**UK Covid-19 Inquiry**

**Long Covid roundtable**

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Leicester and online

*Participants*

Ben Connah, UK Covid-19 Inquiry

Martin Hogg, Citizen Coaching and Counselling

Lesley Macniven, Long Covid Work

Professor Amitava Banerjee, UCL Institute of Health Informatics

Valentina Viduto, Long Covid-19 Foundation

Dr Alison Twycross, Long Covid Nurses and Midwives UK

Elaine Maxwell, Long Covid Support

Ondine Sherwood, LongCovidSOS

Professor Brendan Delaney, Institute of Global Health Innovation, Imperial College London

Sammie Mcfarland, Long Covid Kids

**Ben Connah:** [00:05:11] Hello everybody and thanks very much indeed for joining us today. I will say something about recording in a moment. But first of all, I'll introduce myself. My name is Ben Connah. I'm the Secretary to the UK Covid-19 Inquiry. It's an independent inquiry, as I'm sure you'll know, chaired by Baroness Hallett, a retired Court of Appeal judge. And it's being set up to look at the UK's response to the pandemic.

Huge thanks to all of those of you who have been able to join today's meeting. Some of you in person, many thanks for coming, and some of you online. We recognise that everybody here today will have had, at the very least, a personal and in some cases, also a professional response to the pandemic. And today's meeting might raise some difficult issues for some of us. I want therefore, to introduce at the outset, Martin Hogg, who is sitting here in the room with us today. Martin is available today to anybody who needs support, either during the meeting, or afterwards; Martin's contact details are on the first page of your agenda. But Martin, can I just ask you to say a little bit about why you're here.

**Martin Hogg:** [00:06:33] Thank you, Ben. I'm Martin from Citizen Coaching and Counselling. And I'm here for that moment when you need to just step away and maybe take a time-out. And we know that people are affected differently by discussing these kinds of things. Even if in a couple of days' time, it would be useful to have a debriefing session with me or one of my team, then just make contact with us and we'd be happy to arrange a time to speak to you. Everything you say to us is confidential, and not recorded in any way as part of the Inquiry.

**Ben Connah:** [00:07:08] Thanks very much indeed, Martin. So over the last three or so weeks since we launched the consultation on the Inquiry's Terms of Reference, we as a team have been going around the country with Baroness Hallett, meeting a number of bereaved families, and also organisations that have been affected by the pandemic. I'm talking to you from Leicester today. We met a group of bereaved families earlier today. But this afternoon, as you will know, is all about long Covid.

And so I'm here today with my team to hear from you about the different perspectives that long Covid has brought about in your lives, both personal and professional, over the last year or two. I need to be clear at the outset, though, that these sessions are not about giving evidence. That will come later, once the Terms of Reference for the Inquiry have been finalised. Today is about those Terms of Reference.

We were presented with a draft set of Terms of Reference by the Prime Minister about three weeks ago now. And since then, we've been consulting on his behalf but really on behalf of the Chair Baroness Hallett to understand what the public and in particular those who've been most affected by Covid think the Inquiry ought to be covering. Organisations that we've met, we've tried to group according to sector or particular interests. So we've met a lot of organisations, for example, who work on various equalities issues. We've met with some business organisations, we've got a session on arts and culture later this week. As I say, though, today is about long Covid.

And of course, we're asking the public to give their views online as well. So not many people are able to come along to these sessions, because we want to keep them focused, and we want to make sure that we hear from everyone. But we've also opened a public consultation on our website that we hope will enable anybody who's got a view on what the scope and what the Terms of Reference for the Inquiry should be, to be able to give their views.

One of the reasons why, just as we started this meeting, you will have heard a little message saying that this is being recorded, is that we're really keen to capture everything that's said today. So the recording of this meeting, which is an audio recording, will go to form a transcript. And we're intending to publish that transcript at the end of the consultation process along with transcripts of all the other meetings that we've had to discuss specific issues. We're not publishing transcripts of the meetings we're having with bereaved families, but where individuals are representing organisations or their professional roles, we will be doing that. And as a result, the default is that you should expect to be named in those transcripts. Now, if there are reasons why you would rather not be named, please do let us know and of course, we'll find a way to achieve that.

At the end of this session, I'll aim to summarise some of the key points that I've heard. But please rest assured that if I miss something that you've said, that isn't the end of the story. Like I say, the transcript is here as the failsafe. And it's the transcript rather than my own musings, that will become part of the record of this consultation process, and will feed into the analysis and then into the chair's final recommendations to the Prime Minister.

The consultation is open until 7th April and after that, I anticipate it will take a few weeks for the Chair to get her head around the full scale of the opinions that have been set out, and then to make her recommendations to the Prime Minister. We hope that the Prime Minister will then very quickly turn things around and provide us with our final Terms of Reference, because at that point, we can really begin work in earnest. And it's from then that we will begin establishing the shape of the Inquiry, according to those Terms of Reference, and we can begin to take evidence from the various organisations from whom we'll be asking.

I will over the course of this session try to keep us to time as best as I can. The bulk of the session, of course, will be focused on the four particular questions that we've asked in our consultation. But I'm really keen, given that this is a very specific issue that we're talking about today, to spend a little bit more time than perhaps we have in some other sessions on introductions, because I'm really keen to understand people's professional backgrounds, but also, whether there are any personal circumstances that people would be happy to share today about their own experience of long Covid.

We will keep the chat function open on this Zoom call. And so those of you who are online, if you wish to add anything to the chat, please do. But what we won't be able to do, partly because I'm not brilliant at multitasking, will be to respond to every single thing that's in the chat today, we will go keep a record of it and feed that into our overall consultation. If you do, though, want to make a point, ask a question, make an observation, then I'd be really, really grateful if you could raise your hand either in the room, or just catch my eye, since there are only two of you, or online please use the ‘raise hand’ function.

And if that doesn't work, or you can't find it, then waving your hand might be just as effective because I will occasionally look down to my right. That's because I've got my laptop in front of me, I can see all of you who've got your cameras on. And I will make sure that I'm keeping more than half an eye on that screen so that I can see if and when hands do go up.

For those of you who are joining from organisations that aren't based in England, I'd be really, really keen to understand whether there are any differences in the other nations of the United Kingdom. And likewise, for those of you that are in England, whether you're aware of any disparities or differences with Northern Ireland, Wales or Scotland. This is a UK wide inquiry. And so we need to keep that in mind.

It would be remiss of me not to acknowledge the fact that some of you will have had very difficult experiences during the pandemic. And of course, we're here to talk about long Covid. And one of the most common symptoms of that is the fatigue and concentration issues that can occur. So we've agreed that today we will have rather more short breaks than normal, just to allow people to collect their thoughts and just take a breath in between discussions.

I'm anticipating that we will take a break round about every 20 or 25 minutes over the course of this session, but I'll try to make sure that they fit neatly within the narrative rather than interrupting people's flow. Please do either let me know if you think I'm drifting a little bit on that promise, or of course, if you just need to take some time out, either on your own then do, or if it's helpful to get in contact with Martin then again, he's here to help for exactly that sort of thing.

So I suppose I ought to say that for those that are in the room, at any rate, we're not expecting any fire drills today. So if there is a fire alarm, we will show you where to go, and I offer my apologies in advance if there is one, but we will find a way to make sure that we recover matters if that happens. I'm sincerely hoping it won't happen, it would be the first time on our tour of the UK.

I hope that is a clear enough introduction about what we're hoping to get out of today. But it would be great, as I say, to hear from all of you about who you are, if you're representing an organisation which organisation it is, and also if you feel able and you're willing to just say a little bit about your experience of the pandemic and in particular of long Covid. I wonder if I could start online, please. First of all, I'll ask: is there anyone who would like to go first? I'd be most grateful for a volunteer. I think it's Ondine, many thanks Ondine.

**Ondine Sherwood:** [00:16:11] Thank you very much. My name is Ondine Sherwood. I am one of the co-founders of Long Covid SOS, which is a campaign group. We're currently applying for charitable status. We formed in June 2020. And can I please apologise for the noise, the background noises, there's some terribly noisy demolition going on behind me.

I caught Covid – suspected Covid in March 2020. It was quite mild, but it turned into a relapsing and remitting condition. And I had it on and off for well over a year. I still have some symptoms, but I'm much better now. In my other life, I'm an IT consultant. I'm also a member of a research ethics committee. I think I've covered everything. Thank you very much.

**Ben Connah:** [00:17:01] Ondine. Thank you very much indeed. That's perfect and sets the tone really nicely for the intros. We will, of course, come back to the particular issues that long Covid is presenting as we talk about the Terms of Reference. So thanks, Ondine. And that's great. Perhaps if you don't mind, I'll stay online and I'll work my way around those people who I can see on screen. Lesley, do you think I could come to you next please? Thank you.

