



# LIVED EXPERIENCE OF LONG COVID

Session 3  
13:30 – 15:00

Hosted by: Cervantée Wild, University of Oxford) and  
Alice MacLean, University of Stirling

[#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**





# Session 3: How Long Covid Impacts Families

## Amplifying the Voices of Children and Young People

25 July 2023

**PATIENT EXPERIENCE NETWORK**  
Lived Experience of Long Covid

FUNDED BY

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

# Collaborators

FUNDED BY

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



UNIVERSITY of  
**STIRLING**



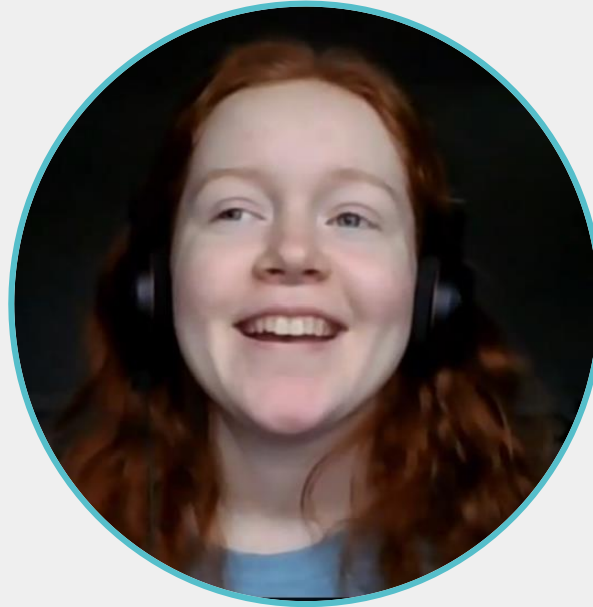


# LONG COVID KIDS



**Sammie McFarland**  
CEO & Founder  
Long Covid Kids

*Advisory Panel, Long Covid in Families study*



**Rosie Pidgeon**  
Artist

*Interview participant, Long Covid in Families study*



**Colin Pidgeon**  
NI Representative  
Long Covid Kids

*Interview participant, Long Covid in Families study*

# ONE OF FOUR SISTER STUDIES EXPLORING EXPERIENCES OF COVID-19 IN UK

## 1. Variation

Exploring differences (and similarities) in experiences of Covid-19, with a particular focus on seldom heard groups

## 2. Severity

Exploring experiences of COVID-19 patients (and their families) who were treated in ICU

## 3. Duration

Exploring experiences of Long Covid in adults

## 4. Long Covid and family dynamics



Economic  
and Social  
Research Council

THIS.



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



**73 narrative interviews with children, teenagers, young people, parents  
(maximum variation sample)**



**Patient and clinician perspectives on communication about Long Covid in  
GP settings**



**73 narrative interviews with children, teenagers, young people, parents (maximum variation sample)**



**Patient and clinician perspectives on communication about Long Covid in GP settings**



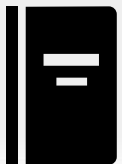
**Experience-based online resource on [healthtalk.org](https://www.healthtalk.org)**



**Cross-country comparative studies of Long Covid experience**



**Ongoing dissemination: theatre-based workshops, policy engagement**




**Publishing scientific papers, archive of interviews for secondary analysis**

# Online dissemination

- Public-facing collection of topics
- Diverse range of experiences
- Video, audio, text extracts
- For patients and the public, learning and teaching, service improvement initiatives & policy makers

## Family experiences of Long Covid

- > Overview
- > Understanding Long Covid
  - Realisation of Long Covid
  - Talking to other people about Long Covid
- > Experiences of being unwell with Long Covid
  - Symptoms and changing symptoms
  - Self-management and self-care of Long Covid at home
  - Mental health impact of Long Covid



02:37

A clinical psychologist contacted Gracie's school to arrange for her to reduce to half-days at school. Her attendance at school was down to 23%. She felt stressed and sometimes felt she was behind everyone else.

View full profile

Age at interview: 11  
Sex: Female

SHOW TEXT VERSION EMBED CODE PRINT TRANSCRIPT



01:24

Danie said her daughter's school was assertive and adaptable in responding to her changed needs. They were understanding about absences from school to attend hospital appointments.

View full profile

Age at interview: 38  
Sex: Female

SHOW TEXT VERSION EMBED CODE PRINT TRANSCRIPT



01:34

Zubair reminded us that not everyone has internet access, especially in his community.

