UK Covid-19 Inquiry
Equalities roundtable - disability discussion

Tuesday, 15 March 2022
Cardiff and online

The Inquiry held an equalities roundtable. This was one of three breakout discussions and focussed on disability.

Participants

Sam Hartley, UK Covid-19 Inquiry

Kamran Mallick, Disability Rights UK

Rhian Davies, Disability Wales

Richard Kramer, Sense

Tim Nicholls, National Autistic Society

Gemma Hope, Leonard Cheshire

Jackie O'Sullivan, Mencap

Robert Geaney, RNID

Nuala Toman, Disability Action Northern Ireland

Nana Gyamfi, UK Covid-19 Inquiry

Sam Hartley: [00:00:00] Kamran, you had your hand up straight away. So let's go to you first.

Kamran Mallick: [00:00:03] Thanks Sam. My name is Kamran Mallick, I'm Chief Exec of Disability Rights UK. And just before we kind of get into that first bit, I just wanted to a little bit – of awareness of the consultation process itself, just to make out I think some kind of concerns that we have.

So it's just in terms of accessibility. If we're looking at the consultation site, there's no Easy Read facility. There's no BSL introduction to the Inquiry on the site. And given that kind of disabled people have suffered from the lack of adequate communication throughout the pandemic, we felt it's really important that we don't repeat those mistakes when we're now doing the Inquiry, so just as a base wanted to just mention that to you.

Felt that the time period for the consultation is very short, given that for many disabled people, there are access requirements that they may have. And also, in terms of the lack of Easy Read means this additional translation interpretation is required. It's unclear how the Inquiry has chosen which groups to include and not, so you’ve got a kind of broad question around how organisations have been invited, for example, to today. And the last one was really on that point is – the online consultation looks like it's for individuals. So if we're responding as an organisation, how should that be pitched?

Sam Hartley: [00:01:32] Sure, okay. Kamran, if I take – if I try and address as much as I can, some of the concerns which are very fair, very fairly made. Now, I don't think I've got – these aren't excuses at all. But what I would say is that Baroness Hallett is very keen, and very aware of the criticism that has been laid in the Government so far about the delay to the start of the Inquiry. And she has been very, very keen and putting as much pressure on as possible. So to get to a position where she can start the Inquiry and start the – which is the meat of it, absolute – absolute meat of it.

And with that in mind, we have tried to do this as quickly as possible; that is not an excuse. And that does not excuse some of the issues that you have raised at all. But that's just a bit of context in terms of the kind of competing – competing pressures. I will take away today and speak to my – my team after this meeting some of the concerns you raised in terms of accessibility. And certainly there are – I know that there are email addresses on the – on the website where people can come and if they need things in alternative formats. We have made those emails available, but I do absolutely take the point and I'll take it away and try and get you an answer today on some of the accessibility points – if that's okay.

On the other points you've raised, again, on how the organisations were selected, first of all, I would say we're trying not to be exclusive about this, we are trying to reach as far and wide as possible. I wasn't necessarily involved in the – in the detail of searching for the disabilities and general equalities organisations, but we have tried as a general rule to speak to large umbrella groups, membership organisations, sometimes regulators, to try and identify the best people and best organisations to invite to these groups. Again, in terms of, you know, doing things as quickly as possible so that we can get on with the investigations and learn the lessons and make recommendations.

And I should also say obviously that the consultation is open to everybody to participate in and respond to online. Indeed, as well. And to your point about individuals responding online, yes, we deliberately designed it so that people can only respond as individuals – not only respond as individuals, but they don't have to put their names and contact details in. But there is, of course, the – you can respond as an organisation through our email address as well. So you can put together a written submission and send it to the email address, which is on the website as well, if you want to submit as an organisation.

Kamran Mallick: [00:04:12] Thank you.

Sam Hartley: [00:04:16] Thank you, Kamran. To the point of the question, or does anyone else want to come in at that point? I mean, I will assure you – reassure you that the points have been well made Kamran, and I will promise to go away and look into the accessibility issues today. If anyone else wants to come in, please do at this point. If not, we could move on to the question about the areas that are covered by the draft Terms of Reference as set out by the Prime Minister. Tim?

Tim Nicholls: [00:04:42] Hi, sorry, I just dropped a note in the chat. Just to say, firstly, apologies for being late we are – there a number of us who ended up in the wrong room. And so we haven't heard your opening. I don't know if we've missed anything particularly. I know there's Rob who was in the same room as me. We're also expecting Jackie to move across and maybe Kirsty, who haven't yet, but just wanted to check. Have we missed anything important?

Sam Hartley: [00:05:10] Thanks, Tim. Apologies for that. I can see my colleague Nana is in Cardiff in the room and I hope she is looking into – can you hear me, Nana? Give us a wave if you can.

Nana Gyamfi: [00:05:21] Sorry, one second. Yes, sorry about this. There's been some problems with people in the wrong breakout rooms. Are we going to move them? Okay. If there's people – people from the gender and equalities group here, or…?

Sam Hartley: [00:05:47] No, I think we – I think our – the ones that were in our room erroneously have moved, but I can see as Tim's just said we've been joined by him, but there may be Jackie, I think you mentioned Tim, didn't you, who's still not in the right room. I'll leave you to that, Nana, if you want to…

Nana Gyamfi: [00:06:04] Leave us to sort that out. We'll get Jackie moved. Sorry about that.

Sam Hartley: [00:06:08] Okay. Tim, I apologise for – I thought we'd been joined by everyone that was missing. I do apologise for that. I'm not quite sure at what point you came in. Just so you know, I'm Director of Policy Research and Analysis at the UK Covid-19 Inquiry, and Deputy Secretary. I hope you heard Ben's preamble at the start of the meeting, in which he sort of set out the purpose of today, the background and how we will run today. I won't go through that again. I think I can see you're nodding at that point that you heard that bit.

And what we did hear from Kamran to start with is some very fairly made points about the website and the consultation itself, which I have committed to take away and come back with a response on today. I did just explain, not by way of excuse, but just to add some context about the pace at which we are trying to do this consultation in order to start the Inquiry such that we can learn those lessons. But I do absolutely take the point that it does need to be accessible to all.

Did I see Tim, did you want to – to add anything at that point? No. Okay. Rhian, I think your hand was up next.

Rhian Davies: [00:07:24] Yeah. Hi, everyone. I'm Rhian Davies, I'm Chief Executive of Disability Wales. Glad to be here, meet everyone. I fully support the points made by Kamran. And you know, it is vital that the Inquiry doesn't repeat the mistakes made by the original or ongoing handling of the pandemic.

I think I particularly wanted to raise I note whilst I feel that there should be provision made for expert groups to be directly involved with the Inquiry, and I suppose working with the Inquiry Chair and others to kind of interpret information coming in, I think one of the – we – in Wales, we had our minister set up a group to – of the disability equality forum to coproduce a research document, a report into the impact of Covid on disabled people. It's known as the Locked Out report, and I can post a link on it.

So we were basically a group of disabled people working with Welsh Government officials. And, you know, we sort of looked at over 300 items of evidence, produced the report, made a number of recommendations. And as a result, the Welsh Government has now set up a disability rights task force to respond to the findings and recommendations and to produce a disability rights action plan.