**Lesley Macniven:** [00:17:29] Sure, and thank you. Very similar to Ondine helpfully in that I've also been ill since March 2020. And still as bad at the moment as I was, at any point, to be honest, which has been a two-year journey. In that time, I thought I was recovering quite early on in the process only to be hit with the relapsing, remitting nature that Ondine mentioned. But over that period, I've dedicated what energy I've got to campaigning for people with long Covid starting with being a founding member of Long Covid Support, which is another long-standing patient-led organisation now forming a charity. And I also co-founded Long Covid Scotland, because I'm up in Edinburgh, to try and look at devolved issues. And so I would be able to signpost you to people that you can speak to in Scotland.

Most recently, in 2021, I took on the role of Chair of the Long Covid Support Employment Group to look specifically at employment. So the reason for that is that my background pre-Covid was - I'm an organisational development consultant and a fellow of the CIPD. I'm looking at this through the lens that I was looking at immediately before I contracted long Covid, which was from an inequalities and diversity and inclusion angle. So I'm interested that you've looked at equalities as a separate thing, but I think there's huge links, which we'll see, between this conversation and that conversation as well.

The last thing I was doing was writing about inequality in the workplace and so I started taking notes about what I saw happening to people as a result of long Covid. So my perspective for the last two years has been what are the impacts of long Covid. And most recently, as a writer, I've been enabling people with long Covid to do creative writing about the experience of long Covid and running public events where they can share that story as part of their healing journey, but also to give people insights into what it's been like for us.

So I'm delighted to be part of the conversation today from several perspectives, mainly as a as a CIPD HR professional; a change management perspective, in terms of how we could do this better, is really important – excuse me – I think for us to be looking at this, but also from an inclusion perspective. So as well as looking at what's in the Terms of Reference, my first thought was what's not in the Terms of Reference that needs to be. So thank you for inviting us along today.

**Ben Connah:** [00:19:58] Great. Thanks very much indeed, Lesley. I'm really grateful. Alison, can I come to you next please?

**Alison Twycross:** [00:20:09] Hello, I'm Alison Twycross and I'm a nurse. I don't work – I haven't in many years. I'm an academic. I used to be a Deputy Dean and Professor of Children's Nursing in a previous role. I had just started full time work again after a year's gap seven weeks before I caught Covid, and have been off sick for two years. And have recently handed my notice in at that new job.

Like many others, I caught Covid in March 2020, and I am better but nowhere near back to the person who could commute to London and work 14 hours a day. I have to pace very carefully. I had to have a super early lunch today so I could have a sleep before this meeting. As someone who's used to writing, my cognitive dysfunction from long Covid makes it quite hard to do and takes much longer, and I have to have much better proof-readers than in the past.

So I'm still struggling with ongoing symptoms, I did have long term conditions before getting Covid. Those are multiplied. And you said to talk a bit about long Covid experience: I remember ringing NHS 111, the first weekend that I had Covid symptoms and asking them, 'Do I need to stop my immunosuppressants? When do I worry about my asthma? And just being told to stay at home. Stay at home.' And there was no advice.

So as someone who was very used to managing my long-term conditions, overnight, all my support for that disappeared. And that's been mirrored in how I've had to fight to get tests and support for my long Covid. And that's a bit of an ongoing battle. I'm here as Chair of the recently set up Long Covid Nurses and Midwives UK, which I set up at the end of January, because I was hearing so many stories on social media about how badly many – most – NHS nurses and midwives who have been off sick with long Covid for a year or two are being treated. I should declare that I'm also a member of the Long Covid Support Employment Group, but Lesley's here supporting that. So that's not part of my remit today. And yeah, looking forward, as we said, to discussing what's missing from the Terms of Reference. Thank you very much.

**Ben Connah:** [00:22:57] Great. And thank you, Alison, for joining us today. Brendan.

**Brendan Delaney:** [00:23:05] Brendan Delaney, I'm a general practitioner one day a week, this happens to be it. So I'm in between seeing patients. I'm also chairing Medical Informatics and Decision Making at Imperial at the Institute of Global Health Innovation, and Co-Chief Investigator of one of the NIHR long Covid studies called Locomotion, which is the one around service pathways and clinical management.

I also tend to say to people that I didn't choose to go into research on Covid; it found me. So I also caught Covid in March 2020. And I think I really had to manage very carefully. But looking back over the past two years, I would say for most of 2020 I was very suboptimal. And if I didn't have the ability to really micromanage my tasks, as an academic, most of the time, and also my practice were very helpful in terms of working from home and splitting things out, I really wasn't working optimally at all for 2020. 2021 was better. But I think it's really only this year, apart from a couple of issues, which I won't bore people with, generally much better, particularly the cognitive side of things. Again, I'm very interested in working out how we can actually represent long Covid properly in the questions because one little bit at the end is inadequate. Thank you.

**Ben Connah:** [00:24:37] Great, thanks very much indeed, Brendan, and yeah, you'll have guessed, I hope that although I can't pre-empt the outcome of the consultation, one of the reasons why we wanted to run this discussion was to understand whether that bullet was enough. And you've begun to answer that question. Thank you very much indeed. Sammie, can I come to you please?

**Sammie Mcfarland:** [00:25:03] Thank you very much. My name is Sammie Mcfarland. I'm the CEO and founder of Long Covid Kids, which is a UK-based international charity supporting families, children and young people living with long Covid. My daughter and I got Covid in March 2020, before community testing, and then never recovered. Two years into our journey, I have had to give up my work and she is not able to attend school.

I was International Women's Wellness Coach of the Year in 2012 and 2019, just before I got Covid. And I never really used to sit down. Now I rarely stand up. And my husband who runs Search & Rescue for Dorset Police Constabulary is our full time carer. I'm unable to care for my child in any capacity, really; we're both still experiencing ongoing symptoms, and neither of us have had any meaningful help or support. She's unable to access education.

Within the support services of our charity, we have over 10,000 members and my daughter's experience and my experience is not unique. And so I have used my transferable skills from the business that I won awards with in the year before I got Covid to setting up the charity to be able to support other families navigating this novel condition in the same way that we are. I identify now as a disabled person. And I am unable to participate in any previous activity that I used to participate in. And I'm here really to ensure that children and young people are represented with long Covid that they are now living with as part of the Inquiry. Thank you.

**Ben Connah:** [00:27:06] Sammie, thanks very much. Great to have you here. And of course, that you can speak on your daughter's behalf but also on behalf of so many members. Thank you very much for joining us. Valentina.

**Valentina Viduto:** [00:27:20] Hello, my name is Dr Valentina Viduto, I hold a PhD in computer science. I'm a founder of the Long Covid Foundation. We have been in operation for a year now. Well, the story is really sad, I think, on long Covid in the UK and globally as well. I had Covid, again, March 2020. And all my family had it; my children had continuous symptoms for half a year with no support from GPs. And at that time, I saw a really big lack of knowledge in healthcare. There was no support from GPs, not even trying to understand what was happening.

So at that time, as I have extensive research skills, I decided to look for expertise globally. And I found this expertise and I set up the charity to educate people on their symptoms to discuss issues around long Covid with top scientists and medics, and we provide – via recorded interviews, we provide this expertise on our YouTube channel. We also have over 11,000 people with long Covid from around the world. And people are really concerned about how they're being taken by medical professionals – experts.

So there is so much going on in terms of psychologising the disease and putting people on antidepressants, rather than treating them. So there is a huge lack of training for GPs and they still have no idea what long Covid is, how to diagnose, and what treatments to advise. Even though there are diagnostic solutions, there are treatments available. And we communicate this information to all sufferers who need us. So I would be really keen to have discussions on what it is available now and why it is not addressed in the UK yet. Thank you.

**Ben Connah:** [00:29:43] Valentina, thanks very much indeed. I'm going to come to the room and Ami, can I start with you please.

**Amitava Banerjee:** [00:29:53] My name's Amitava Banerjee, Ami for short. I am a Professor of Clinical Data Science at University College London, and a consultant cardiologist across UCL and Barts. So, I spend my time doing three things really: being a health professional, being a teacher, and being a researcher. And I think Covid and long Covid have affected all those three functions.

It seems that most of us here today are affected in the first wave, I was a bit later than some in April of 2020, was when I got Covid first time, and I've had it more recently again, and not had long Covid myself, but very much in front of me in both family members and colleagues are affected to varying degrees.

So I reflect that, you know, a cardiologist has no business looking at infectious disease or long term aspects of infectious disease, but I also fell into it, because initially, I think to the point that I think Brendan was raising about this not being a final bullet point. I think of long Covid as being very much related to what I call the direct and indirect effects of the pandemic. And I find it unhelpful to think of it in isolation, that it's part of the overall way that the pandemic has affected us and what our response should be.