View full profile

Age at interview: 47  
Sex: Male

SHOW TEXT VERSION EMBED CODE PRINT TRANSCRIPT

# Key messages about help-seeking, care pathways, & Long Covid clinics

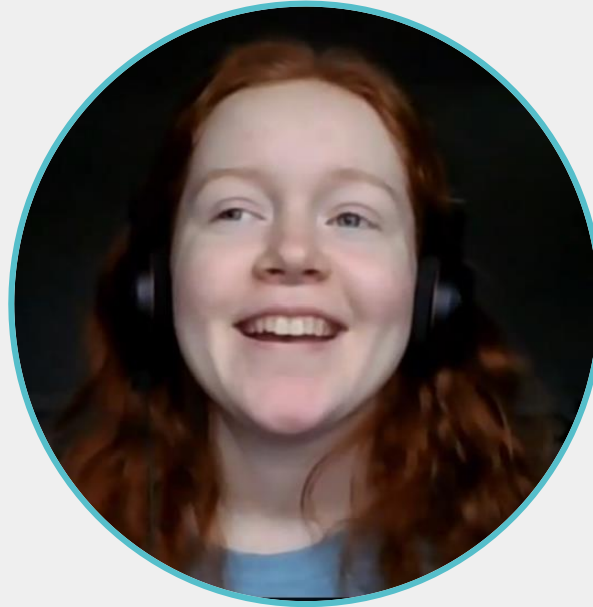
- Access to Long Covid clinics
  - Disparate coverage across four nations
  - Awareness & access to referral from primary care
  - Burden on patients to navigate & coordinate
  - Inequalities – how does a ‘typical’ patient present, economic inequality
- Meeting and managing expectations
  - Acknowledgement of the journey to get there
  - Personalisation depending on symptoms
  - Expectation of screening, testing (if not treatment)
  - (Appropriate) psychological input
- Self-management vs treatment
  - Strategies for self-management of symptoms in the absence of treatment
- Monitoring and surveillance function
  - Discharge from service not helpful for monitoring purposes

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# **Children, young people & Long Covid**

**Long Covid clinics: mini film**

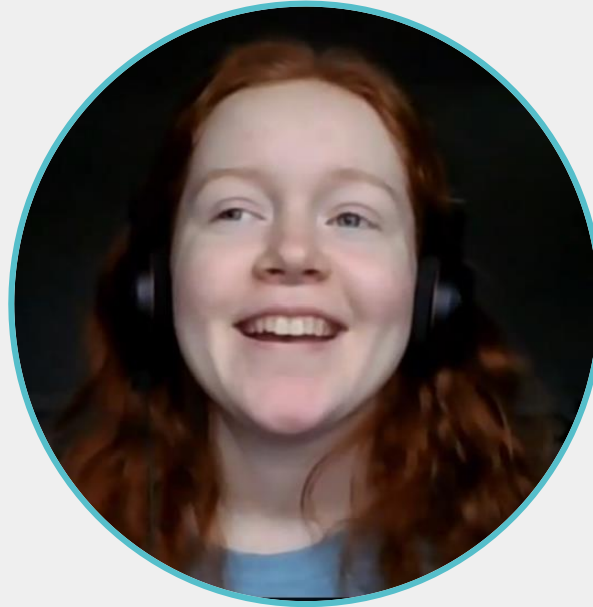


# LONG COVID KIDS



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# Gold Standard Paediatric Service

## Planning The Paediatric Perspective

Sammie McFarland

Helen Goss

CEO & Founder Long Covid Kids

[smcfarland@longcovidkids.org](mailto:smcfarland@longcovidkids.org)

COO & Scotland Lead

[hgoss@longcovidkids.org](mailto:hgoss@longcovidkids.org)

LONG  
COVID  
KIDS

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# Our Families Experience

Colin Pidgeon  
LCK Rep Northern Ireland

Rosie Pidgeon  
Youth Representative

[cpidgeon@longcovidkids.org](mailto:cpidgeon@longcovidkids.org)

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COVID  
KIDS**

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## THE PIDGEON FAMILY EXPERIENCE

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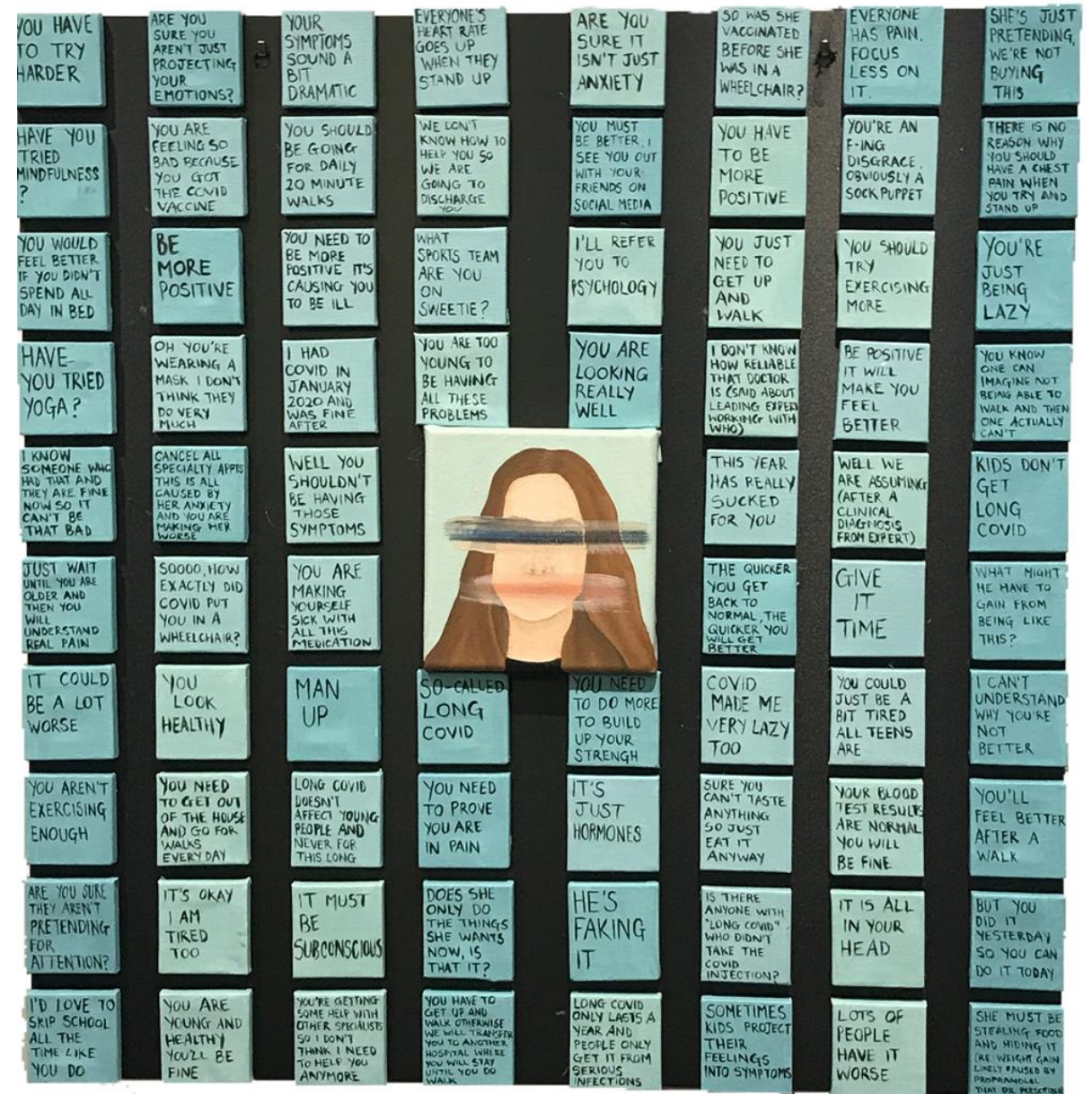
- Rosie's infection August 2021
- Initially mild symptoms but instead of recovery, symptoms worsened
- Mental and emotional distress lagged the physical illness, watched as she shrank physically and crumbled in a spiral of decline
- Success! (??) Referral to Long Covid clinic

