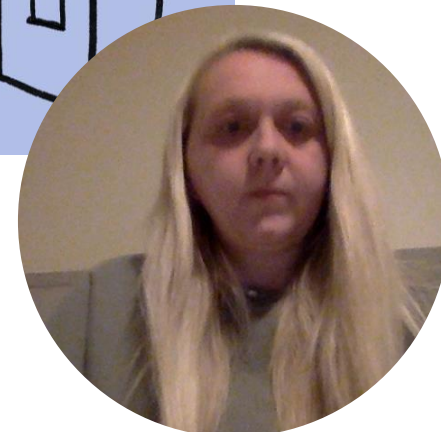
But lucky participants had supportive + proactive doctors



Some with privilege could purchase private care, or get NHS referrals e.g. doctors



Many end up having to cobble together their own treatment/self-care programme



Experiences of discrimination/racism

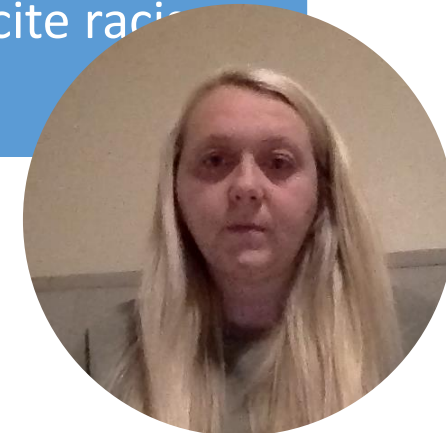


A layer over the top of general disappointment in LC healthcare

People may already suspect racist healthcare due to past experiences of racism

People frequently suspect racism in healthcare

Some made comparisons to white patients to cite racism



Racism and healthcare



I do think that getting a chronic illness when you're from a minority background, and you've been shaped by previous times where race would be a barrier. Even if those barriers aren't there today, I think it would still affect people today.

Female, age group 30-39, Middle Eastern



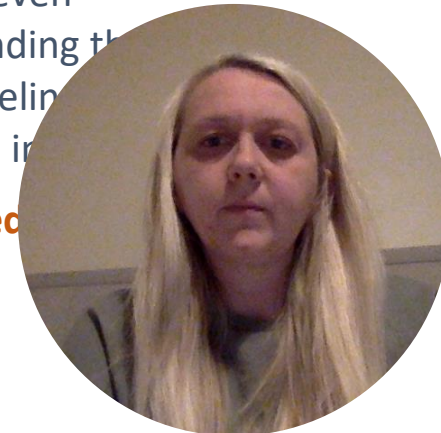
For ethnic minority people, their symptoms are not taken as seriously, and it takes a greater level of suffering for a GP to recognize that something's happening.

Female, Aged 20-29, South Asian



'You see a nurse is coming to check up on you and they talking to you harshly...It's not really the way they attend to other white people, you understand? (...)when it comes to people who are Black, like me, you see them talking to you, commanding you, and then not even understanding that you are not feeling that point in