So I think the – one of the key findings was that the lack – in terms of the decision makers, you know, the lack of disabled people in the room, in terms of influencing and contributing to some of the decisions that were made. So, I think it's really vital – vital that the team involved in the Inquiry, one, is representative, but also has some kind of reference group of experts around disability, amongst other things, you know, that will be able to advise and work with the Inquiry, make sure that there aren't any gaps - advice on being able to reach out to in our case to, say, well, people across the UK - so, I wondered, one, has thought been given to that and two, what can be done to make sure that level of engagement and expert references is included.

Sam Hartley: [00:10:00] Thank you, Rhian. That's great. Richard, before I bring you in if I just help with that, with Rhian's question. And also welcome Jackie, I can see that you've joined in the chat. I do apologise again for the mix up with people in the wrong breakout rooms. We are – as Richard has responded to we are – we're just sort of moving on towards the first question of the consultation. But we were picking up some very fairly made points about accessibility of the consultation itself. And Rhian, to your point I could – what I can assure you obviously that Baroness Hallett is absolutely determined to be supported by experts in every field. We don't know what that looks like yet. And we're working through exactly how she can achieve what she wants to achieve, which is exactly what you said, in the disability, rights, equalities field but also wider. I mean, in, of course, in more technical expertise as well. Thank you for the report you just posted there.

I can assure you that that is happening. We can't sort of finalise that until we know what the Terms of Reference finally say. But I do assure you that is happening in parallel to what's going on today. Richard, would you like to come in at this point.

Richard Kramer: [00:11:15] I'm Richard Kramer, I'm Chief Executive of Sense, the disability charity. And to be very quick just on accessibility, just to really echo the points already made, which we fully agree with. I think the other additional point to say is that the whole Inquiry needs to be run in an accessible way so disabled people can participate and engage with it. And Kamran's rightly mentioned, the actual consultation, the Terms of Reference, but we're also thinking about the evidence-giving stage as well, and making sure that that's fully accessible. So it's the need to get it right now for the later stages. The panel to lead the Inquiry, we felt that that should be representative of disabled people. And it's critical that – I think this is implicit, but it's probably good to be explicit about it – that the voices of disabled people need to be central in terms of evidence-giving, as well as organisations representing them.

Sam Hartley: [00:12:19] Thank you, Richard. Yeah, absolutely accept. And to both points, I will come back to the accessibility of the website. And, again, I can assure you, Baroness Hallett is committed to running this in the most accessible way. Partly, that's why we want to do this roundtable first, to hear views. And the question of a panel – whether it's a panel, a formal panel, as you will be aware from a statutory requirement point of view or advice from expert groups, is yet to be determined. But as I said, as I said to

Rhian, she's absolutely committed to have that – that resource available to her in whatever way she can.

I can't see another hand up at the moment. Can we – can we turn to that question one about are there areas –

Tim Nicholls: [00:13:09] There are just a couple of hands. There's me and there's Kamran.

Sam Hartley: [00:13:16] Sorry, Tim?

Tim Nicholls: [00:13:15] Yeah, that's – sorry. I was just going to say, I think we've covered well, the kind of like the inputs in the process and accessibility there. And I just wanted to put out a plea – sorry, I'm Tim Nicholls from the National Autistic Society – for the kind of the outputs and outcomes of this inquiry, so the report and the findings to be as accessible as possible. And I'm thinking here in terms of, particularly for autistic people, also, for people with a learning disability, I think it's going to be crucial for transparency and ultimately, justice, that the actions that come out of this are really clearly expressed and specific. And also the language that's used around it is really clear, because this is something that's affected everyone. I know that sometimes these reports can be hundreds of pages of dense text. And I think we need to think really carefully about that. Because I do think it's a fundamental issue.

Sam Hartley: [00:14:07] Thank you Tim. Kamran.

Kamran Mallick: [00:14:10] Thank you. And so just in that response to question one, which is kind of Terms of Reference, do they cover everything? I think having looked at the Terms of Reference, one reference to – the use of the word harm. And I just think it's important that the Inquiry agrees that the term harm includes not just the impact of Covid-19 infections, so including deaths, but also that the impact of pandemic response itself and how decisions being made by Government actually created that situation of harm for disabled people. Because of things like the impact of those lockdowns, removal of services, no access to healthcare, and so on. There's kind of this endless list of changes that were made at the time.

And harm should include the impact of – so the Covid restrictions on people's ability to access community services as well. So we heard from parents who had, you know, young people who would be using day centres, and suddenly that was withdrawn for months on end and lasting into years, where that young person who, you know, was used to that routine suddenly was found to be at home. And parents were often ill equipped to then support that young person to manage [inaudible]. That's just one example. But just defining what we mean by harm I think is really important.

Sam Hartley: [00:15:41] Thank you, Kamran. It's a really good point, really well made. And if I may, what I won't ask people to do is think about drafting now. But obviously, if you would submit a written response to the consultation, if you think about how we can turn what you've said into something that we can put into the Terms of Reference, that'd be really helpful. Thank you.

I'm really sorry. I'm afraid my Zoom isn't telling me who – in what order people put hands up. I think it might be Gemma next. Apologies if Gemma is jumping the queue over other people.

Gemma Hope: [00:16:10] It was Jackie next, then me.

Sam Hartley: [00:16:11] Jackie, thank you.

Jackie O'Sullivan: [00:16:12] Go for it, Gemma, though you've got – you're unmuted, go for it.

Gemma Hope: [00:16:18] Yeah, so I completely agree with what Kamran said I think for – so I'm Gemma Hope, Director of Policy at Leonard Cheshire. I think for us, you know, it's good that in the Terms of Reference, you talk about the impact on care homes and what went on in care homes. You also talk about, you know, looking at things like PPE, and they're some of the things we've been campaigning on throughout the pandemic.

And I know you mentioned protected characteristics. But just building on Kamran's points, I do think the impact of the pandemic on the lives of disabled people warrants it to be an Inquiry point, because as Kamran said, this isn't just in terms of – and I know, you talk about clinically extremely vulnerable people. So this isn't just in terms of the disproportionate impact in terms of people losing their lives, amongst disabled people. But this is in terms of, you know, our research shows that, as Kamran says, people had their care withdrawn, and that was put into law that local authorities didn't have to provide care.

So people have gone without care, not just for that period, when the local authorities enacted those powers. That is still happening now. You know, it's had a disproportionate impact on disabled people's employment. And we've done research in our locked out labour market report to show that disproportionate impact, which again, people are still feeling now.

And so I understand where, you know, we can come in and give and show evidence around how disabled people's lives have been affected. But I think, you know, [inaudible] people and they need to be [inaudible] a frequent afterthought in government policymaking all the way through the pandemic. And it would be remiss if this Inquiry carried on that trend. So we really would like to see some specific points in the Terms of Reference looking at disability.

Sam Hartley: [00:18:10] Thank you, Gemma. Points very well made and heard. Jackie.

Jackie O'Sullivan: [00:18:14] Thanks very much. Jackie O'Sullivan from Mencap. I agree with everything that Gemma said, I think there were a few things just to add, that you talk about care and other care settings. And I think bringing out the other care settings and the importance of those specifically for working age disabled adults who don't live in residential care homes. And a lot of the focus of all the media coverage at the start of the pandemic was around that. But actually the impact on other settings, sort of dom care and supported living were just as grave. And right at the beginning, we were told that people in those settings didn't need – you know, workers in their settings didn't need PPE because of the priority was giving it to, first of all the NHS and then residential care homes.

So there was a lot of lack of understanding about social care that led to poor policy-making and then put people at risk. So I think actually drawing out specifically the other care settings and the impact that that had on disabled people would be a good idea.