**LONG COVID KIDS**



# ROSIE'S EXPERIENCE OF THE LC CLINIC

- Zoom assessment (2 x 45 minute sessions – caused PEM)
- Sent material to read, and diary to complete
- Told to walk every day 20 minutes/day and increase
- Discharged



# ROSIE'S ARTWORK

- Expression of the experience of Long Covid for children and young people



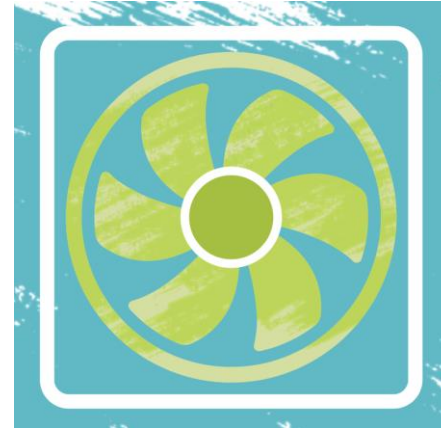
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# Long Covid Kids Vision for a Gold Standard Paediatric Long Covid Clinic

LONG  
COVID  
KIDS

# INFECTION CONTROL

- Acknowledge and address the risk of reinfection and widespread transmission.
- Implement suitable and effective air filtration and ventilation measures to ensure a safe environment.
- Support mandatory mask-wearing to prevent further transmission.





## PAEDIATRIC CONSULTANT LED

- Ensure the clinic is staffed by paediatricians with understanding, awareness and experience in treating post-viral illnesses and conditions associated with Long Covid, inc;
  - ME/CFS,
  - POTS,
  - Dysautonomia,
  - MCAS,
  - PANS.

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**LONG COVID KIDS**



“ Jay loved boxing, football and playing outside with our pugs. Now he can hardly weight bear, using a wheelchair and mostly bed bound with fatigue. Initially, he improved after 6 months then a rapid decline in th last 2 months and now unable to participate in any of his usual activities or attend school.