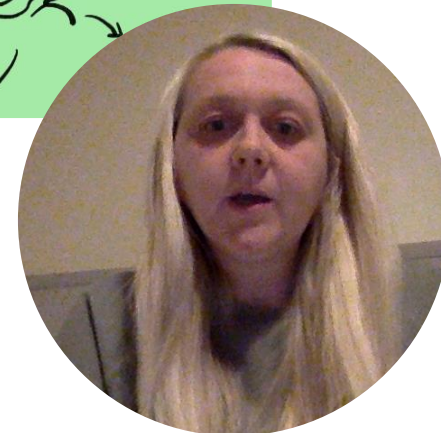
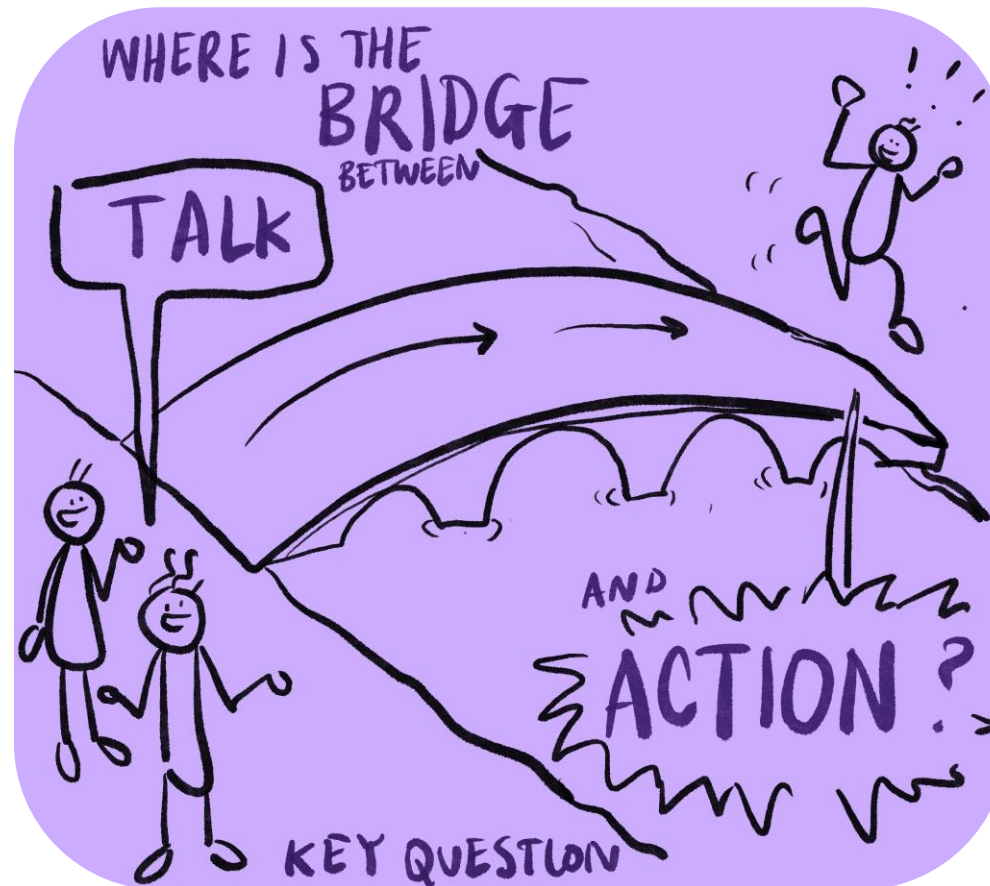
Male, aged 20-29, British



Conclusions

'...I don't even bother going to my GP anymore...hope that I get better on my own...'

Black American Male, 20-29.





The meaning and importance of Long Covid diagnoses

Alice Faux-Nightingale, Helen Twohig, Claire Burton, Victoria Welsh, Glenys Somayajula, Carolyn A Chew-Graham, and Ben Saunders

SPLaT-19

Aims:

- to provide a picture of the longer-term effects of an acute COVID-19 infection in children and young people aged 8-17 years, residing in the West Midlands.

Qualitative study:

- Explore the impact of Long Covid on the lives of children and young people and their families (including personal, family, social and educational effects)

Methods

Interviews

- Invited 67 young people with persistent symptoms
- 4 people replied and attended interviews - All female, ages 10, 12, 14, 17
- Parents present in 3 interviews

Focus groups

- 2 focus groups with professionals who work with young people: GP, paediatric consultants, physiotherapists, primary school teacher, nurse consultant

Data were analysed thematically, drawing on the constant comparison method (Glaser, 1965)

Findings

Main findings:

- Impact of Long Covid on CYP – personally, hobbies, education, family
- Lack of knowledge about Long Covid in children – impact on parents
- Difficulty talking to other people about Long Covid – stigma
- Difficulty accessing Long Covid services
- Meaning and importance of Long Covid diagnoses**

Meaning for young people and parents

"The GP has mentioned it and she said it is probably but there's no research on it, we can't really say one way or the other." Parent of 16 (Female, aged 10)

*"So we had to go private, get this diagnosis but it wasn't particularly for any treatment, it was just for the diagnosis just to show school"
Parent of 01 (Female, aged 14)*