So I started out, I'm trained in research as an epidemiologist or data scientist, so looking at excess deaths. And that's really where we've been focused as a country and as a globe really, as to what the effects of Covid are, and that's partly because of how we have tended to always look at mortality and not morbidity within diseases. And that's disadvantaged the way we've looked at long Covid in my opinion, as well as the indirect effects, which are things that have been delayed,

you know, whether it's cancer care, cardiovascular care. So many people with long Covid can have other health conditions as well, which contributes to the lack of care.

But really, I got into this space, because I was seeing longer term cardiac complications in April 2020. I initially was working in the Nightingale hospital and then back at UCH. And then with a colleague [inaudible], we set up a study called the COVERSCAN study to look at doing MRI scans of people to follow up whether there was a basis for ongoing symptoms. And we found there is, to some extent now. But there's been barriers along the way, some of that from within the scientific community, some of that from clinical colleagues, some of that from policy-makers. And I think there's lots that we can learn about how to do it better next time.

And I should say, like Brendan, I'm co-leading a large NIHR funded study called STIMULATE-ICP, which is looking at three things: current care, looking at developing the best pathway including medications, and trying to see how we can address inequalities during and beyond the pandemic. Thank you.

**Ben Connah:** [00:34:04] Ami, thanks very much indeed. And finally, Elaine.

**Elaine Maxwell:** [00:34:09] Hi. My name's Elaine Maxwell, I'm a trustee and co-Chair of Long Covid Support, which is an organisation that was started in May 2020, and currently has over 51,000 members, that's internationally as well as within the UK. And actually, I'm sure we'll come back to it, but your point about, is long Covid different in the devolved nations? Yes, it is. Different policies, different services available, so that does need to be considered separately.

My background is, I was working for the National Institute of Health Research before the pandemic, and my role there was as a knowledge broker to bring together different research projects and try and synthesise them and see what the state of knowledge on a subject matter is rather than just reporting a single research study. Before I became an academic, I was a nurse. And in the first wave, I went back and worked in intensive care, which is a whole other story. And I was actually involved in the national evaluation of the staffing preparedness to the first waves. But that might be another part of the Inquiry.

When it came back to NIHR, it was already abundantly clear that there were people who had not died but had not recovered. So we started looking at the evidence, and we published our first review of the evidence in October 2020. And a second review in March 2021.

One of the questions I think the review should look at is when policymakers started looking at the evidence, because at the time at which I was writing the first review, Chris Whitty was the head of the NIHR. And I was doing briefings for him and for the Cabinet Office, on the evidence on long Covid. And I think there's a really interesting question about how quickly that evidence was adopted or acted on by policymakers. Because I'm sure we can all give evidence. That perspective study was happening very early on in 2020. There was definitely evidence, not just anecdotal patient stories early on. And I think that needs investigating.

**Ben Connah:** [00:36:32] Elaine, thanks very much. I think that tees us up rather nicely for the first substantive part of this consultation. But given where we are, and I promised that we'd have two or three breaks, I'm just going to suggest that we take five minutes now. But just as a teaser, in case people want to be thinking about this during the break, I'm keen that we spend the next

probably 20 minutes or so on the first question. It's usually the one that prompts most discussion. It's whether the Inquiry's draft Terms of Reference cover all the areas that you think should be addressed by the Inquiry. We've already had a few bids, I think for other things that ought to be. So we'll spend 20 to 25 minutes on that from about 14.38 according to my watch, so we will just let people have a bit of time now. We'll put the room on mute so that you can have your own time and you'll all of course, be on mute too.

[Break]

Hello, everybody, thank you very much indeed, I can see that people are coming back gradually. So we will get cracking. And during the break, I was just catching up on some of the chat, which many of you will be able to see here. Ami, you will be pleased to know there was some support for the points that you were making, but also, clearly an awful lot of commonality and experiences between people who spoke. Thank you very much indeed again for that.

I'm going to move on to the meat of this meeting; we've got an hour and 20 minutes left and experience suggests that the bulk of the discussion tends to focus on the first of these questions. So having said that, I'd give it 20 to 25 minutes; we may well end up giving it a little longer. But the first question of the four that we have asked in our consultation is whether the Inquiry's draft Terms of Reference cover all the areas that you think should be addressed by the Inquiry.

I'm going to assume that not many of you will think that the answer is 'yes'. And so we can probably take 'no' as read. But I think if I may, I'll ask for comments from anyone who would care to come in. I've got a hand in the room already. So I will go to Ami and then Ondine and then Valentina and Sammie will come in after that. But please do, if anything else occurs, please do put your hand up or catch my eye if you'd like to say something on this too.

In the interest of fairness, I'm just going to ask people to speak for no more than three or four minutes. And so if I interrupt you, please forgive me. It's simply so that others can have a chance to get their points across too. Ami.

**Amitava Banerjee:** [00:45:05] I'm going to aim for less than a minute. So hopefully I won't need you to step in. I think that I would like to see long-term implications of Covid as being part of most of the bullet points, actually, rather than a standalone bullet point or in addition to, because you could argue that the UK Covid-19 Inquiry, by definition, includes both short term and direct as well as the longer-term effects. And therefore, whether it's looking at the inequalities or the impact of non-pharmaceutical interventions, or preparedness, all of that applies to long Covid.

And my other point was specifically about preparedness: I think it's a different kind of preparedness. In general, we have prepared for pandemics. This has been the remit of virologists and public health physicians, and doing mathematical modelling and looking at longer-term effects in relation to a pandemic, whether it's effects on other services, whether it's the potential longer-term effects, that's never been done before. You wouldn't find people like me or Brendan invited to that room to do that kind of preparedness or modelling and that shouldn't happen again.

Because that's part of the problem that we faced is that we have people from infectious disease communities who haven't necessarily been thinking about the longer term. And some of these

problems – sorry, final point – is that some, if not many, of these problems are pre-dating the pandemic. And we must use the opportunity to look at long Covid as a way to improve our services and our offering for other longer-term conditions as well.

**Ben Connah:** [00:47:18] Great, thank you very much. Very clear. Very succinct. Ondine.

**Ondine Sherwood:** [00:47:23] Thank you. Yes, to follow on from what Ami was saying about preparedness. We knew from SARS-1 that people did not necessarily recover, some of whom are still sick. And yet that was never really taken into account and so we weren't prepared for morbidity, only for deaths and hospitalisations. And what's more, that tendency has continued throughout the pandemic so that we're still not taking into account the fact that this disables people. So we're still only using hospitalisations and deaths as a basis for policy.

And unfortunately, that error in Government policy to ignore long Covid in the face of increasing evidence cannot be repeated in the Inquiry; we have to make sure that long Covid is at the heart of this Inquiry. And that it needs to flow through the entire Inquiry, along with hospitalisations and deaths. We may need a focus on long Covid, a particular module say, to focus on long Covid. But in the Terms of Reference, where it's only mentioning a provision for those experiencing long Covid, we need to look at why it wasn't predicted and why it took so long.

It was down to the patient groups like us to bring it to Government notice, to bring it to notice of the NHS in our case, and to the WHO. And so why did that happen and that has happened, and yet it's not been corrected, it's still the case that people are allowed to get infected in many, many numbers, despite the fact that we know a significant percentage of accounts have continued to be ill months or years later. So it's really, really important that it has a much more a much more clear distinction in the Terms of Reference than it does at the moment.

And that should also include the economic impact of long Covid, which, again, is something that is going to hit us soon. But it's still being avoided in terms of a policy discussion. And finally, we believe that the Human Rights Act has something to say here. And that we need to look at the Government's obligations under the Human Rights Act to take reasonable measures to protect health. And that's not happening at the moment. Thank you very much.

**Ben Connah:** [00:49:50] Thanks very much indeed Ondine. Very helpful indeed. As we go through this process, I'd be really keen to to build on either what you or others are saying. It just helps us to see how we could change or how we could recommend to the Prime Minister changes to these Terms of Reference. But that's incredibly helpful and your point about still not using the impacts of long Covid and the disabling effect in policy-making is really well made. Thank you. Sammie.

**Sammie Mcfarland:** [00:50:28] Thank you. I'd like to pick up the point about schools, please. It says restrictions on attendance of places of education, when I'm unclear if this will allow for discussion around investigating infection rates in schools, mitigation measures, recognition and risks of long Covid in children. There's been a theme throughout the pandemic for families to be hounded for attendance. And in fact, the education secretary recently hired many, many new attendance officers, and yet there's been no support for families who are actually living with long

Covid and how we can support those families to access education or just simply to be supported in the community.

So at the moment, I'm worried that the current term reads a bit narrowly. And it's simply about attendance. And I'd like it to be clarified whether we can include or we must include the devastating effects of allowing children to be infected. And in particular, most recently, we're learning that children who did not develop long Covid in their initial infection, have now had multiple infections – two, three, four infections for some children, and these children are now developing long Covid.