There's vaccine prioritisation as well. So we had to campaign really hard to get people with a learning disability included on the vaccine prioritisation list, even though there was really clear evidence that they were at greater risk. And part of that was a perception that it might overwhelm the vaccination because we might have people coming forward with dyslexia and saying they had a learning – you know, that was part of the fear that that seemed to be behind not allowing that decision to be made in the first instance.

I think there's something around the centre versus local decision making and sometimes issues where people fell between the cracks because there was a policy coming up from central Government and local didn't understand what was going – you know, and there was a lot of mismatch between those services and lack of join up. I think there's digital exclusion as well, that as services switched online and still are, you know, a lot of the talk around the future of the NHS is around remote access, GP appointments, remote, you know – virtual wards even they're talking about and actually how excluding that can be for a lot of disabled people.

And then, really thinking about the situation, the ongoing situation. So we've just done a piece of research and we found that there are still people who haven't been out of the house for the last two years because their anxiety levels are so great. And, you know, people who are in receipt of maybe a couple of afternoons of day care or a little bit of respite, and they've been told, actually, they haven't needed it for the last two years. So actually, why should they have the budget for it now? So there's an awful lot of the hangover of what's going on, as the rest of the world's, got – you know, gone back to normal or the new normal. There's an awful lot of people that are still left in lockdown and at risk of being forgotten.

Sam Hartley: [00:21:22] Thank you, Jackie. Before I ask others to – I know there's some hands up - can I ask just one question back to you? The point you made at the start, I think you mentioned about that lack of understanding about the sort of care set up and then indeed, sort of access prioritisation.

How much of that do you think goes to the point about preparedness for the pandemic? And how much is more general public health policy work?

Jackie O'Sullivan: [00:21:45] I think there's a bit of both, I think preparedness definitely – because, you know, social care had been – was fragile when we went into the pandemic, and the pandemic then showed up those cracks. And I think there was also a lack of understanding centrally, because of the way that the social care market works, and the way commissioning works, there's a lack of understanding centrally about what it actually was, and a lack of understanding, you know, in society, as well around what it is.

And then because of the response, you know, I was talking to people in the Department of Health who had been seconded in from other government departments and had absolutely no idea how social care was delivered. And those were the people that were then trying to make – you know, doing their very, very best, but had really imperfect understanding of the way that the system worked.

So I mean, I'll give you a – for example, a certain amount of PPE – when they decided that social care settings should be given PPE, a certain amount was sent out to each registered carer. Now, that would be – if you were in a setting for an older person, that will be enough for a care home, perhaps for a few weeks; you know, one of our network partners, regional members had 300 masks, and that was going to last him probably six hours because he was, you know, his – his registered setting, actually was a lot of people's houses that they he went to support people in. And so that was a lot of the challenge. Just that lack of understanding of how it works.

Sam Hartley: [00:23:24] Yeah. Thank you, Jackie. Okay, I think I've got Rob next and then Nuala.

Robert Geaney: [00:23:28] Hi, I'm Rob from RNID. I agree with a lot of what's already been said by Jackie and particularly Gemma's point that I think the disability elements of this is crucial because disability was an afterthought during the pandemic and if that carries on through the Inquiry, then it just compounds those errors.

I – the Terms of Reference, broadly supportive, I think there's very little that we want to say, outside the Terms of Reference. There's a couple of points where I think there could be a greater emphasis even at this early stage. And I think there's one line in there about how policies or decisions were communicated. And I think it's one of the three-part bullet points, sort of, how policy was made, communicated and implemented. I actually think that the pandemic was the biggest ever public health behavioural change campaign in this country we'll ever see. And it wasn't communicated very accessibly. So I'd like to see if possible, sort of greater focus on that.

And I do think it comes back to the point that Richard and Kamran made in the sort of remarks about the accessibility of the Inquiry itself. That's both important in and of itself. But it's also important because accessibility wasn't considered during the pandemic, and it was an afterthought. And I don't think disabled people will trust the Inquiry to make judgments on the Government's accessibility, if the Inquiry itself doesn't get its accessibility right. So I think that's really important.

The term clinically, extremely vulnerable, I think, hasn't always worked well for lots of people in the disabled community. And I think there are some issues there. I think it was actually a colleague at Mencap who first started talking about people who are socially vulnerable. So their underlying health conditions are that disability doesn't make them more susceptible to the virus but their inability to access information to access services means that they will not do the things or they are unable to do the things to protect themselves from the virus. And so I just wondered if there could be some counterbalance to the clinical extremely vulnerable group, to that societally extremely vulnerable group.

And one last thing that is quite a minor point, in the Terms of Reference, you've got some of the direct new economic interventions the government made to support jobs. I think one of the things that we found was the continuation of existing schemes, sort of most notably for our community Access to Work. That sort of went into crisis mode, it didn't support deaf people in the workplace, and therefore they lost their – or they had issues or they were more likely to lose their jobs or not find new work. So as well as looking at the impact of new interventions in the economic response, whether existing services, whether Access to Work, employment support continued and adapted, is quite crucial to working out why the pandemic had a bigger impact on disabled people than others.

Sam Hartley: [00:26:07] Thank you, Rob. I think Nuala next.

Nuala Toman: [00:26:11] Thanks very much, and thanks for the opportunity to contribute. And firstly, I just want to apologise because I was in the black and minority ethnic and asylum seekers group. And I felt even uncomfortable expressing my need to leave the group because there was a danger that I – you know, at one point, they were going to table an intersectional discussion. And I felt very uncomfortable, because I had prepared to speak on disability. And I felt like I would be taken away from, you know, a very important discussion around black minority ethnic and asylum seekers and why intersectionality is, of course, important and essential in addressing issues around disability. I actually think, by trying to put that on record I might have came across as a little bit disruptive, but I thought it was an important – important comment and to make, but I think the chair of that group was under a bit of pressure.

So thanks for, you know, getting me into this room to comment on some of the comments that I would have liked to make being made already, particularly around the accessibility of information. And just in noting that, the changes that were enacted in terms of Access to Work – you know, because there's obviously different levels, there's the collapse of health and social care services that people have articulated really well. But there was also the information around how to access services that are provided in society that aren't necessarily public services, but which the public and people need to access in order to survive on a day to day basis.

And the lack of accessible information that was available, you know, in terms of access in shops, meant that disabled people were left at risk of having no access to food, and other essential items; you know, we would have a very strong example on record at the Disabled People's Parliament, where a blind person went to access the shop and walked into the door. And then people asked him to queue at the back of the queue. And you know, there was nothing available to indicate to him the change to society, you know, he was not aware that you couldn't just walk into a shop anymore. And these things need to be taken into account.

There was also very limited information available around how we should work to protect deaf and disabled people and vulnerable people during the pandemic and how we could help as a society. And I think that is a – you know, that should be taken into account, I think the impact of the pandemic is likely to have had increased – to have increased the invisibility of deaf and disabled people. And that it's important to try and explore whether the – you know, almost like removing people from society will have an impact moving forward on inclusion, as we – you know, as we transition out of Covid.

And in our region, there is very limited information around the number of deaf and disabled people who have died due to Covid-19 because the data is collected across all settings. It isn't of the same quality of ONS data, and there are still challenges with that data. And one of the most significant issues is the lack of attention to the disproportionate impact of Covid-19 on deaf and disabled people. And there's also a challenge in terms of what the impact of each transition is. And, you know, I don't want to take over the whole meeting, but I guess it's going back to that point by including people in planning, because when you include people then provision is better and there are less gaps. So thank you for the opportunity to speak.