"[...]they're talking about Long Covid in children on BBC news, it was like a huge thing, and we watched it and we were like 'oh!', and obviously they were saying all the things that were like the symptoms and we're like 'That's so me, like that's me!'" 20 (Female, aged 17)

Meaning for healthcare professionals

“Whether their fatigue is related to Covid or whether it’s related to pre Covid fatigue is largely irrelevant because clinically they’re indistinguishable.” (Paediatric consultant, Long Covid clinic)

“If a child comes to me with fatigue that comes from a viral episode [...] since February or March 2020, as far as I am concerned, that can go on my Covid stats. [...] I am going to label everything as post Covid because it means they can have treatment” (Physiotherapist, Long Covid clinic)

Summary

Differing perceptions of diagnosis between young people with Long Covid and their families and professionals involved with their care:

- Young people and families
 - legitimisation and understanding, access to support
- Healthcare professionals
 - medical burden for patients, not necessarily associated with treatment, but can be used to enable access to services



Thank you

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a.faux-nightingale@keele.ac.uk

A background network diagram with nodes and connecting lines in shades of blue and yellow, set against a light grey background.

Key themes from the QLC network Long Covid and health inequalities workshop

Professor Ghazala Mir (University of Leeds, LOCOMOTION)

Dr Sarah Baz (University of York, CONVALESCENCE)

Wider team: Donna Clutterbuck, Chao Fang, Jordan Mullard, Mirembe Woodrow, Nisreen Alwan

LC and health inequalities workshop

- QLC network – academics working on qualitative Long Covid projects across the UK.
- Workshop – took place 19th June 2023, in-person UCL/hybrid.
- Presentations from 6 research project teams focusing on LC in relation to health inequalities: CONVALESCENCE, HEALTH TALKS, HI-COVE, LOCOMOTION, SPLAT-19, STIMULATE-ICP.
- 1 PPI representative sharing lived experiences (CONVALESCENCE) and 3 representatives from LC charities ([Long Covid SOS](#), [Long Covid Kids](#), [Long Covid Support](#)).
- Qualitative research – centred around ‘lived experience’

Key themes

The unfairness of LC and unequal access to care

Stigma, mistrust, not being heard, lack of awareness of LC and discrimination

Gatekeeping

- GPs, welfare benefits, social and political, exhausting to navigate systems

Some positive experiences of healthcare

– validation is important

Inequalities and intersectionality

- racism, age, socioeconomic circumstances, digital poverty...

Barriers to accessing and engaging with healthcare services.

Importance of addressing psychological symptoms and distress alongside physical symptoms

The importance of getting a diagnosis

Drawing comparison and sharing practice between LC and other long term conditions

Resources

CONVALESCENCE

- [Journal article: 'I don't know what to do or where to go'. Experiences of accessing healthcare support from the perspectives of people living with Long Covid and healthcare professionals: A qualitative study in Bradford, UK. Health Expectations.](#)
- [Journal article: 'I am just a shadow of who I used to be' — Exploring existential loss of identity among people living with chronic conditions of Long COVID. Sociology of Health & Illness.](#)
- [A guide to Long Covid and mental health](#)
- [Policy brief: identifying mental health support gaps for people living with Long COVID](#)
- [CONVALESCENCE project website](#)

HI-COVE

- [Study website: https://blog.westminster.ac.uk/hicovestudy/](https://blog.westminster.ac.uk/hicovestudy/)
- [Study protocol: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0275166](https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0275166)

Health Talks

- [Journal article: Negotiation of collective and individual candidacy for long Covid healthcare in the early phases of the Covid-19 pandemic: Validated, diverted and rejected candidacy. SSM - Qualitative Research in Health](#)
- <https://healthtalk.org/>

LOCOMOTION

- [Journal article: Towards evidence-based and inclusive models of peer support for long covid Soc Sc & Medicine](#)
- [Study protocol: LOnG COvid Multidisciplinary consortium Optimising Treatments and services acrOss the NHS \(LOCOMOTION\): protocol for a mixed-methods study in the UK. BMJ Open.](#)