So how are we learning from this to make sure that we are reducing risk right now for this preventable condition on this generation of children? And I forgot to say in my introduction that I'm actually currently with my second infection at the moment; two years, one day after getting my first infection, I've contracted Covid again. So I'm sorry that I'm sitting in bed, and I keep turning my camera off, because I'm coughing. Thank you.

**Ben Connah:** [00:52:19] Thank you, Sammie. I hadn't realised you were still poorly or you were poorly again, I'm really sorry. Certainly not an anniversary to celebrate. I hope you get well soon. Thank you for that. Just to answer your question, I suppose the Terms of Reference is the set of hooks on which the Chair, Baroness Hallett, will be able to hang her investigations. But nonetheless, she is keen that those hooks should be as clear and as extensive as possible to enable as much as we need to hang off them.

So if we do need to make that clearer, then we'll look really hard at that. And you'll know that there's been quite a lot of commentary since we opened the consultation on children – or the lack of mention of children in the Terms of Reference, so it's certainly something that's at the top of her mind. Thank you.

I've got a hand in the room. So I'm going to go to Elaine and then – forgive me, Valentina's hand was up first, and then it went down. I'll come to Valentina and then Elaine. And then it's Alison, Lesley and Brendan. Valentina.

**Valentina Viduto:** [00:53:28] Yes, so first of all, I think it needs a little clarification, whether we are doing an inquiry on Government decision-making or NHS decision-making, because throughout the document, there is a mess in terms of wording it uses. For example, the first bullet point says local public health decision-making. And then we talk about the response of the health and care sector.

So I think before we dig into specific points, we need to clarify whether the NHS made any decisions on PPE or any sort of things that are discussed such as procurement and distribution of key equipment and all these points. Are we assessing the NHS, or maybe the Government was responsible for making these decisions, and maybe not local public health institutions.

So this is one point; then I think, first bullet point, again, talks about that relation to central devolved or local public health decision-making. And then we have the justice system, how does this link to the justice system, how does this link to immigration? I mean, if we're talking about healthcare, and the way how it's handled the pandemic, and long Covid, why are we including

these four points under the first bullet point? I think it's a little nonsense over here. So it needs some clarification. What are we doing here?

But overall, the point I want to make is, we don't have any statistics here on Long Covid. So it definitely needs to be put here. And it's going to be very tricky to record what we have. And we have vaccinated people with long Covid, unvaccinated people with long Covid, we have long Covid with single infection, we have long Covid with double infections, we have people who suffered long Covid and recovered, we have people with long Covid who died.

So it's a mess, definitely. But it needs to be recorded and needs to be communicated. And it will lead to better assessment and better diagnostics and better treatments. Because we have so many groups of people who had two, three, times Covid infection, which leads to severe long Covid and chronic disease after all, and disabilities, as was discussed previously.

So we need to include long Covid as a disability. And people are struggling to get benefits for this disease. And people are struggling to get blue badge signs, because long Covid is not, at the moment, treated as a disability widely. And all the services that do assessments on these people need to have proper guidelines to take long Covid seriously. That's my point.

And actually, another thing just to say, it says 'additional funding for relevant public services'. What are these relevant services? Who decides on relevance? Are charities included into these services? As a charity, we have received zero money from the Government and we do have lots of volunteers who do this work for free. I work 14, 15, 20 hours a day, to support these people on my own, and have no grants from Government to support my work. Even though we as Long Covid Kids probably also do the same work, we need support from the Government to help people on the ground.

I know there are huge research grants given to universities. But this is a long term solution. This is long term outcome, it requires years to publish final results from these research papers from research projects. And we need help today and we would definitely need to be included into this funding for relevant public services that we do. Thank you. That’s all.

**Ben Connah:** [00:58:14] Valentina. Thanks very much indeed, you probably haven't seen in the chat, but one or two people completely agreeing on your point about stats. One of the key things that the Inquiry will have to look at is what expert opinion and statistical evidence exists out there. And how can we bring a kind of as authoritative a view as we can on the impact here? Thank you very much.

**Valentina Viduto:** [00:58:39] Another thing I think I should have mentioned here, sorry.

**Ben Connah:** [00:58:42] Valentina, I'll have to ask you to be fairly swift, if I may, but do go on.

**Valentina Viduto:** [00:58:46] So we have long Covid clinics, I think we need to include key performance indicators for these long Covid clinics to assess how well they're doing in terms of self-assessing and treating people with long Covid.

**Ben Connah:** [00:58:59] Many thanks. Elaine.

**Elaine Maxwell:** [00:59:02] Yeah, I think my point carries on from that. I think the Terms of Reference should be specific about looking at services for people with long Covid. We know that

those differ across the devolved nations. We know that the capacity within England is for 68,000 people. And yet ONS estimate that about three quarter of a million people have been ill for over six months. So there's a mismatch.

It's less clear what's happening in Northern Ireland, Scotland and Wales because they have dedicated clinics. So I think that there should be something specifically about what services are available, but also about research. So the NIHR covers England, Northern Ireland and Wales, but doesn't cover Scotland. So an investigation about the different approaches in the devolved nations to research as well as services.

**Ben Connah:** [01:00:02] Thanks very much indeed. Alison, I think you're next.

**Alison Twycross:** [01:00:11] Sorry, I'm not very good at this because I didn't do Zoom calls for two years because I wasn't well enough. Thank you. I mean, this is about preparedness. And as other people have said, it's kind of unbelievable that there was no recognition that there was going to be some sort of post-viral impact of the SARS virus, because there's many, many papers that demonstrate it. And that clearly wasn't factored in as far as I can see.

I agree that long Covid should be integral to all of the points in the Terms of Reference. I think there needs to be something about the impact on key workers. Now I'm saying this as a nurse, and as Chair of Long Covid Nurses and Midwives UK, but I'm also contacted by teachers, I'm also contacted by physios and pharmacists, all of whom put themselves on the line when we needed them to. And now depending on which part of the UK they live in, are facing financial devastation.

People are having to rent their flats out and move in with friends in order to survive. People are having to sell their house and downsize in order to not have a mortgage. Those are the lucky ones. In Wales, at the moment, from 1st April, people who've had long Covid for more than 12 months are supposed to be going on half pay. It's the 29th of March today, lots of people haven't been notified of this yet. But there's a complete sense of panic – in the Welsh guidelines there is a statement that if their manager wants to be nice, they can continue it.

I understand that health unions are talking to the Welsh Government, but people just don't know. So there's a lack of communication. In Scotland and Northern Ireland, people do appear to be staying on full pay; whether that will happen after the May elections in Northern Ireland, we don't know. In England the unions tell me, and the guidance says, that Covid sick pay should still be there. But many, many, many people are being sacked, put on half pay, getting emails to say they're going on no pay at the end of the month.

So I don't want to rant about this. And it's the same for teachers – teachers probably had an even worse deal than nurses because they're only getting like four months full pay and four months half pay apparently. People are leaving the workforce: we already have a depleted workforce in many – like in the NHS, in teaching. The economic impact of this isn't being looked on. It's really hard to access benefits. And there's [inaudible] immoral about not caring for the people who are working on the frontline and for the teachers who have been in school teaching without the right protections.

So I think decision-making about that. And this is where the patient narrative can come in to an extent for those key workers, or what's actually happened to them. And why they are kind of

almost being discarded, is how they feel. And that links into the fact that there was inadequate PPE provided at the beginning of the pandemic. We didn't wake up to the fact that Covid was airborne – or the policy-makers didn't wake up to the fact that Covid was airborne. And some hospitals still aren't having adequate PPE.

I can't remember – Brendon might know – but I can't remember when the first paper came out that said, 'It's airborne. We need better masks.' People are telling me they were measured for the FFP-3 masks, but they never arrived. They're being told that because the hospital or employer, care home, whatever followed the guidance at the time, they are not entitled to compensation, even though we know that guidance was wrong. And yeah, so that is maybe something the Inquiry should look at is exploring what those healthcare organisations', educational organisations' risk assessments said at the time to see whether they were adequate and to see what can be learned for future pandemics.

Only other thing, my last point is that I believe that the Health and Safety Executive were told by the then health secretary, Matt Hancock, 'not to bother' investigating any RIDDOR reports that came in from the NHS, about staff catching Covid at work, because the NHS was trustworthy and would investigate that. And if that is true – and I've been told it by a fairly reliable source – that definitely needs to be a question that is explored about decision-making about how they were going to investigate what was happening among key workers and see whether guidelines need to change. Anyway, I'm going to shut up now.

**Ben Connah:** [01:05:38] Alison, thank you very, very much. I've got one hand in the room, but Lesley and Brendan's hands both went up before; forgive me, I didn't notice who was first. I think it might be Lesley by the look of that hand.