Sam Hartley: [00:30:29] Thanks Nuala, and, again, I can only apologise for the mix up at the start with the breakout rooms. This is, again, not an excuse the first one, obviously, something's going a bit wrong to start. I do apologise. But we've absolutely heard your points just there. And actually, I'd like to come back to your point about including people through the life of the Inquiry, not just in the design point, which we're trying to do at the moment, because I do have a question about how we can best hear from people over and above the representative groups, campaigning groups and people affected directly, which we'll come back to.

And I'm back in that position where I don't know who had their hand up first I'm afraid. Richard. Okay, you're waving. So we'll come to you first. And I know Tim and Rhian have both got their hands up for afterwards.

Richard Kramer: [00:31:14] Thanks, Sam. I think my first point, hearing the others speak, the draft Terms of Reference are broad enough so we can see the areas that we want to talk about in terms of increased death rates, wider inequalities, employment welfare, lack of inclusion in policy-making, struggles to access pre-existing services, including services prior to the pandemic and supporting the community.

I think the issue is whilst the Terms of Reference make reference to protected characteristics, given the combined impact across so many areas, it's really important that disabled people are explicitly mentioned in the Terms of Reference, rather than just simply saying, they're considered under the Equalities Act. So I think that's the first point, just listening to everyone. Otherwise, the first draft does include the things that I think we're concerned about.

The second point I want to make, which I think Jackie talked about, was that, from my perspective, the Terms of Reference are really quite narrow in the sense they look at the response during quite a restricted period, in terms of the impact of the pandemic in the short term. And I think it's really important the Inquiry recognises the short term and long term impacts and how the pandemic exacerbated existing inequalities as well as creating new ones. And I think Jackie's point that some people have not gone out, have not recovered, have not – restrictions still applied to them. And I think we need to be looking at a longer time span. So that's the second point.

The third point was, we've talked about working age adults, I just wanted to stress the case to look at disabled children, as well as disabled adults as part of the Inquiry. Because they're separate legal frameworks, the fact that we're looking at the impact of the whole family as well. And the fact that disabled children and families are supported by a range of services from health, social care, education, and voluntary services and charities. And the withdrawal of support had a huge impact on disabled children and families, which were really wide reaching across all aspects of their lives.

And the last point I wanted to say was something about the impact of mental health and wellbeing. And I don't think that's been fully considered in the Terms of Reference we saw. Again, Jackie talked about increases in isolation and loneliness, the impact of shielding for months at a time, and people feeling exceptionally anxious even when we come out of pandemic and people not being able to access mental health support, and actually high thresholds of need were required to access support. And interventions provided were generic and not accessible for disabled children or adults. And I think a future pandemic response should be thinking about emotional and mental support, and actually preventing high level trauma at a much earlier stage.

Sam Hartley: [00:34:30] Thanks very much. I think it was Tim next and then Rhian.

Tim Nicholls: [00:34:36] Thanks. I mean, I just completely agree with everything Richard just said so you can put 'times two' next to whatever you’re taking down from what Richard was saying, to be honest, I think he's hit the nail on the head, particularly around like that need for, like specificity with it, within the Terms of Reference because I can see how so much would fit in underneath it. But to make sure that actually all the right things are covered. I think that's going to be really important.

I've got a bit of a list so I'll rattle through them quite quickly. And it doesn't mean that my rapidity means they're any less important. But I think for me, that social vulnerability is absolutely crucial. I think autistic people were one of the groups where that really came through because there was, because there is no underlying clinical vulnerability to Coronavirus unless you have a co-occurring physical health condition, which many people do.

But you are just as at risk if your carers can't come in to see you; you are just as at risk, if you can't go out and get food. I know that frankly, I never thought I would have to campaign for disabled people to be able to buy food, I really thought we'd got past that. And the first few months of the pandemic, trying to persuade DEFRA, in that instance, like, why restricting access to the priority slots, just to clinically extremely vulnerable people was a dangerous move. And it was a really disheartening and awful situation to be in for us. And obviously, much more awful for people who are actually experiencing it. But I think that that social vulnerability is something that really needs unpacking for this inquiry, because it's one of those things where, while lots of other good stuff happened, that really fell down.

The other thing, I think, to mention around care and access to care restrictions: it's really important to look at what was the impact of the changes to the legislation. But what I was hearing was a week before any of that stuff was on the statute books, people losing their care, and it didn't matter a damn what the law said. It had already gone. And that went across adults, and it went across children as well. I think actually, it may even have been worse with EHC plans because there was less scrutiny around what represented 'reasonable endeavours' in terms of making sure that people's EHC needs within EHC plans were met.

There's been practically no monitoring of either of the restrictions of adult social care or children's education, health and care. But there's been even less when it comes to education. And I think that's really worrying because of that legacy of who is still struggling without support. And then I think there's something around, as well as people who couldn't access virtual interventions, telecare appointments, things like that. When – when – when were reasonable adjustments not made to have people going in in real life? I think that's a really important thing. Also, what's been the impact of that on waiting lists? Because that's key to getting back to any sense of normal.

Data came out a few days ago, suggesting there's 88,000 people on the autism diagnosis waiting list in England alone. And that's rocketed since coronavirus; we don’t have a particularly reliable figure from beforehand but the trajectory like recently is definitely going up. it's – then that's an outcome, at least partly of what's been what was happening during the Inquiry.

Then just a couple of small things that I think are really important to remember, when going through the Terms of Reference: I'm really glad to see care home visiting in there. I think what's really important is that we make sure that we consider well, actually, wider care settings, visiting, but that's been mentioned especially by Gemma and Jackie, but not just visiting into care homes but visiting out. Because when you look at Christmas before last, one of the big issues was that people weren't able to go home to their families at Christmas. Working age adults weren't able to go home to see their families for Christmas. And then they weren't prioritised for a vaccine, necessarily. And it's all of a sudden it was like, 'You're not vulnerable enough to be clinically – treated as clinically extremely vulnerable. But you're vulnerable enough that we're going to keep you trapped in your house. And we're not going to allow you to go and see family.'

And for autistic people up and down the country who are in those care settings, that was possibly the first Christmas they had never spent with their parents and it was, you know, quite a huge strain on their families and on them. And also on – we're a service provider as well – on staff and our services to try and deal with that distress. So visits out as well as visits in because I think those visits out are often not thought about because people think of this within the paradigm of older people's social care, and families going to visit people in care homes.

And then my very last point, I think there's a wider point around the information that came out and the timing of when that information came out. What was the impact of guidance to providers, and to give clarity about the rule changes coming out only the night before it came into force, when it'd been pre announced a week before, but with absolutely no detail about who it applied to. And let me tell you, autistic people are always left off the list anyway, of whether it applies to them. And when it would come into force, how people would make sure they were – they were complying with it.

That meant that every single time we went to update the information on our website, which we did regularly throughout the pandemic, and are still doing, we had to not only scrabble around with the Government to try and figure out what was happening, what was the clarity, but deal with the anxiety and distress that a lack of certain communication was providing to autistic people. So it ramped up things even worse and then the change was even more difficult to deal with.

Sorry, I really went off on a rant there, having said I was going to go through my list really quickly, but I think those are just a few really like, like, specific things that the Terms of Reference should really be focusing on.