Resources

STIMULATE-ICP

- [Long Covid active case finding: a co-produced community-based pilot within the STIMULATE-ICP study. PLOS ONE](#)
- [Defining usual care and examining inequalities in Long Covid support: protocol for a mixed-methods study. PLOS ONE](#)
- [STIMULATE website – Long Covid Inequalities](#)

Other

- [Long COVID stigma may encourage people to hide the condition](#)
- [Long Covid stigma: Estimating burden and validating scale in a UK-based sample | PLOS ONE](#)
- [My cruel teacher – Long Covid | Nisreen Alwan | TEDxSouthamptonUniversity](#)

SPLAT-19

LOCOMOTION STUDY

Good practice in referral and access

Invisible inequities

- Identify excluded groups (access and use data), prioritise and tailor services

GP as barrier

- GP symptoms training/targeting; 3rd sector involvement in LC referrals/navigating support

Low awareness

- Community/OH/HR outreach/influencers

Waiting times

- Information/education/ signposting to peer/other support while waiting for specialist care

Geography

- Diverse clinic sites

Finance/capacity

- Choice of virtual/ face-to-face/home visits
- IT support and equipment to address digital exclusion
- Signposting - benefits/support grants/food bank/housing

Good practice in treatment/management

Integrated
treatment plans

Multidisciplinary/multisector teams; tailored care pathways/holistic support

- Reduce adverse impact of referral to multiple clinics with long waiting lists for groups with high level of existing ill health
- Balance new patients with existing cohorts of those with long term conditions
- Help with uncertainties about comorbidity and self-management of changing needs

Move
beyond monitoring

- **Flexibility - adapt care** as research develops and needs are recognised
Evolving service – establishing new pathways through trial and error
- **GP liaison with employers** to support return to work
- **Employer support networks** (consistency across NHS staff)

Next steps for research

- A collaboration and joining up of the studies and findings
- Importance of linking stories with the evidence
- Linking quantitative and qualitative work
- Developing a healthcare tool for Long Covid (HI-COVE and STIMULATE-ICP)
- Sharing good practice examples for inclusive services
- Ultimate goal to influence policy and practice
- Covid is still circulating, so LC is still a hugely significant issue, prevention and addressing health inequalities matters

Presenter contacts

Professor Ghazala Mir (Professor of Health Equity and Inclusion, School of Medicine, University of Leeds, LOCOMOTION)

G.Mir@leeds.ac.uk

Dr Sarah Baz (Qualitative Research Fellow, Health Sciences, University of York, CONVALESCENCE)

sarah.baz@york.ac.uk

Interactive activity

Based on today's presentations and discussions:

What do you think are the key practical steps and commitments needed to address Long Covid health inequalities?

How can this be achieved in your own practice?

Jamboard link to share ideas:

<https://jamboard.google.com/d/1K5zqibWlbuchwBqTo3wC4MRImz3PWrGe5-jVvhUpYdg/edit?usp=sharing>

BREAKOUT ROOMS

Main Room	
First Name	Surname
Camille	Alexis-Garsee
Deta	Almond
Nisreen	Alwan
Sarah Akhtar	Baz
Sarah	Baz
Jodie	BCU
Sumina	Begum
Andrea	Bell
Vicky	Betts
Derwena	Bowsher
Tricia	Bradbury
Emma	Brazier
Bridgett	Broughton
Eden	Byrne
Donna	Clutterbuck

Click Breakout Room 1	
First Name	Surname
Vicky	Collins
Gill	Davis
Paloma	Diaz Estevez
Emma	Dillon
John	Dunning
Kate	Duxbury
Alex	Evans
Alice	Faux - Nightingale
Katherine	Flanagan
beth	Fletcher
Jenny	Gaunt
Robin	Gorna
Michelle	Gray
Pam	Hancock
Bethany	Hawthorne