**Lesley Macniven:** [01:05:52] And I want to follow up nicely from Alison anyway, so I'm pretty sure it was up first. Sorry Brendan. And I completely agree with what Alison was saying. We have been lobbying with nurses at the forefront of our campaign, all of 2021. Because it is so hypocritical that we said, these people who put themselves in harm's way, are now being discarded, and yeah, collateral damage. We're using all these terms. And even with the moral, ethical and ridiculously damaging economic implications, because we already have scarcity in that workforce. Nobody has been picking that up.

So what this is telling me is that decisions that have been made are not rational. So if we come back to the question of, you know, what issues or topics do we think the Inquiry should look at first? A good analytical technique to use when analysing why organisations do the things they do is to look at what the impact is, and then look at, well, why did that happen? And then there'll be a decision and they look at, well, why did that decision get made?

And so there's a thing called the 'five whys', and you keep asking 'why' until you get back to the actual reason. And I think what's really important is for the Terms of Reference, to be deep enough to actually identify some of the basic reasons why decisions that were made, were not as good as they could have been. So for me there are several points that we've talked about, where we need to look at why those decisions were made.

So for me, we could have a separate angle to the Covid Inquiry, which is what was done, let's critique and analyse what was done, what wasn't done, and why wasn't it done. And that speaks to the point Ondine and I agreed about and others have agreed about that, you know, there was a second invisible pandemic of people with long Covid, who were just not visible, who were just not factored into decision-making, who were not factored into public health advice.

And the patient groups that were set up basically filled a vacuum, where people were not seeing themselves being supported, or reflected, is mind boggling. A few months ago, in our support group, somebody joined who had been ill since March 2020. And they didn't know other people had long Covid. And they only joined our group two years later. And they'd just been struggling on and wondering why they were so debilitated.

So there is a huge elephant in the room when it comes to long Covid. Because we're like, 'Oh, why didn't people think, you know, to do this?' People could see it. I mean, very naively in March 2020 onwards, in the early days of the campaign, we genuinely thought if we told our story, people would see it, and they would respond. People printed our stories for clickbait headlines, they listened and said, 'We're really sorry.' And then people make decisions about us without our input.

And that, for me is – the biggest missed opportunity is, there's been a lot of top-down decision-making, and a lack of understanding that people who are very capable people – I call the people in the room who've got long Covid, who could basically run a small country because there are so many of us, banded together to collaborate and to try and find solutions. So we were absolutely hanging onto research, finding the solution. But we weren't naive enough to think this is something that would happen in two weeks, or two months or two years even. So we were very much focused on the here and now and what we could do to help ourselves, and what we could do to help each other, which has led to these career pivots where we're now doing all this couch based activism and peer support and so forth.

Because there was nothing for us. I've never had a psychologist offer to debrief me after any point in the last two years. And it's lovely to be offered that, but basically, I would go to the patient group and I would speak to peers and say, I've had a really hard day, and we would support each other. So my conclusion is, a huge part of this Inquiry is to tell the factual narrative account from the perspective of patient groups. And that is something that I think has been omitted from the narrative. Patient groups, for some reason, have an element of stigma attached to them, which I don't fully understand. And they therefore, are undervalued in terms of the data that we have gathered, where there hasn't been official data gathering.

We have got surveys that look at impacts of long Covid on people in regards to employment, as well as to health issues. We've worked with the Trades Union Congress, with the CIPD, with the Society of Occupational Medicine, to produce resources that people can use. But we are the only people disseminating that information, because officially, nobody will endorse it, because it comes from patient groups. Yet we have volunteered to produce useful information and we don't seem to be able to get official support to validate and share that.

So there's a huge duplication of effort. And there's a lack of joining up the grassroots with the top-down approach. And so given, interestingly, this Terms of Reference was written by the Prime Minister, which is as top as you can get, it would have been interesting to ask patient groups to set up a Terms of Reference for an inquiry from the grassroots level up.

And potentially, you could have parallel investigations; I suspect that's not up for negotiation in this conversation. So what we do need to do is adapt this existing Terms of Reference to make sure that the weight of this is not just analysing what has been done, but is very much what was missed, what could have been done better? And why were decisions taken, they excluded a significant group of people – 1.5 million – who are now effectively a marginalised group, alongside those who were marginalised, pre-pandemic, and suffering layered, intersectional inequalities, because many people with long Covid are already impacted by other inequalities, hence your reference to the Equalities Act.

So there is lots that could be said and done. But I think there needs to be an understanding as to how we're doing this, that this is not just reviewing what's been done, but it's a review of the system that was involved in putting these decisions forward. So I think there's a very high-level critique of this, so there's lots of real detail that we want to get into in the evidence gathering. But I think this is pivotal to make sure we don't omit marginalised groups, we don't omit people with a lot of data to contribute from our patient groups. And that's Long Covid Kids, Long Covid SOS, Long Covid Support. And advocates who've been working with other professional bodies, like Long Covid Work has been working with other organisations to try and influence change –

**Ben Connah:** [01:12:56] Lesley. I'll ask you to stop there if you don't mind. You've put your points so clearly, and so forcefully if I may. That was incredibly helpful. You're right, we don't have the luxury as an Inquiry to set our own Terms of Reference. They are in the gift of the Prime Minister who sets them up like with any inquiry, but the reason why we've spent the last three weeks on the road, and the reason we wanted this conversation was precisely to get the insights of people who haven't always been able to give their voice. You're right, we can't just start with a blank sheet of paper. But what we can do is make sure that what we hear today, and as we go around the country, is properly reflected in both the Terms of Reference, but actually, in some ways, more importantly, in the Inquiry itself. Because like I said, the Terms of Reference are just the hooks on which we'll hang the investigation.

**Lesley Macniven:** [01:13:49] I think it's important to, as has been said already, have a number of bullets. So there are multiple opportunities to hook the evidence onto not just one hook, and also the multidisciplinary nature that's been talked about, you know, there's a danger that we submit everything and look at everything in its component part, when actually a huge finding could be that people weren't talking to each other, collaborating, and working together. So how people were working together is as important as what they were doing. And so again, from an [inaudible] perspective, we tend to look at the visible bits, the bits that are structural and tangible, and we forget some of the behavioural things, and the decision making rationales and the impact on people.

**Ben Connah:** [01:14:31] Thank you very much Lesley. I'm rather taken by the idea of you lot running a small country as well. I think I'd live there. Thank you. I'll go to Brendan and then Ami if I may.

**Brendan Delaney:** [01:14:42] Yeah, I'll be relatively brief. Because there's so much eloquent stuff said before. I think, to me, it's a question of long Covid really being a mass disabling event, hidden in plain sight in the midst of the pandemic. I think that comes over very clearly. Now, the question is how to make sure the Inquiry actually pays attention to that.

We could just say, rather blandly, consider longer issues, morbidity, long Covid, with every point that you've got for the acute Covid impact, but I'm not sure that will really pick out the nuances. So I do think you need to think quite carefully whether there needs to be a section, which says, we've got long Covid and the Inquiry should consider whether, for example, long Covid, or extended problems with a viral illness should have been expected. Whether they were planned for in pandemic planning, whether they have been specifically measured appropriately at points where they should be and included in planning and outcome measurement throughout. Whether they were considered in the justification of mitigations and actions and economic things that were considered through the pandemics. So I think there needs to be these sets of things on their own very clearly. So you can say, well, that's a very clear remit here. It's not just an afterthought. So that's my bit.

**Ben Connah:** [01:16:17] Brendan, thank you very, very much. Really, really helpful. And, you know, the Chair has got a real job on her hands to figure out how she's going to segment this Inquiry. But if we are to have a module on long Covid, then I think you've gone a fair way to writing the kind of heads of terms for that as well. Thank you. Ami.

**Amitava Banerjee:** [01:16:35] Thanks very much. One thing we've heard quite a lot throughout the pandemic is following the science and that our research response has been quick. And actually looking through, I didn't see – unless it comes under preparedness or resilience – I haven't seen that put down. Because I think a good news story, in some ways might be that compared with some countries, if you could say, for example, compare NIHR with NIH, there were grants awarded quicker. But there's been delays that I can speak about personally, I faced in terms of regulation, the knowledge around the table within the regulators were there people who were acute Covid or acute medical experts and weren't able to look at long Covid, objectively. And so, you know, whether it's looking at what we were proposing or looking at drugs, and so there have been delays that are not due to the funder, not due to the policy, but due to, like, further downstream.

So I do think we need a bullet on research or research preparedness and be quite objective about what's gone well, and what's gone wrong. Secondly, I mentioned earlier about what we can learn for other conditions: there's some things that are different, and there's some things that are similar to other things we've seen before. And one of the differences with the acute side of Covid is that we didn't know and still don't know, other than the temporal kind of, beyond 12 weeks, we haven't yet got the full definition of this condition. With all these different studies going on in the world, we haven't yet got reliable population level data about what the trajectory of this condition is.

And we need to be open about you know, the kind of Rumsfeld 'unknown unknowns' here.