Sam Hartley: [00:40:54] Thank you, Tim. No rant at all. I thought that was very well and passionately made. Rhian?

Rhian Davies: [00:41:00] Yeah, thanks. I mean, I think a lot of the points have been made, you know, can be summed up in how – and I think needs to be reflected in the Terms of Reference - in how quickly and rapidly a rights based approach was just ditched, you know, by governments across the UK. And, you know, to the extent of things like, you know, like the Coronavirus Act, you know, and actually, you know, you know, actually taking people's rights away from them in terms of access to assessment and services, and also kind of an over interpretation on the part of local authorities, really, in terms of what they felt they could or couldn't provide, you know, and which wasn't, you know, at all based on, you know, people's needs.

So, I think, you know, I think the fact that we – you know, we lost sight of people's human rights, and the sense that, oh, it's an emergency, you know, so, you know, rights are a luxury, when, in fact, that's when you need rights the most. And also, I think the way that, you know, we just – society just defaulted to a medical model approach to disability, not a social model. So everything was in terms of what your actual impairment was, or your condition, and whether you're on that list or not. And actually, you know, talking about people in terms of whether or not they were clinically extremely vulnerable.

And I understand the points being made about using social vulnerability, but even so, I think the word vulnerability is still being used. And I think we need to be talking about people, talking about this in terms of people's rights. So, you know, we saw things like deprivation of liberty, particularly for people living in group and residential homes, not – not having very – again, over-interpretation of rules, and people were not allowed to go out – just had no agency over their own lives.

That Do Not Attempt Resuscitation, I know, in Wales, we had to stage an intervention to get the Chief Medical Officer, Chief Nursing Officer to issue a circular to clinicians that, you know, a blanket approach to DNA CPR should not be issued, that individuals had to be assessed according to their particular circumstances. Vaccination policy was another one.

And I think also, you know, we can't escape the death rate. In Wales, it's 68% of disabled people. The death rate of Covid comprised 68% of disabled people. And I think there was this sense that there was this inevitability, if you were a disabled person, if you had some kind of impairment, underlying health condition, then you would become ill, that you would die. And, even the way it was reported in the media, you know, it would be noteworthy if somebody young had died, who wasn't seen as having some kind of underlying condition.

So, I think – and again, a lot of this is reflected in who were the decision makers, you know, the – the fact that disability was seen in such a narrow view, and it was about what condition you had, not about societal factors – that make people disabled. So, I think those are the – you know, I think the Inquiry should be framed in terms of a rights-based approach, and also looking at how do we reset, how do we get back – or not even get back because, in terms of what was before was often very excluding anyway. But how do we ensure, how do we take this opportunity to ensure that the policies and provisions that we put in place, you know, actually reflect rights, and a social model understanding of disability? And, you know, how do we make sure we're progressive rather than regressive? Thank you.

Sam Hartley: [00:45:26] Thank you Rhian. I've got Gemma and Kamran. And then I think Robin and Nuala in that order. Before I do invite Gemma, I think you may have been promised a break about now. I'm very open to whether people want to carry on, this feels like a really, really good and productive conversation. We are going through to about 11.45, before we go back into the main room. If people do want a break, please do let me know

now, we're very happy to take five minutes, if necessary. If people are happy to carry on, I'm very, very happy to do so as well.

I don't see anybody calling out for a break. So I will carry on if that's okay, if you do need to pop away for five minutes please do of course. So let's go to Gemma.

Gemma Hope: [00:46:12] Kamran is actually before me.

Sam Hartley: [00:46:15] Sorry. Apologies Kamran. You're muted Kamran.

Kamran Mallick: [00:46:25] Sorry, I clicked – it had to happen once, didn’t it. I mean, I just want to echo everything Rhian just said and Tim before that, as well. So I absolutely agree with everything that's just been said. And I actually was going to pick up some of those points myself, I just think explicitly mentioning a rights-based approach, a social model of disability approach, in the Terms of Reference is, I think, vital, and it must be in there.

I think reference is made to, it's been mentioned as well, the rights we all enjoy in the Human Rights Act, and the commitment to investigating how kind of that was interfered with during the whole pandemic response really. And I think it provides a helpful framework, when we're talking about how people suffered as a result of decisions being made. So everything from right to life, right to freedom, right from inhumane, and so on. I think that's really important to have in there.

And then the couple of other things was, at a time when actually the people we were talking about who this – now the stats show that people who died were the people the Government was originally saying we're going to protect and put a shield round, were the very same people that the coronavirus immediately came in and removed all the kind of rights that people had and access to support services. Gave local authorities permission to remove the very services that are designed to support those very same individuals.

And we had it – we heard from many disabled people up and down England, who were saying that actually my support services have been reduced, even though my local authority hasn't actually publicly said that they're enacting the Coronavirus Act. And that was happening up and down the country. So it wasn't isolated to one or two areas of the country. So there's obviously something going on there.

Then talking about some of the measures that were put in place to support disabled people; in particular we're thinking about a kind of failure, purchasing food has been mentioned. But the other one that we kind of campaigned on with colleagues here as well was the failure to award the £20 uplift to disabled people who were on legacy benefits. And it makes me incredibly angry that the response back was that the reason it was done was because the IT system didn't allow it. Wholly unacceptable response from the Government, that that's why we didn't give millions of disabled people that additional uplift. So if you weren't on the new benefits, kind of tough: wholly unacceptable.

And it just felt like the Equality Act was just thrown out. Decisions were being made with absolutely no regard to legislation that we have in place that has a requirement on Government and decision-makers to take account of. Completely discarded. So I think those points from my – I would just kind of add as well.

Sam Hartley: [00:49:27] Thanks, Kamran. Gemma next.

Gemma Hope: [00:49:32] Yeah, I fully support what Kamran just said and particularly with the benefits uplift, we did a big survey of disabled people and carers during the first lockdown and people were using their PIP to pay for cost of living expenses. And yeah, that didn't get upgraded. That's not how PIP should be used. But that's the financial situation people were forced into, so I do think that warrants further examination.

I was just going to make a different point around where unpaid carers are being looked at in the Terms of Reference? I appreciate in terms of the Equality Act, that can be by association into disabled people and older people. But you know from our experience, again from that survey, so many people, because social care was withdrawn from their family members either took a leave of absence from work or left the labour market to care for their loved ones. And that situation has continued for many people.

And so, for those people who maybe had some local authority support as part of a package, and they also provided support for a loved one as well, that local support has disappeared. So the amount of caring they have to do just increased. It's something I know personally, because I became an unpaid carer during the pandemic, and had to juggle a full-time job and full-time caring for my dad, and there isn't any support left. So I just think it'd be remiss not to consider the impact of unpaid carers as part of this Inquiry and in the Terms of Reference, so I just think they need to be explicitly mentioned somewhere.

Sam Hartley: [00:51:12] Thanks Gemma, lots of nods around the virtual room as well. I think Rob was next and then Nuala. And I know that Richard and Jackie have their hands up, too.

Robert Geaney: [00:51:23] Yeah, thanks. It was actually just quite a small technical point, we were speaking earlier about the benefit of saying disabled people as opposed to protected characteristics. And we're talking about it from sort of a moral or a policy perspective. I also think there's a key accessibility thing here about how these Terms of Reference are written. And, sort of, for RNID thinking about deaf BSL users for whom English is a second language, protected characteristics might not mean very much. And actually something that's jargon free plain English and translates well into BSL is really important to make sure the people you need to engage with the Inquiry do. So I think as well as thinking about the contents of the Terms of Reference, there's a few points there where you might just need to think about the language and its simplicity as well.