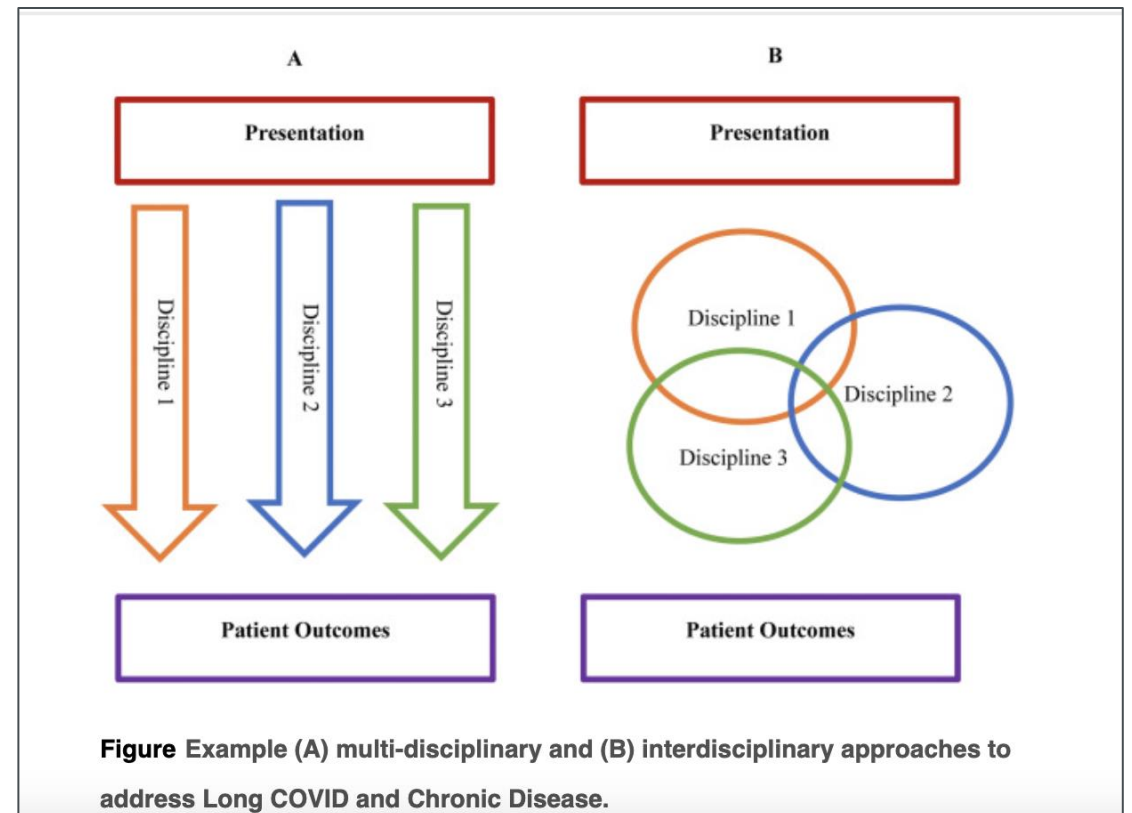
Jay  
Age 12  
Living with Long Covid since January 2022

*“COVID HAS COMPLETELY CHANGED MY LIFE, I AM MISSING OUT ON ALL THE THINGS I WANT TO DO.”*

# INTERDISCIPLINARY TEAM APPROACH

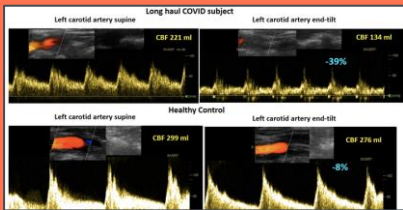
- Foster collaboration among clinical specialisms, including;
  - Cardiology,
  - Neurology,
  - Psychology,
  - Endocrinology,
  - Gastroenterology,
  - Immunology,
  - Rheumatology,
  - Dietetics,
  - Occupational Therapy,
  - Physiotherapy,
  - Speech and Language Therapy.

## Long COVID – Integrated Approaches to Chronic Disease Management?

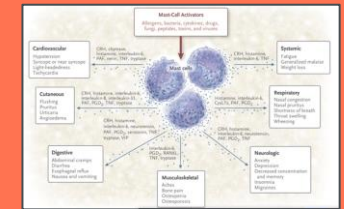


# PATIENT SAFETY

- **Prioritise multi-system screening BEFORE commencing rehabilitation.**
- Screen for conditions associated with Long Covid to tailor treatment accordingly.
- Obtain consent for data collection and commit to recruiting patients to clinical trials.



PEM/PESE - follow NICE guidelines for ME/CFS.  
POTS/Orthostatic intolerance



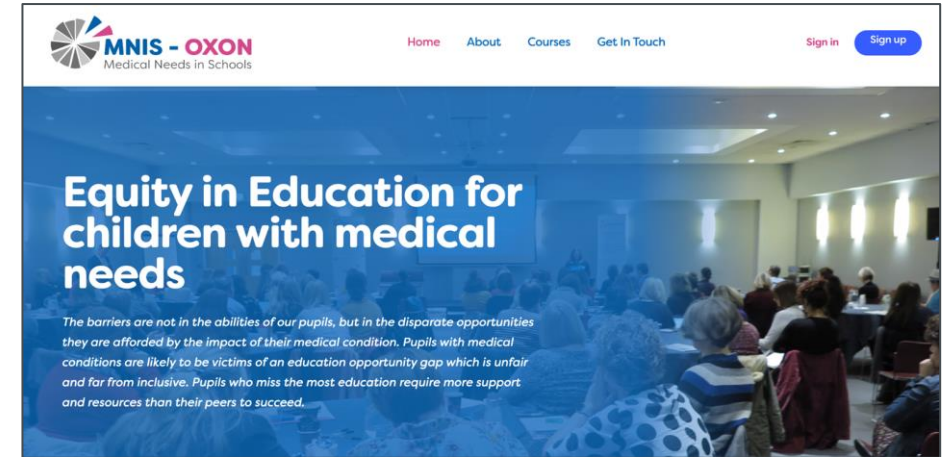
Cardiac abnormalities  
Mental health  
Hypermobility and connective tissue disorders  
Pain  
Food intolerances / new or worsened allergies

Autoimmune disease  
Inflammatory markers  
Microclotting  
Mood and/or behaviour changes  
Neurological disorders.