**Elaine Maxwell:** [01:19:03] The known unknowns.

**Amitava Banerjee:** [01:19:04] But there's no – and I was going to come – you've stolen my words Elaine, that the known unknowns are – the best way to avoid long Covid is to avoid getting Covid in the first place. And that was absent – is absent in the narrative. And I think we do need in part of the Inquiry to look at how actually, the long Covid message didn't fit with political narrative, you know, as we live with Covid, as we open up, as we drop restrictions, actually to tell people that there is a long-term condition didn't fit.

And so there is a problem there where, you know, the messaging and the public information that's going out is disjointed and totally apart from what we're seeing clinically, what patients and people with lived experience are saying on the call. So I think we should be able to look at that. Because the reality is that, we knew this, at least a year and a half, two years ago. And yet still, as we fully open up, as infection rates are rising, this is not mentioned nationally or regionally as an effect of the pandemic.

**Ben Connah:** [01:20:40] Ami, thank you very much indeed. Yeah, we had a discussion this morning with some individuals who were bereaved by Covid. And they were talking about Freedom Day. And the kind of jarring, slightly chilling sense when we look back on what that meant on the 4th July 2020. And, yeah, it's easily forgotten by some but your point about the political narrative is really well made. Thank you.

Ami, we started with you, and then we went to Ondine, and I don't want us to get into an eternal circle on this. So Ondine, I'm going to go to you and perhaps ask you to just close off this section of the discussion, if I may.

**Ondine Sherwood:** [01:21:23] Yes. It was about the fact that in the Terms of Reference, there is this mention of comparing us to other countries. And I think we have comparatively done well, in certain sectors, recognising long Covid, which is probably due to the efforts of the patient advocates, in terms of counting long Covid in terms of the NHS setting up clinics. But fundamentally, that has been absent in terms of policy-making.

And another point about – I don't want – I would hate that, sort of – that aspect of yes, we've done better than other countries in recognising long Covid to cloud the Inquiry, because it's important to recognise that, fundamentally, we're still not getting treatment. And the Government is not recognising it. And one of the problems with the Government not recognising it, is that the public don't understand their risk. So public messaging has been so absent on long Covid that people don't understand why they should avoid infection.

And that impacts on people's safety, public safety, and their perception of their risk. And I think that's really, really important to consider. Because by ignoring it, you're putting people in a situation where they can't make the right decisions about what they – whether or not they should wear masks, whether they should take risks and put themselves into risky situations.

**Ben Connah:** [01:22:51] Thanks. Thank you very much indeed Ondine. And yeah, Brendan's made a point in the chat about the UK having been historically abysmally behind with post-viral

conditions because of a professional fixation on – I'm not even trying to say that – psychologisation, which is probably not how you say it. So thank you very much, indeed. And thank you, Brendan, for causing me that difficulty. Sammie, I will have to ask you to be very, very brief, if I may, because I do want to make sure that we get on to those other questions. But since your hand has gone up, I will ask that this is the last hand on this stage, if you don't mind.

**Sammie Mcfarland:** [01:23:25] Thank you so much, I promise to be brief. It's just a note about the vaccine response. I wonder if it can be clarified. It currently states that development and delivery of therapeutics and vaccines; does it need clarifying to include Government messaging on risks and policy, including the uptake of vaccines for children, young people, which I believe has been significantly impaired by the false narrative that children only experience mild Covid harm, and in fact, they needed to be very honest from the offset about the catastrophic effects of long Covid on children, and then perhaps people have more information to consider taking out the vaccine. Thank you.

**Ben Connah:** [01:24:09] Thanks, Sammie, really, really good point. I don't think I've heard that on any of our travels. So very many thanks for making that.

Okay, we're at 15.20. So we've got 40 minutes left. I'm just going to give people four or five minutes' downtime and then at 15.25, if we can come back and, if I may, I will group the next three questions together. We found over the course of our travels that the next three, some people have opinions on one or another, very few have opinions on all three, so it would be great if we can group those, and I'll ask people for their views on whichever are of greatest interest to them. And then if it's okay with people we'll run on until 16.00 at the latest without a break. If that doesn't work for you, then please either let me know via the chat, or if you prefer, just self manage and take a break yourself. You don't need to let us know if you're doing that. But yeah if we can come back at 15.25 then we'll try and nail the last three questions. Thank you.

[Break]

[01:29:37] Hello everybody; thank you very much for coming back. Do turn your cameras on as and when you are back and that way I'll know that I can get going with the third part of this meeting. As I said before we broke, it would be really helpful if you can bear it – if we could group the next three questions together. As I say, not everyone will have views on each of these questions and it's absolutely understandable if not.

I might, though, if you don't mind introduce the three of them. Because I don't think it's always entirely clear why we're asking the questions that we asked. So let me just give a little bit of the rationale. I think the second question rather speaks for itself, which issues or topics do you think the Inquiry should look at first.

So you'll see right down at the end of the Terms of Reference, there's a provision for the Chair to make an interim report or interim reports to ensure timely findings. Baroness Hallett is really keen to do this, and to make sure that if there are issues on which early findings and early recommendations could help, either with the here and now or with any future pandemic, that could be just around the corner, that she is able to make those decisions in a timely way. And therefore, she's asked us to test which issues people think ought to be looked at first, by the Inquiry.

She's also keen to understand whether it would be helpful or not for the Inquiry to set a proposed end date for its public hearings, again, to help ensure timely findings and recommendations. Now, there are pros and cons to this. And without getting too much into the detail of public inquiries, it really comes down to the tension between depth and length. So you know, there have been public inquiries in the past that have gone on for a decade or more. And I think we're all clear that that is absolutely something that we must avoid in this Inquiry; it is too important and too urgent a question to allow it to drag. And so there might be something for setting ourselves a target early on to get things done and dusted.

On the other hand, we're right at the outset. And, as you've heard today, we're talking about the Terms of Reference and learning as we go along at this stage. And we'll continue to learn as we seek evidence and hear from other groups and other organisations. So we're equally nervous about not getting into enough depth, compassing the issues in sufficient detail. We're not asking any of you to make that decision for us. That's absolutely for the Inquiry to do. But just getting your views on whether there is a particular desire for a very quick inquiry, or on the other hand, a very detailed inquiry would be a great help.

Elaine, are you going to answer that question? If you don't mind, I'll just come to the last one. And then since you've got your hand up, I'll come to you first and then Lesley.

The final one of our questions is about how we can make sure that the Inquiry is designed to ensure that bereaved people, yes, but also others who've suffered harm or hardship as a result of the pandemic can have their voices heard. And that certainly includes those people who are suffering from or survivors of long Covid. So, several of you have already said about the importance of hearing your voices and the voices of those with long Covid. It would be great to just get views on how we might best do that, throughout the length of the Inquiry.

The Chair is really keen that we develop some kind of listening project that goes alongside the formal hearings, and is able to give people the opportunity to have their stories heard, perhaps without that formality and, frankly, the intimidating nature of a courtroom. But also – no matter how long we go on – we will only ever be able to hear so many people's evidence within the formal inquiry structure. Through a listening project, we hope to be able to hear from far, far more people and to feed their experiences into our work.

So views on what we should look at first, whether or not we ought to set a proposed end date for hearings and how we can make sure that people who suffer the most harm and hardship are having their voices heard throughout the life of the Inquiry would be gratefully received. I'm going to go to Elaine first. Then I've got Lesley and then Sammie.

**Elaine Maxwell:** [01:34:50] So we then actually canvassed some of our members about these questions. And there are three discrete categories. So the first thing is, whatever Boris thinks, the pandemic isn't over. So there's something about looking at the current and ongoing response to Covid-19 that should be done first. And there probably needs to be a target date for doing an interim report on that, because we've already heard today about the public health messaging and people are recklessly getting Covid and therefore getting long Covid that really needs to be

urgently addressed. So that should be looked at first, what can we do to prevent more harm in the current pandemic.

The second thing is about the planning for future pandemics, which actually, we've got a bit more time to do, and that could have a later timescale. And then there are the wider learnings about public services that aren't specifically related to an infection. So it's already been highlighted today, that the Covid pandemic has shone a light on inequalities. So one of the things I'm particularly concerned about, nobody has talked about long Covid in prisons, and yet I'm hearing there's a lot of it. So there's a lot of those structural inequalities that have been highlighted. So those might be three different timescales.

In relation to how can we make sure that people can participate, you haven't really talked about core participant status. And I know that different inquiries take different approaches to this. I know, Grenfell Tower has said, anybody who was in the tower on the night can be a core participant. Same with the Infected Blood Inquiry. That's probably not reasonable, given the number of people with long Covid, or Covid. But there is something about core participants, and you've heard there's a number of organisations on the call today, who are volunteer organisations who are collecting views.

None of us get any state assistance with finance to do this. But we all have networks to access this. So we could get a lot of that experience and present it to the Inquiry. But the question is, who's going to fund that? Because we're all going to need some money to do that.