Sam Hartley: [00:52:10] Thanks, Rob. Nuala.

Nuala Toman: [00:52:08] I would just echo what Rob has said, it's really important to recognise the dual identity of the you know, the deaf community, as not, you know, protected in this region, like deaf people do not necessarily want to be defined as disabled. I think it is really important to recognise that. Just in the context of the – I agree with what was said around ensuring that the Inquiry is based on a human rights model, and centred upon, you know, human dignity, and considering how human dignity and human rights were breached during the pandemic.

And, you know, it's – I realise this is challenging because decisions were made, you know, decisions were being made very quickly and in the early stages in the context, you know, that it was an emergency situation. I think, at some point, and comments were made earlier, and I think it was Richard who said about looking at the short term and the long term. I think it's really important to consider if lessons from the initial stages of the pandemic were applied to future stages, particularly in terms of, you know, the accessibility of communication, the nature of the measures that were put in place, and the wider impacts on deaf and disabled people.

And I think there's a need to explore the process through which people were identified as shielding and what that meant in terms of services people could access. I would be aware of many people who needed to shield and have valid reasons for shielding who never received an official shielding letter. And they were not on anybody's assistance list. So you know, you would have like, a lady two doors down from another lady, one receiving a food package and one not, both unable to leave their house. And those kind of disparities I think, need to be addressed, particularly in this region, where the department invested in – the Department for Communities invested in initiatives that were around access to food and services and – and you had referred to the lived – you know, the importance of the lived experience, and I think that is by working with groups like this to get the information out directly to deaf and disabled people.

I mean, here in this region, there was such a lack of attention to the stories of deaf and disabled people that we had to push – after going through every official channel, we had to push the Disability All-Party Group to hold an informal review. And that was so limited because it was the representations of three deaf and disabled people articulating their experience on record to open up the discussion.

And so I think it's really important that we look at ways that people's voices are heard and amplified in a positive way. So that we don't lose or reduce anyone's experience during the pandemic, particularly as we move through transitions, it becomes more and more difficult to reflect on what it was like at the early stage when there was so much fear.

Sam Hartley: [00:55:55] Thank you Nuala, that's great. Thank you very much, Jackie and then Richard, if I may, just before you come in, Jackie I would really like to hear – I mean, you know, the second, third and fourth questions, although not specifically relating to the content of the Terms of Reference are really important to us as well. So two and three are about prioritisation. What should we look at first, if anything? And then number three is a really hard question about how quickly should this Inquiry happen? The trade-off between breadth and depth, and real forensic scrutiny of what's gone on, versus that ability to have an impact with meaningful recommendations really quickly. So really keen to hear thoughts on that.

But actually, the fourth question is the one that I know Baroness Hallett is, arguably outside the Terms of Reference scope, most interested in and that is, how can we make sure the Inquiry process – once we finished the consultation and the Prime Minister has set the Terms of Reference - how does she make sure that she is hearing outside the formal structures of hearings and evidence collation, which obviously are intimidating for a lot of people – how can she make sure that she is hearing from people who have been affected? Not just bereaved people, but people that have been affected in any way through the course of this pandemic as we go through the course of the Inquiry. So really interested if anyone's got any thoughts on that? Conscious that we've got sort of 25 minutes or so left before we have to wrap up but I'll leave that with you. And over to Jackie.

Jackie O'Sullivan: [00:57:19] Okay, I'll talk quickly. And I'll cover off some thoughts around those other questions as well. I agree absolutely with Gemma about unpaid carers: we've seen families break down because they've been under so much stress and ultimately, you know, actually need a lot more state support in order to carry on.

I wonder on the Do Not Resuscitate notices, I think there are two strands to that. One is the blanket use of Do Not Resuscitate notices. So where entire households were written to and told, you know, we'll give you palliative care, but you're not getting an ambulance and you're not going to hospital. And, you know, really shocking, but also where there were pre-existing Do Not Resuscitate notices that meant that people didn't get treatment, even when they could have been treated. And I think just reflecting on Kamran talking about the IT system, and the benefits, I think there is something about, you know, one of the key messages here was 'protect the NHS,' and that became the overriding driver at the expense of people that rely on the NHS. And I think it's that – you know, it's the fact that it's the focus, I think that would be worth picking.

In terms of dates. And I mean, it is a hard decision, isn't it? To what extent do you do depth or breadth? I think there's probably an interim stage because there are so many people who are still suffering the effects of Covid, there's probably two phases to this. One is interim immediate recommendations that will go and help people here and now in the building back process. And then perhaps a slower recommendation about long term societal shifts that we need to – lessons that we need to learn as a society on the back of that. That was just my thought there.

And then in terms of hearing from people, don't forget, there are a lot of people who don't have families who died during this. And, you know, but lived with people, have friends and, you know, made a contribution to their society. And it's how we could capture that, where there's no one person that you could bring in an interview. And I wonder whether some sort of storytelling approach might be a good idea. I can connect you with some – you know, a few people who might be able to help you with that. But that might be an interesting supplement to this. So you can actually really analyse the impact of somebody's loss and the impact maybe on a household where, you know, they also suffered the trauma of losing a friend, the fear of – of succumbing to Covid themselves, and – and not forgetting as well, the loss, the people that support and paid carers feel as well at losing somebody because I think that's – the guilt of having that happen to someone that they are supposed to be caring for and the guilt that people might feel that they unwittingly brought that infection into a service, especially in the early days when there was no PPE for people in social care. I think it's really important that that story comes out as well.

Sam Hartley: [01:00:38] Thank you, Jackie. Richard, next, and then Kamran and then Rob.

Richard Kramer: [01:00:43] So thanks Sam. I'll just answer questions two and three. I think four, I think we'll probably have a broader discussion. And Kamran probably has got quite a bit to say on that. But I think in terms of which issues or topics you think the Inquiry should look at, I think hearing everyone today, rather than starting from looking at systems and processes, I think it's looking at individuals and impact. And therefore if you start on that premise, you will think about which group to be disproportionately impacted. And, you know, disabled people make up 22% of the population, but they made up six out of ten deaths. So that's the, that's why the starting point should be looking at those individuals most affected.

Then the second bit. The second area, I think, is the impact of cuts to pre-existing services that really impacted on disabled children, adults and families. And just picking out what Tim said earlier about you – we didn't think we would be campaigning for people to access food. I think if I think about disabled children living with families at home, particularly the people we support with complex needs, they rely on support for personal care, to eat, to drink, to communicate, to move to take medication, therapeutic support, to be – to grow, to be free from pain. And I think as the pandemic commenced, those rights were regarded as add ons, and discarded in favour of general population strategies.

So services vital to disabled children and adults living at home were withdrawn as services were diverted or closed. So we didn't ensure the safe care of disabled children. We didn't protect them. And I think that – that emotional call, but probably based on what Tim was saying, really, drives home to me personally, why disabled children’s families and their carers should be central to the Inquiry.

Just on the date – should there be a proposed end date for public hearings? I suppose the question for you because we thought the Inquiry was due to begin in spring. But we think that now the public hearings won't start until 2023. And I suppose that's a bit of a disappointment. Good to hear from you there, because we would like further clarity and transparency about why hearings won't take place for another nine months. And what will happen ahead of this time, given next week is the two-year anniversary of the first lockdown. And people are still dealing with the consequences. We haven't learned lessons or investigated decisions that were made. So we just need to understand that. And I think having a proposed end date is quite important to ensure timely findings, recommendations, without jeopardising the ability to take part in the Inquiry. So I suppose, I wanted to focus on that, particularly just to get your response to it.