# HOLISTIC APPROACH

- Provide empathy, support, and validation to patients and their families.
- Begin treatment pathways for pathology before initiating rehabilitation.
- Communicate with schools, school nurses, hospital schools and community services to support and develop appropriate hybrid academic support plans for children during their recovery/duration of illness.
- Offer sleep and lifestyle advice for overall well-being.

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# RECOGNISE NON NHS HEALTH CARE

- Acknowledge and incorporate external expertise in a collaborative manner.

**Buonsenso&theKids**

In children there is already experience with Ivabradine before the pandemic!

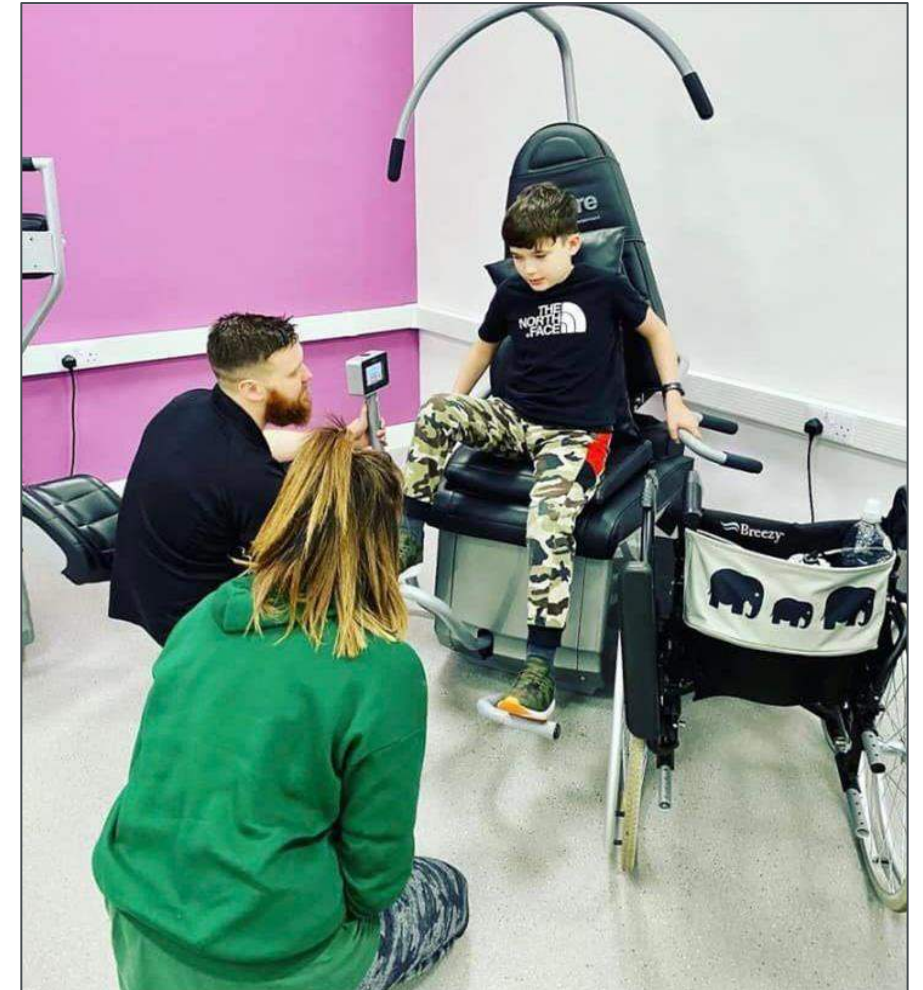
Review  
**Role of ivabradine in pediatrics: A review article**

Pallavi Choudhary<sup>a</sup>, M.D. Ehtesham Ansari<sup>b</sup>, Murtaza Kamal<sup>c,\*</sup>

<sup>a</sup> Consultant Department of Pediatrics, Mahavir Hospital, Jhunjhunu, India  
<sup>b</sup> Consultant Department of Pediatrics, Nestiva Hospital, Patna, India  
<sup>c</sup> Consultant Department of Pediatric Cardiology, Madhukar Rainbow Children's Hospital, New Delhi, India

PEDIATRIC STUDIES	Randomized, double blind, placebo controlled phase II/III study	Age group 6 months to 18 years 116 children Patients with DCM with a history of class II to IV symptomatic heart failure functional class and an LVEF ≤45% on stable treatment for chronic heart failure	Starting dose of 0.02 mg/kg twice daily for children 6 months to 12 months and 0.05 mg/kg twice daily >1 year. For children >40 kg dose of 2.5 mg twice daily. Dose adjusted every 2 weeks	Monitoring for 12 months on treatment with monthly visits up to 3 months and then visits at 6,9 and 12 months, ACE inhibitors, diuretics, beta blockers, digitalis and angiotensin II antagonists	Primary endpoint (≥20% reduction in heart rate from baseline without inducing bradycardia) achieved by 70% taking ivabradine versus only 12% taking placebo. NYHA functional class improved more with ivabradine	Similar frequencies of adverse effects for ivabradine and placebo groups
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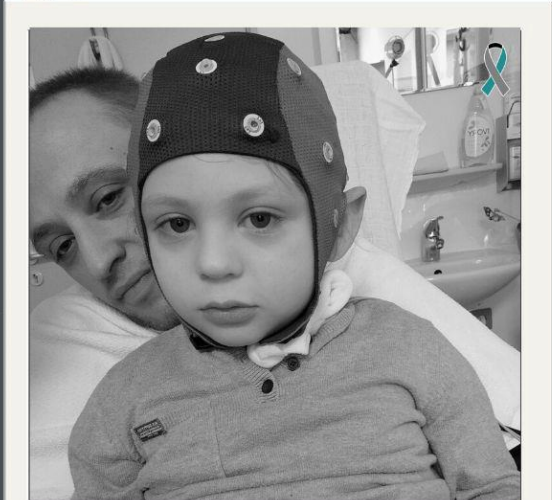
Abbreviations used: ACE inhibitors - angiotensin converting enzyme inhibitors, β blockers - beta blockers, NYHA class - New York Heart Association, OD - once a day, BD - twice a day, DCM - dilated cardiomyopathy, LVEF - left ventricular ejection fraction.