**Ben Connah:** [01:37:13] So thank you, Elaine. That's very kind. You're right. We've not mentioned core participant status. And really, that's because we haven't got to it yet. So until the Inquiry is formally established under statute, it can't make any decisions on that sort of thing. And indeed, I can't designate anyone as a core participant. I would really welcome a conversation a bit later on down the line once our Terms of Reference are settled about that. Thank you for your points. And thanks for canvassing views from your members. If you've got any other views that you want to pass on to us, either here or via the online form, then please do; that'd be fantastic. Thank you ever so much, Elaine. Lesley. Yes, it was Lesley next and then Sammie.

**Lesley Macniven:** [01:38:02] Yep, delighted to be going after Elaine just to say, bravo, agree with all of that. And maybe say my points in reverse order to pick up where Elaine left off. This idea of core participant status, I think that was something I brought along to say, it's really important to make sure the right people are involved, and that they do represent people, because we often see our patients expected to represent every patient with long Covid, when there are as many people with long Covid with different symptoms as there are people with long Covid, if that makes sense.

And so actually, selecting people who can represent discrete groups is really important. And that's why we've organised ourselves in the way that we have, so that we can do some of the legwork. And so for me, one of the things that I brought along today was this idea that we devolve responsibility and resources to patient groups to produce some of this data. And so similar to what Elaine was saying, we can do it if we're funded, but actually just building [inaudible], that has a lot of existing resources. And one of the dangers is to avoid replication and duplication.

People have already told stories and written down their experiences. And so there is a real danger for me as a person who's a moderator for a group of very ill people, that we're asking people to keep doing the same thing over and over again, hence my frustration that comes across as being forceful. Because when you've been asked to do the same thing 20 times you get a bit impatient.

And so there's an element of this, which is we have to design it in a way that's not going to further deplete patient resources. But I do agree with this idea that some sort of listening project could be a therapeutic intervention. But again, I would look at the data we've gathered on existing interventions we've been doing for people to tell their story, that tell what aspects of that are helpful, and the fact that they've been done and developed by people with long Covid. And, you know, it's something that we've got to offer the Inquiry as well.

Working back, I would agree with Elaine as well about, you know, having logical outputs at different points for different questions. And I liked what she suggested. But I think the very first thing that I wanted to say in terms of which topics we should be looking at first, it's been very apparent when you analyse what's been happening, that the public messaging, the narratives have all been focused on the majority of people. Even to the point of people saying in briefings, most people with long Covid will just get better. But yeah, there's a minority there that won't, and you're just ignoring them.

So for me with my equalities consultant background, but from my lived experience, and just from overseeing everything that's been happening the last two years, it's time to now balance things out a bit. And to start by looking at the marginalised groups, and for people for whom we can still do something. So sadly, we can't bring back those who died. But people who've been in limbo for the last two years, and have been managing things ourselves, we would bite your hand off at the offer of some actual practical support. And therefore, I think for me, that becomes the priority for the people I represent in my cohort.

**Ben Connah:** [01:41:16] Understood, understood, Lesley, thank you. Fantastically clear. And a really, really helpful suggestion. Thank you very much indeed. I'm going to go to Sammie, and then Ami.

**Sammie Mcfarland:** [01:41:30] Thank you, so actually, my brain fog's kicked in a bit now, but I've made some notes, thankfully. So about the listening part of the project. To understand the experience, something that we've done with our members, and that has worked really well, is they often find it very difficult to write down their experience. But actually, if you put someone in front of a camera, they can talk and explain their experience.

So I wonder whether patient groups could be used and funded to collate a wide breadth of experiences and pool them together in some sort of video diary that could be used as a way of presenting evidence in a concise way. I think that could also be very validating for the families affected and would give the opportunity for the voices of young people themselves to be heard. Because I think that could be a very safe and familiar space for a young person to be able to share their experience because they spend almost all their time on their phone.

Finding funding for – sorry, that was funding for the project. And then the pandemic is not over, as has been said multiple times in the chat. And prevention has to be, in my opinion, has to be our priority. Looking at what we can do now to reduce the risk – the ongoing risks the very real ongoing risks for the many people who are not yet in the same situation as us, but may well be if we take the early evidence of the multiple infections creating long Covid in people that didn't get on Covid in the first infection. And specifically, from our point of view, as Long Covid Kids, the improved indoor air quality in schools, we have a generation of children we have a duty of care to protect and they are not being protected, they have not been protected. And they must be. Thank you.

**Ben Connah:** [01:43:33] Thank you very much indeed, Sammie. Yeah, I really, really like and welcome the idea on the offer to help us with finding better ways than bureaucrats like me might be able to, to hear from people about their experiences. So thank you. Ami.

**Amitava Banerjee:** [01:43:52] Thank you, sir. So which issues first? I agree with a lot of what my colleagues have said. I think the number one priority for me is messaging around prevention and around the risk and how we improve that immediately. And I think workforce as well – with over a million people with this condition, stretched services, backlogs, etc. how we address things in the coming months and also I do think the related to that the services and research so that it's in an action research way not delivering results in two years' time. So I do think that we need a quick inquiry, interim findings, I will hide under the table if this is a ten year job.

And then in terms of reaching the people who have suffered or bereaved, I think this is really important. And I – this keeps me awake at night that, you know, a new condition where there are 1.5 million, if we're having meetings where we're seeing the same people, Brendan's getting sick of seeing me, and I know there are representatives of different organisations, but how do we do better to make sure people are heard, one of the things is that we know that, whether it's due to health literacy, digital literacy, a digital only solution is not good enough.

So just doing Zoom calls, and emails and WhatsApp groups is not going to reach those 1.5 million people. So I would urge you to follow a digital first solution, but you need paper or non-digital ways of reaching people. And I think related to that, we know from the first wave, we know from the acute effects of Covid, that, for example, ethnic minorities are disproportionately affected, it's highly unlikely that they're less affected in terms of long Covid. Yet, whether it's low SES, whether it's ethnic minority groups, they're less represented in referrals to long Covid clinics, is that because there genuinely is a different biology and pathophysiology or more likely that they're not being reached by services? So we need to make sure that they're reached in the Inquiry to find that out. Thank you.

**Ben Connah:** [01:46:55] Thank you very much, Ami. And as others have been talking, I've been pondering a question that we've come back to several times over the last weeks is how we can increase our reach. Because as incredibly helpful as these conversations are, as this conversation in particular is, I'm acutely aware that we are only scratching the surface of those 1.5 million people that you talk about. Thank you. Alison.

**Alison Twycross:** [01:47:25] Thank you. I agree that we need some interim report to look at how we can prevent people getting infected, prevent things getting worse. And with my nursing and midwifery hat on, one of the things that I think needs to be looked at is PPE for health and social care workers in all settings, and this kind of applies to other key workers as well. How can we make sure that people are getting the right PPE? And I know that they're not, whatever the national dialogue is, and also that people get the appropriate support to return to work. So some sort of focus that looks at how well we're supporting people to return to work. Are they getting extended phased returns? I'm hearing that they're either not or HR says, 'No, it's four weeks,' or their manager says, 'Oh, yeah, that's a good idea,' and then HR says 'No.' So if we want to address some of the economic and workforce impact of long Covid and the pandemic, that probably needs to be included in the prevention bit at the beginning. That's me.

**Ben Connah:** [01:48:49] Alison, thank you very much indeed. Ondine.

**Ondine Sherwood:** [01:48:53] Thank you. One of the sections of the Terms of Reference is lessons learned. And obviously, that does have to come at the end. But maybe we need to start with trying to find out what lessons we should be learning. Try and put that in a little bit earlier so that we can act on them. Because it's going to become clear from talking to roundtables such as these, what mistakes are being made on an ongoing basis. And maybe the Chair can start to think about that so that we can make some changes as the pandemic is continuing to rage around us.

And on the question of people with lived experience being intrinsic part of the of the Inquiry it is extremely important that groups representing long Covid do have core participation status. And it turns out that all these groups are voluntary. They're not funded. There's no big charities who are doing this work. And so there is an issue of funding. It's absolutely essential that the people who understand long Covid and who've been advocating for long Covid for all of these months and years are there to be part of the Inquiry to be able to question witnesses through their legal teams, in order to make sure that long Covid is covered properly. Thanks.

**Ben Connah:** [01:50:18] Ondine, thank you very much. As I say, we're not we're not quite there yet with core participant decisions. But I know that Baroness Hallett will consider them all really, really carefully. As she will, the ability, which she does have [inaudible] to means test and to grant funding. Brendan, I did see your real hand before you put up your yellow hand, forgive me for making you do that.