Sam Hartley: [01:03:40] Of course. And I will respond to that, Richard, if I may before I bring Kamran in. So just, I mean, you're quite right. I think I will be the first to admit we wouldn't want to be starting from now, we'd want to be starting quite some time ago. But unfortunately, for reasons outside of our control, the Inquiry's control, we haven't had the draft Terms of Reference until now. As I'm sure you know, setting up a public inquiry of any scale takes a long time and involves going through a lot of legal processes before the first evidence collection and hearings can begin. And I think our best estimate, and we do want to – you know, part of what we're doing today over the next few weeks is trying to manage people's expectations. Our best estimate is that we won't be able to start actual hearings about the specificity of what's going on until 2023.

We are doing everything we can to expedite that. But there is a long series of processes that we've gone through in terms of identifying core participants, making sure that actually we take this very broad scope as you will appreciate better than everyone that this touches on every aspect of life in the UK, unlike any other inquiry so far. And Baroness Hallett is very keen not to over-promise that things don't happen much quicker than they will do because these things do take time. But that's not to say that we, that we think this is a good outcome. We are trying hard to get to those points for the hearings as quickly as possible, but as I said we do want to make sure that that people – that we're honest with people about how quickly that can happen. Kamran.

Kamran Mallick: [01:05:06] Hi, thanks Sam. So I'll just go through kind of those questions two, three and four, just – I'll go through them as quickly as possible. So on to the main, I think which issues or topics do we think should be looked at first. I think the first one was around the kind of current decisions to drop restrictions and the impact that that's going to have, and is having on disabled people already. And I think it's leaving many disabled people isolated at home, because they're fearful of going out. So these are decisions that have been made. And we think those are really pressing and should be considered.

In terms of Inquiry end date, we think, yes, there should be, but not at the expense of a thorough inquiry and making sure that it's accessible to disabled people. So yes, there should be an idea of when the Inquiry is planning to end. And if that kind of thought has already been started within the Inquiry team, about what that kind of timeframe looks like, we think that should be made public. So we know roughly what timeline we're talking about. And we also think that based on that, there should be a commitment to make some kind of interim recommendations, rather than having to wait until right at the end. So we can learn as we're going along. And kind of at the earliest opportunities in relation to, I guess, things that are going to urgently save life, reducing that idea of significant harm, and so not waiting till the end.

And then on point – question four, about hearing from people. So we were thinking about could the – would the Inquiry benefit from having a kind of like a modular format. And in that context, thinking about discrete focus on the impacts on disabled people given the kind of end result of what the impacts of Covid-19 has been. We think that disabled people led organisations should be granted core participation, core participant status, and representative organisations because as a membership organisations, disabled people's organisations, we know that they have a wealth of knowledge and information and experience and access to actual stories and case studies of what's been going on for disabled people up and down the country, and how they've helped to respond to that where there have been failings.

We think disabled people's organisations should be placed on a level playing field with the Government in terms of equal access to legal representation. I think that's really important. Because a lot of local disabled people led organisations don't have the funds to bring on board legal representations; I think it is really, really important. And then creating some space within the Inquiry for individual cases to be heard. Because I think that really brings it to life in terms of both families who've lost loved ones, but other people who've had and experienced significant harms throughout the period of the pandemic and creating specific space for that. We've got lots more but we'll submit them by email.

Sam Hartley: [01:08:25] Thanks, Kamran. That's really helpful. Rob and then Nuala.

Robert Geaney: [01:08:30] Yeah, to start with question four, agree with everything Kamran said, and just to follow up with quite a technical point, again, is that a lot of our organisations – not sure this would almost be part of the evidence initially made to the Inquiry – wrote an accessible comms checklist for Government, to how they deal with the pandemic. And in terms of the Inquiry, as an organisation that will broadcast, I hope, you would sort of take that from us and treat it as an absolute baseline of the minimum standard you will do in terms of communication, and look to go much further than that.

But also, there'll be a lot of work, too complex and too nuanced for this discussion, about how you interact and how you make your channels accessible and open. And hope you go through that process.

In terms of question two, I'm slightly reticent to lead with my own stupidity here. But I don't necessarily understand, are the issues you look at first, an indication of your priorities? Because that isn't necessarily the process I would go through or how I understand it. And so I wasn't sure why what comes first is necessarily the most important and I think because Richard suggested, actually, what comes first should be the impact and the output.

So you can then go and look at the impact of decisions. So it's almost throwing the question back and saying, why is what you look at first an important question?

Also, I agree with Kamran's point around interim reports, and I think there are parts of the endemic stage, if you want to call it that, that are still impacting people now. And I hope the Inquiry, if they can make some early recommendations, do that. And then I think the rest – there's sort of two categories. There's backwards looking and specific to Covid. But there's going to be lots of questions that come out of this Inquiry, I hope, on civil contingencies, Government's preparedness for any sort of emergency and any sort of crisis and how they failed disabled people in that one. And hope that those issues come to the fore quite quickly, because we don't know what the next crisis is. We don't know how the Government will respond. But we do want the lessons from this to be part of that as quickly as possible.

Sam Hartley: [01:10:29] Thank you, Rob. Nuala. And then Gemma.

Nuala Toman: [01:10:34] The comment that I was going to make is quite similar to Rob's comment, in terms of what does prioritisation actually mean? Because, you know, you almost need to engage with stakeholders, have the discussion, receive evidence and hear testimony before you could consider any kind of prioritisation framework. I think that is very, very challenging. And in terms of issues, you know, in the work that we do, we would use the UN CRPD to gauge how we approach issues.

And, you know, and again, that's going back to using a human rights framework in terms of exploring issues and impacts. So, there are some key areas to be explored. So there was the impact of planning, gaps in decision making, the impact of those gaps, the – everything that we've raised, the use of Do Not Resuscitate orders, the misinterpretation of Do Not Resuscitate to do not treat, and the collapse of services, the impact on physical and mental wellbeing – any kind of relationship between increased socialisation and decline in mental health and absence of provision, and who got PPE and how and who didn't.

What services were available and maintained, how did people access the limited healthcare that was available, and were there more barriers? The list is endless, in terms of looking at how it was, people's privacy, you know, even now, are people's right to privacy being protected, in how they access healthcare? Is the right to health protected in terms of access and healthcare, and is healthcare actually accessible?

Again, we would have multiple case – cases in which, you know, deaf and disabled people have tried to access healthcare services and find that they can't, and including a family in which both parents, you know, experienced sight loss, and were asked to send a photo of their child's ailment to the doctor, but neither person – there was nobody in the house to take the photograph. And also how did you access testing. And, if you're a deaf and disabled person, because you were required to kind of go alone at one stage here – the recommendation is go alone, but then people felt they were risking other people's health by asking someone to take them to a testing centre. And how accessible is lateral flow testing to people with visual impairments?

You know, so there's multiple – and again, I don't want to take up all of the discussion, but there are multiple issues that would need to be explored. But thank you for the opportunity again to speak.