Click Breakout Room 2	
First Name	Surname
Nicki	Hodson
Sharon	Hui
Kate	Hunt
stacey	Hunter
Michelle	Hutton
Bilal	J
Victor	Jeganathan
Martin	Joinson
sam	knight
Pamela	Lawi
Fiona J.	Leggat
Ana	Leite
sally	longley
Joanne	Loughlin-Ridley
Tim	Lucas

Click Breakout Room 3	
First Name	Surname
Alice	MacLean
Sarah	Markham
Claire	Marshall
Sammie	McFarland
Claire	McWilliams
Ghazala	Mir
Natasha	Munoz
Carol	Munt
Michael	Natt
Mandy	Neophytou
Julie	Newell
Fiona	Newlands
Victoria	Newton
Aimee	Nixon
Susan	Nyandoro

BREAKOUT ROOMS

Click Breakout Room 4

First Name	Surname
Margaret	O'Hara
Moh	Okrekson
Nikhyta	Patel
Nicky	Payne
Colin	Pidgeon
Rosie	Pidgeon
Harriet	Pinel
Mary	Rankin
Jules	Rhodes
Jackie	Robinson
Jackie	Robinson
Martin	Rogers
Tracey	Ryan
Nathan	Samuels
Colin	Sandiford

Click Breakout Room 5

First Name	Surname
Naila	Shadi
Joanne	Smallman
Felicity	Smith
Nikki	Smith
Gemma	Smith
Nina	Smyth
Carly	Snowball
Emma	Solway
rebecca	spilsbury
abi	stothard
David	Sunkersing
Michael	Suter
Louise	Sutton
Roxanne	Talbot
Lisa	Till

Click Breakout Room 6

First Name	Surname
Emma	Tucker
Laura	Tuhou
Sudharma	Weerakkody
Charlotte	Welch
Victoria	Welsh
Ann	Westcott
Sarah	Weston
Cervantee	Wild
Jo	Worsfold

NHS England's #StartWithPeople Learning and Support Offer

...to drive improvement, set national approach to supporting and developing people, empower local leaders to make decisions

Self-service resources

Self-service resources via [NHS England website](#) & [#StartWithPeople](#) Future NHS page to support implementation of [NHS England » Working in partnership with people and communities](#) statutory guidance

[Introduction to working with people & communities](#) via Futurelearn

Targeted learning & support for practitioners at NHSE and in systems

[#StartWithPeople webinars](#) and virtual events

Supporting learning programmes offered locally including [Local Trainer Community of Practice](#)

For support with involving people with a learning disability and autistic people read <https://www.england.nhs.uk/learning-disabilities/about/get-involved/> contact engage@nhs.net or follow @NHSability

Support for Patient and Public Voice (PPV) Partners

[Resources and learning to support PPV Partners](#) incl:

- [PPV Partner Welcome Pack](#)
- [PPV Partner network](#)
- [Mandatory and optional elearning modules](#)
- [Developing Influence & Impact in your role as a PPV Partner training course](#)
- [Citizens Advice Bureau helpline](#) for advice on payment
- Supply of devices to support [Digital Inclusion](#)
- [Recruitment opportunities](#)

Expert networks of policy makers and practitioners

ICB People and Communities Leads Network (and thematic working groups)

Arms-Length Bodies Forum

- NHS England forums incl:
- Engagement Managers Community of Practice
 - Engagement and Equality Champions
 - Regional Leads Network

Building awareness of good practice through digital and social media

#StartWithPeople Newsletter

Twitter: #StartWithPeople @NHSCitizen

[Working in Partnership with People and Communities Podcast](#)

[People and Communities Blogs](#)

For advice & support, contact us at:
england.engagement@nhs.net

NHS England's Bitesize Guides to Patient Insight

A series of short guides to help providers and commissioners understand the use of patient insight better and to use it effectively in delivering local services.

[NHS England » Bite-size Guides to Patient Insight](#)

- Insight – what is already available
- How and when to commission new insight and feedback
- Writing an effective questionnaire
- Building greater insight through qualitative research
- Seeking feedback in distressing or highly emotional situations
- Helping people with a learning disability to give feedback
- The National Patient Reported Outcome Measures (PROMS) programme

For advice & support, contact us at:
england.insight-queries@nhs.net