# TREATMENT AND MONITORING

- Individualised goal orientated treatment plans based on ongoing symptoms and emerging issues.
- Ensure continuous objective monitoring and evaluation of quality of life.
- 6 monthly or annual reviews for all those not back to premorbid health and activity status.
- Discharge survey for monitoring, research and future planning.

LONG COVID KIDS



“ From then to this day, he has constant pain in his hands, feet and teeth.

The rest of the unpleasant symptoms are a "bonus", they come and go when they want.

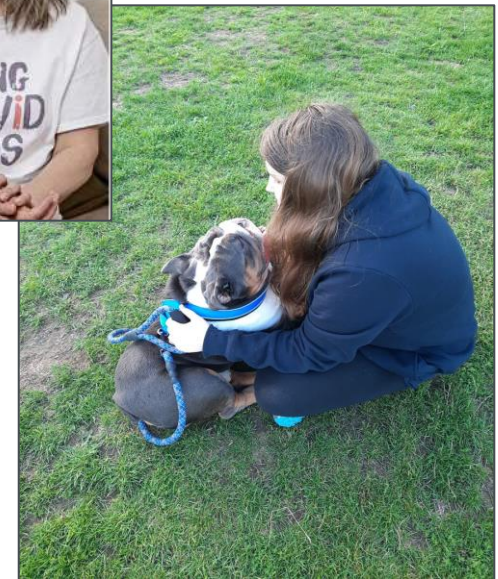
He has not stopped visiting different hospitals to accept everything that his fragile age allows. At the moment there is absolutely no change in his condition. ”

**Borimir**  
Age 4  
Living with Long Covid since December 2020

LONG COVID KIDS

# FOLLOW UP CARE

- Provide detailed patient-specific guidance for GPs/primary care teams.
- Deliver expert advice on monitoring, ongoing medication, and access to community support services.
- Determine the decision for discharge based on sustained progress and the family's readiness, rather than adhering to a rigid time frame.
- Consider a LC Community service with open access pathway back to the Long Covid clinic



# CONTINUED PROFESSIONAL DEVELOPMENT

- Ensure continuous reflection, learning and the sharing of best practices across national and international services.
- Stay updated with the latest research and advancements in paediatric Long Covid.
- Educate Primary Care staff to improve awareness and diagnosis for prompt referral.

**LONG COVID KIDS**

**nature reviews immunology**

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nature > nature reviews immunology > review articles > article

Review Article | Published: 11 July 2023

### The immunology of long COVID

Daniel M. Altmann , Emily M. Whettlock, Siyi Liu, Deepa J. Arachchillage & Rosemary J. Boyton

Nature Reviews Immunology (2023) | [Cite this article](#)

67k Accesses | 3624 Altmetric | [Metrics](#)

#### Abstract

Long COVID is the patient-coined term for the disease entity whereby persistent symptoms ensue in a significant proportion of those who have had COVID-19, whether asymptomatic, mild or severe. Estimated numbers vary but the assumption is that, of all those who had COVID-19 globally, at least 10% have long COVID. The disease burden spans from mild symptoms to profound disability, the scale making this a huge, new health-care challenge. Long COVID will likely be stratified into several more or less discrete entities with potentially distinct pathogenic pathways. The evolving symptom list is extensive, multi-organ, multisystem and relapsing-remitting, including fatigue, breathlessness, neurocognitive effects and dysautonomia. A range of radiological abnormalities in the olfactory bulb, brain, heart, lung and other sites have been observed in individuals with long COVID. Some body sites indicate the presence of microclots; these and other blood markers of hypercoagulation implicate a likely role of endothelial activation and clotting abnormalities. Diverse auto-antibody (AAB) specificities have been found, as yet without a clear consensus or correlation with symptom clusters. There is support for a role of persistent SARS-CoV-2 reservoirs and/or an effect of Epstein-Barr virus reactivation, and evidence from immune subset changes for broad immune perturbation. Thus, the current picture is one of convergence towards a map of an immunopathogenic aetiology of long COVID, though as yet with insufficient data for a mechanistic synthesis or to fully inform therapeutic pathways.