**Brendan Delaney:** [01:50:47] That's alright. But anyway, I think the thing that really comes over to me is, try and get stuff out, that's going to make a difference to the pandemic right now. And that means not being the only person in the Tube carriage wearing one of these things. And also, I mean, coming back to a point that Ami was making about the slow speed of research approvals, we are both fortunate to have large funded studies around long Covid, but my God has it been hard getting those up and running, through all the ethics approvals, the approvals for this, for the drugs [inaudible], for data on us.

It's ongoing, and it's really difficult. And it's such a completely different environment to the urgent public health studies and big trials and things that were done with acute Covid. Things just

happened like that. You know, I had an urgent public health study, we did a risk score. So I know I've personally experienced the difference. One, it was rapidly facilitated, this one's like going out every day, banging your head, it's really hard. And we have all the patient groups, absolutely justifiably saying, 'Why is research not happening? Make it easy to happen.' That's an early thing. Because there's going to be an ongoing need for research in this area. I think that's an important area.

**Ben Connah:** [01:52:09] Yeah, thanks very much indeed, Brendan. Yesterday we were in Cambridge, and we hosted a roundtable on science, where, for the first time really, in this consultation, we got quite a lot of really useful input on research, and indeed, the lack of research within our Terms of Reference. So yeah, you've underscored that, both you and Ami, thank you very much for that.

**Valentina Viduto:** [01:52:35] I would like to make a point.

**Ben Connah:** [01:52:36] Please do Valentina.

**Valentina Viduto:** [01:52:40] There is concern as well, largely communicated in some newspapers, that for example, many UK patients with long Covid travel abroad for treatments. Now, why does this happen? This is very critical that people need to travel abroad to have a treatment. So why is the UK not trialling these existing treatments. And why is the UK not willing to invest into these treatments and make them available to long Covid sufferers at home.

So we know that there is a treatment like plasmapheresis, for example, this is a blood cleaning procedure, which costs quite a lot of money. And it was pioneered in Germany, but it now is in other European countries. We have been talking about it for quite a while and many people have become aware about it. And there is research going on blood coagulation. The UK for some reason, is not up to speed.

I know that some medics talk about these issues, but they're not in a position to get into research because of what Brandon has mentioned, it is very challenging to get funding for a trial on treatment which works. So that's why I think it's important to make a list of things that work abroad and take these practices from working experiences to the UK. Then it will take time of course but there are solutions. The UK is not keen to invest in that, not keen to implement those treatments in the UK for one or another reason, but we know there are solutions available for long Covid elsewhere.

**Ben Connah:** [01:54:42] Valentina, thank you that's really interesting. You mentioned Germany as being a place that's pioneering some of this. Are there other places where people from the UK are going to get certain treatments that you know of?

**Valentina Viduto:** [01:54:57] Yes, there is Switzerland, Cyprus, in other places of Germany, there is also treatment in the USA. And basically, the thing is that, to get onto this treatment, people need to have proper diagnostic solutions. So we know that there are some kinds of tests available, not in the UK, again, to identify specific biomarkers.

**Ben Connah:** [01:55:31] Valentina, I probably need to be clear. That's really useful to understand the countries. Just to be absolutely clear, the Inquiry isn't going to be in a position and nor should

it be to supplant the views of the medical regulators and that kind of thing. But what we can do is look at the research or absence of it. And we're also bound by our Terms of Reference assuming they stay to look at international comparisons. So knowing those countries is really useful. Thank you, I'm not going to suggest that we try and get into a discussion about individual responses to the condition now, but I've got Elaine and then Ami.

**Elaine Maxwell:** [01:56:16] Yes. So I don't want to talk about that particular example about the amyloid clots and plasmapheresis. But lots of countries have done lots of things. But one of the things that is alarming is that because there is a lack of access to services, a lot of people can't get to specialist services here in the UK, people are then going abroad in an unregulated way. And there's a real safety issue because people are going on the internet and accessing things. I think there's a patient safety aspect without wanting to comment about any particular treatment, we need to be careful that people are not put in a position where they're going for unregulated treatments.

**Ben Connah:** [01:57:02] Thank you very much indeed. Ami.

**Amitava Banerjee:** [01:57:05] Yes. Wholeheartedly agree with what Elaine just said, and that each treatment, whether it's long Covid or otherwise needs to have robust evidence, and we have to kind of 'first do no harm'. And we should be aware when people are paying out of pocket, whether it's in this country, not just abroad, that people aren't getting value for money, and where we don't have evidence-based treatments yet, we have to be really careful about, as Elaine said, unregulated care, because we've allowed the numbers of people suffering with this to get so large that, understandably, patients, out of desperation, are buying drugs over the internet, going abroad. That doesn't mean those things work. But that means we do need to get our messaging straight, both from the centre and as healthcare professionals, that the science shouldn't be weakened or cheapened just because it's long Covid, in the middle of the pandemic, I still believe in 'first do no harm' as a health professional.

**Ben Connah:** [01:58:29] Thank you. Fantastic, Ami. Thank you very much indeed. I think that's rather a nice tenet on which to nearly finish the discussion. But I might, if I may – Lesley, I will need to ask you to be brief, because we're almost at time. But Lesley, why don't you close us out?

**Lesley Macniven:** [01:58:54] Thank you, I've just now probably triggered brain fog. I can't remember what I was going to say now. Yeah, I think good points coming through from Elaine and Ami that I wanted to just underline. We tend to work in silos - that has been the observation of patients. So you're sent from pillar to post to see different clinicians, versus perhaps having a long Covid clinic and I think this idea of people doing treatments abroad is symptomatic of the fact that it takes effort to collaborate.

And so part of this is, how could we collaborate more, both across the four nations but also globally to avoid people, desperate people, throwing their life savings at trying to find some treatment because they're despairing as to how they can go on without that, which tells you a lot about the state of mind that people can get into when they've been ill for a very long time.

But again, it's just this idea of how can we encourage cross-silo working, sort of multidisciplinary working, because what we see is, the best things that have been created – this is subjective. But there's been some really good resources created by multidisciplinary groups working together and I think it would be good to, again, highlight good practice where something is being created, that has a lot of engagement and buy in, because it's been created by experts, but with patients' involvement. So yeah, that doesn't come out as coherently as I wanted it to, apologies. But again, it comes back to how we're working and trying to come up with ways to work more collaboratively would potentially mean things would be more inclusive, which again, is a kind of thread that I've been tugging at during today's session.

**Ben Connah:** [00:2:00:45] Fantastic, Lesley, thank you. And actually, I do think that's a really nice point to end on. Because what I and what we have seen today is some fantastic collaborative working across different organisations, sometimes with the same objective sometimes, maybe not, but all of you working together to support undoubtedly a marginalised group.

I've been dazzled by the amount of expertise in the room, real and virtual, from so many different backgrounds. I'm so very grateful to you. And I know, Baroness Hallett, as Chair of the Inquiry, will be as well. Thank you so much for coming and sharing your thoughts with us today. Far too much for me to try and summarise. But an awful lot in what I heard about the importance of making sure that long Covid is factored into policy-making, certainly from now on, and, of course, that it should have been before now too; about research and making sure that that research is accelerated and understood. And then of course, it is incorporated within policy-making and within decision-making.

And lots of lots about the people that you work most closely with, and how we can hear from them as well as from you, including those people who are perhaps not so comfortable sitting in front of Zoom calls or participating in online consultations, which of course has, partly through necessity, been the default for this brief process.

Thank you all very, very much. Not everything that we've heard today and indeed, not everything that I've just said will end up in the final Terms of Reference, I can confidently say that. But please rest assured that in advising Baroness Hallett on her recommendations to the Prime Minister, we will take the points that have been made today. And even if you don't see those in the final version of the Terms of Reference, that isn't to say that the Inquiry won't be looking at them. We've learned a lot today, we will take a lot of this back. And the many, many bullet points that will sit beneath the relatively few bullet points in the Terms of Reference will include many of the issues that we've talked about today.

I said at the beginning two things, of which I'll remind you, one is that Martin Hogg, the counsellor who's working with us throughout this exercise is available to you not just today but tomorrow, if you need any support as a result of this session, and that we will be making a transcript of today's discussion available on our websites at the end of the consultation period along with the other roundtables that we've held.

If you would rather your name didn't feature in that transcript, then please do let us know. Please do not use the chat function for that because we won't necessarily see it in time. Could you email us back on the address from which you received the material that led you to us? Thank you all very much indeed, as I say, we haven't done justice to the chat today. And I didn't intend to because it was just one thing too many. But we will at the end of each of these sessions get a memory stick from the chaps who are making this virtual world work. And that will be fed into our overall analysis of this process.

That's been a bit of a whistle stop. I'm incredibly grateful to all of you virtually and in the room. I can only wish you well, wish those of you who need one as swift a recovery as possible, Sammie to you in particular, get well soon. And thank you all very, very much indeed for taking time out of your days to help us, you really have done. Bye, bye.

[END OF TRANSCRIPT]