**healthcare** 

Case Report  
**A Case Study of Successful Application of the Principles of ME/CFS Care to an Individual with Long COVID**

Lindsay S. Petrack, Camille A. Broussard, Renee L. Swope and Peter C. Rowe 

The Division of Adolescent and Young Adult Medicine, Department of Pediatrics, Johns Hopkins University School of Medicine Baltimore, Baltimore, MD 21285, USA; lpetrack@hopkins.edu (L.S.P.); camillebroussard@hopkins.edu (C.A.B.); swope@hopkins.edu (R.L.S.)  
\* Correspondence: petrack@hopkins.edu; Tel.: +1-410-955-9229; Fax: +1-410-414-1176

**Abstract:** Persistent fatigue is one of the most common symptoms of post-COVID conditions, also termed long COVID. In the extreme end of the severity spectrum, some individuals with long COVID also meet the criteria for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), raising the possibility that symptom management approaches for ME/CFS may benefit some long COVID patients. We describe the long-term outcomes of a 19-year-old male who developed profound impairment consistent with ME/CFS after a SARS-CoV-2 infection early in the pandemic. We evaluated and treated him using our clinic's approach to ME/CFS. This included a history and physical examination that ascertained joint hypermobility, pathological reflexes, physical therapy maneuvers to look for a range of motion restrictions in the limbs and spine, orthostatic testing, and screening laboratory studies. He was found to have profound postural tachycardia syndrome, several ranges of motion restrictions, and most of all activation syndrome. He was treated according to our clinic's guidelines for managing ME/CFS, which included manual physical therapy, movement and both non-pharmacologic measures and medications directed at postural tachycardia syndrome and near cell activation. We report significant improvement in his symptoms over 36 months. His case emphasizes the application of the principles of treating ME/CFS has the potential to provide a direction for treating long COVID.

 Lindsay S. Petrack, Camille A. Broussard, Renee L. Swope, Peter C. Rowe

### How do Covid reinfections affect Long Covid?

Results from an internet survey of people with Long Covid

**Summary**  
Long Covid Support and Long Covid Kids surveyed people with Long Covid about their experience of being reinfected with Covid. Responses were received from 854 adults and 112 children and young people. Reinfection worsens the symptoms of Long Covid in the majority those who are still symptomatic. Reinfection causes a recurrence of Long Covid in 80% of those who were in recovery or remission, 89% of respondents first got Long Covid after their first infection, 10% after their second infection and 1% after their third. Most adult respondents had been vaccinated before their second infection.

Long Covid Support  [info@longcovid.org](mailto:info@longcovid.org)  
Long Covid Kids  [info@longcovidkids.org](mailto:info@longcovidkids.org)

Long Covid Support  [info@longcovid.org](mailto:info@longcovid.org) | Aug 2022 | Reinfections in Long Covid Survey



# EXPECTATIONS AND SIGNPOSTING

- Provide service outline from the point of referral with clear written communications, pre-assessment self-management advice.
- Support convalescence, Pacing, and 'light' PoTS protocols.
- Signpost to Long Covid Kids for community connection, support and resources.
- Be transparent.



**Resources & support**

We have a duty of care to ensure all children avoid infection by ensuring indoor spaces are well-ventilated with clean air and layers of mitigation are considered appropriately. There are many ways we can all improve the health and learning outcomes for children and young people living with Long Covid. The resources below will continue to evolve as we all learn more about the mechanisms of Long Covid.

**Publications**  
**Research and commentary articles**

**Future Microbiology**  
Clinical characteristics, activity levels and mental health problems in children with long coronavirus disease

**Nature Medicine**  
Promotion of non-evidence-based therapeutics within patient-led Long Covid support groups

**The Lancet Child and Adolescent Health**  
Long Covid in children

**medRxiv Pre-Print**  
Long Covid active case finding

**Science**  
COVID-19 and children

**GAVI: The Vaccine Alliance**  
Reinfection Survey

**Books**

**Shining a Light on Long Covid in Children and Young People**  
A chapter within **The Long Covid Handbook** on Long Covid in Children and Young People (Publication October 2022).

**Sec Ed**  
How can we support pupils who have Long Covid?

**Key blogs and professional magazines (continued)**

**WHO**  
The personal stories behind the establishment of 2 Long Covid groups

**WHO**  
"An absolute tsunami of need": a conversation with Sammie McFarland, founder and CEO of Long Covid Kids

**WHO**  
Life as a young person with Long Covid: "you go through so many phases of up and down, it's like being on a rollercoaster forever"

**British Journal of Child Health**  
Supporting children and young people with Long Covid in the classroom

**British Journal of Child Health**  
Long Covid: new guide to recognition, support, and recovery

**Evidence-Based Nursing**  
Supporting Children Living with Long Covid to Return to School in September

**Evidence-Based Nursing**  
Summer Holidays with Long Covid Kids

**Sec Ed**  
How can we support pupils who have Long Covid?

**World Health Organization**

**Long Covid Kids**  
Child Specific COVID-19 Infection Analysis

**OT News**

**Long Covid Kids**  
Child Specific Statistics and Analysis

**Long Covid Kids**  
Pacing Penguins

**Long Covid Recovery for Children**  
A Cautious Tortoise

**Televisual, video and podcasts**

**Nearly 120,000\* children in the UK are living with Long Covid | 5 News**

**FYI Investigates: Long Covid**

**Project NZ**

**Sec Ed Supporting Students with Long Covid**

**Long Covid Kids Awareness Video**

**Resources**

**Shining a Light on Long Covid in Children and Young People**

**Pacing Penguins**

**A Cautious Tortoise**

**LCK Newsletter**

**TWINKL resources**

**Leaflets for professional bodies**

**Pdlet series**

\*As reported on 7 February 2022 – the number of children living with Long Covid has since increased.

**Pictured right: from top, Pacing Penguins poster, Pdlet for Schools & Educational Professionals, Teraki Resources**

10 longcovidkids.org

longcovidkids.org 11

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## CONCLUSION

This clinic should prioritise research, innovation, and family engagement to enhance the understanding and treatment of Long Covid in children.

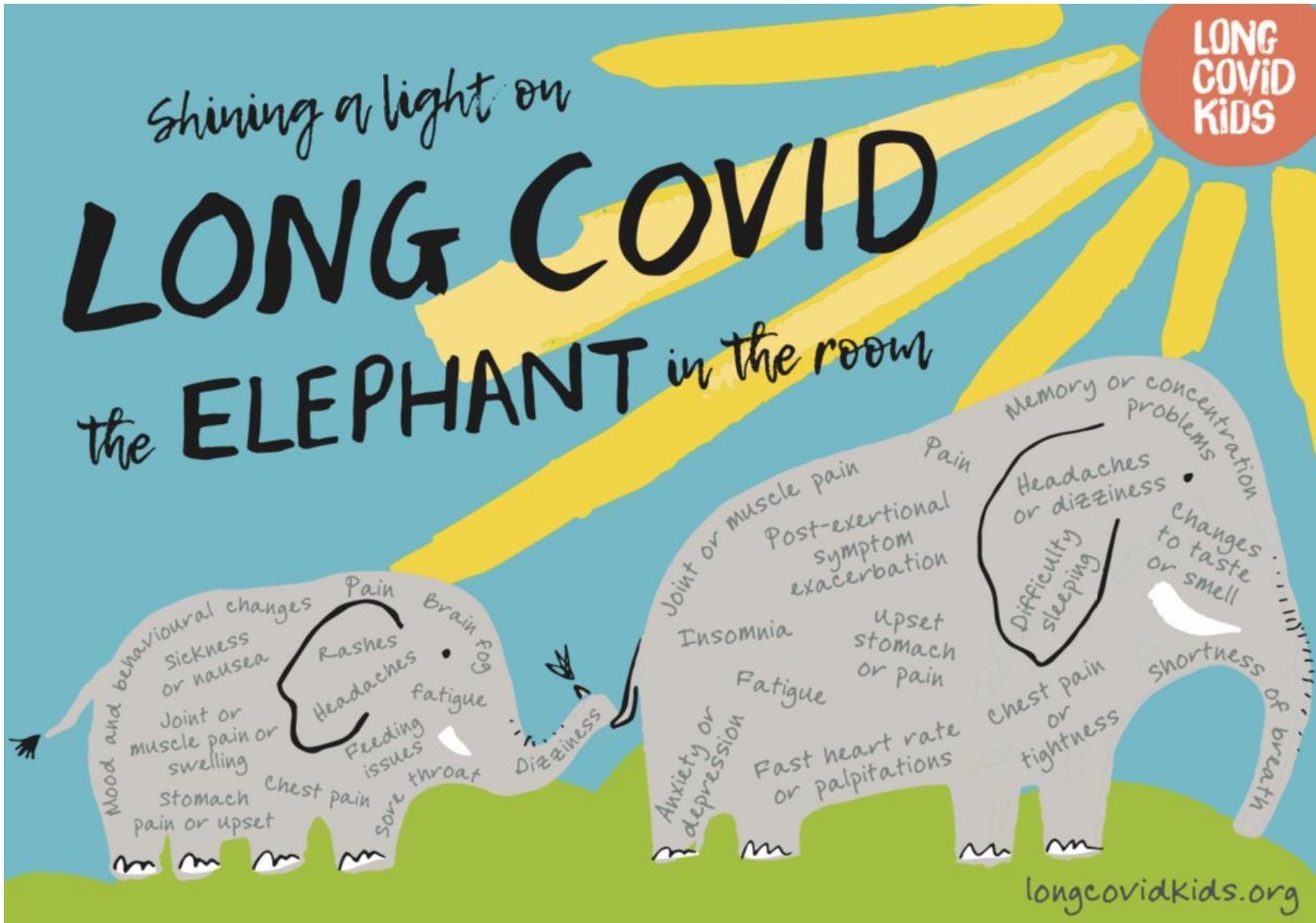
**LONG  
COVID  
KIDS**



**The Gold Standard  
Long Covid Clinic for Children  
should be a centre of excellence,  
offering comprehensive  
assessment, treatment,  
rehabilitation, &  
mental health support.**

By adhering to evidence-based principles and incorporating the key considerations, this clinic aims to improve outcomes and quality of life for affected children, serving as a guiding framework for healthcare providers, policymakers, and communities.

**Together, we can create a brighter future for children harmed by SARS-CoV-2.**



LONG  
COVID  
KIDS

Shining a light on  
**LONG COVID**  
the **ELEPHANT** in the room

Please sign up to our newsletter via our website to stay in touch.

<https://www.longcovidkids.org/>



[info@longcovidkids.org](mailto:info@longcovidkids.org)



[@LongCovidKids](https://twitter.com/LongCovidKids)

Thank you.

**LONG COVID KIDS**

# 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](mailto: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](mailto: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](mailto:england.insight-queries@nhs.net)