Sam Hartley: [01:13:37] Thanks Nuala. Before I go to Gemma, can I just come back and ask you another question just on the last point about hearing from people through the course of the Inquiry? And I think we've heard from Kamran, from Jackie, about this idea of sort of storytelling in some way. Is that something that sounds attractive to you or are there other thoughts you might have on that?

Gemma Hope: [01:13:59] If I could come in, that's what I wanted to talk about.

Sam Hartley: [01:14:02] Oh great. Go ahead, Gemma.

Gemma Hope: [01:14:05] Yeah, I obviously understand, formal inquiries have formal processes to submit evidence, but that is time consuming, and off-putting for so many individuals who'd want to share their stories or groups. You know, it's not accessible for, you know, certain groups as well. So, I just wanted to make a plea that there are alternative ways to submit evidence. So, you know, the House of Lords Youth Employment Committee had video testimonies for young people because they didn't want to go into an intimidating setting and that was really powerful to share their experiences.

So there are innovative ways to collect evidence and you know, we, as part of the research team I manage, do a lot of stuff with Photo Voice. So basically people taking photo diaries and having that as part of the research, rather than someone sitting down and doing a formal interview, because again, that can be not accessible, it can be intimidating, there's a stigma attached to it. So I was just going to make a plea. And I agree with the point around storytelling, kind of alternative ways for people to share their experiences, rather than having to do a 20-page submission and go into a court based setting to talk about what they have experienced, if that can be considered as part of what you're doing?

Sam Hartley: [01:15:32] Yeah, absolutely. Thank you, Gemma. We've got sort of ten minutes or so left, I think we should be ready at 11.45 to be virtually sucked back into the main meeting room, and those that have experienced that before now, it can be quite brutal. I was going to just ask two more things.

One is, if somebody might volunteer to sort of feed back some of the thoughts when we get back into the room just for a couple of minutes. Obviously, I'm very happy to volunteer, but I don't think it should be me, I think it should come from one of you. If you can think about that for a minute. But while you're thinking about that, and hopefully somebody will volunteer. I guess the last – linked to that last question in the consultation about how do we design and as you just said, Gemma, to make sure it's sort of accessible and not intimidating and think about innovative ways. I would just be really interested to know how the Inquiry, how Baroness Hallett and those of us that are supporting her, can earn and keep your trust. I've heard lots of really good pointers and obviously starting with accessibility of all the material that we put out. But what else can we ensure that we keep doing throughout the course of this Inquiry that keeps your trust that we are doing things independently, impartially, fairly, and openly, and the other thoughts about how we might be able to do that through the course of the Inquiry, both to your groups, your organisations and the communities you represent. That would be really welcome.

Kamran Mallick: [01:17:06] My immediate thoughts are, part of it's around transparency. So it's about being transparent with what's being looked at. But also who's involved. And that's the thing where it's really important that the core participant groups are the right groups that are truly representative of disabled people, that are led by disabled people, that it comes with trust.

It's about making the whole process accessible and genuinely taking steps that demonstrate the difference and commitment, as opposed to what has just been experienced through the pandemic by disabled people, that we said – everyone has said, I think at the beginning about being – not making the same mistakes that had already been made before, and issues that had been raised and government continuously ignored. We just take, you know, the briefings that used to happen, the BSL interpretation on those. So transparency, involving disabled people and their organisations, being open with that and getting the accessibility aspect of it really, really well done. My kind of immediate thoughts.

Sam Hartley: [01:18:29] Thanks, Kamran for your help. I can see others putting some ideas in the chat as well, which we will capture. And I'll pass on to you, Rob.

Robert Geaney: [01:18:40] Yes, I think Kamran said most of what was in my head since I put my hands up. But I agree entirely with the point about inclusion of disabled people, but also making sure that's visible and obvious. To demonstrate you're going through this process, I do think the accessibility will be key, is a litmus test, I think, especially for a lot of deaf people about whether you're including them. And so I really would implore you to do that.

The other thing I would say is that, I mean, even as sort of policy people working in a policy world, we come over here and sort of talk to you in a legal world. And it's slightly difficult for us to comprehend and get our heads around and to understand sort of the question about why you do things first, what you prioritise. So I think just to make sure you explain the process, the logic, the decision making, that you've gone through and explain; if you are not looking at disabled people in stage one, to be really clear why you're holding that or why you are doing that. And just to make sure that the rationale and the process is as accessible as the proceedings because I think that's the bit where it's very easy for people to forget that not everyone's a legal expert and understands what a public inquiry does and why; to just to make sure you explain that.

Sam Hartley: [01:19:52] Thank you, Rob. That's really, really helpful. No-one has got their hands up at the moment; please do jump in if I have missed you, or if you've got anything else to add, we'll be back in the main room in five minutes. Did anyone want to volunteer to feed back on behalf of the group? If not, I'm happy to have a go. But I'm conscious that it shouldn't, you know, it's probably not best coming from me, as I’m not directly affected, but I'm happy to have a go and people can jump in, if I get anything wrong. I don't see any dissenting views. Thumbs up from Kamran. Okay. I'll do that. Thank you very much.

I will just say thank you for the way in which you participated in a very constructive way, and as Ben said at the outset, we are capturing transcripts of the conversations. And all of this will be fed into some analysis that we will give to Baroness Hallett before she makes recommendations on changes to the Terms of Reference to the Prime Minister. I will take the opportunity to remind everyone that they are his Terms of Reference, that he gives to the Inquiry. But we will do everything and Baroness Hallett will certainly, I can tell you from experience, will do everything she can to influence that based on what she hears from people.

I did see somebody put something in the chat about showing that we're listening and I'm just scrolling back to see who it was. Thank you to whoever said that about showing that we are listening and I agree entirely. That is a real test of whether an institutionalised inquiry is actually earning the trust of its main organisations that it's working for and with, and we need to show that we are listening as well.

So and the final point is just on that the point you raised at the start, which was about accessibility; as I said, I will go to my team straight after this meeting and investigate where we've got to on that and get back to you I think once we've got your contact details. So I will let you know what happens hopefully later today.

And with that, if no one else has got anything else to add, we might just take two or three minutes and I think – I hope we'll be sucked back into the main meeting room in a couple of minutes. And as I said, I'll do my best to represent your views as clearly and as succinctly as possible. Thank you all.

[All of the breakout discussions join back together into one meeting]

Speakers:

Ben Connah, Director, UK Covid-19 Inquiry

Sabah Kaiser, UK Covid-19 Inquiry

Samantha Edwards, Communications and Engagement Team, UK Covid-19 Inquiry

Ben: [01:29:39] Well, thank you very much indeed. I've been floating around the three breakout rooms that you were all in. And I'm extremely grateful for the huge amount of input that we've had from each of you over the last two hours. The Government only published the Terms of Reference in draft on Thursday, which didn't give us very long to set these up and gave you even less time, I'm afraid, to consider the Terms of Reference. But the discussion that we got was really, really rich. And I'm so grateful to you.

As I said, we're going to take away the transcript of this, but also the key points that were made to make sure that that feeds into Baroness Hallett's consideration towards the end of this consultation process. Before I do that, though, I'm going to ask the three facilitators in each of the rooms to just, if they can, summarise in one point, the kind of mood of the room and the kind of key messages that came out, so that each of us can understand what was going on across all three of the breakout rooms that that we had. I think, first of all, if I can go to Sam Hartley, who is online, and was in the discussion about disabilities.

Sam Hartley: [01:31:02] Thanks, Ben. Hope you can hear me in the room there. For those who don't know me, I'm Sam Hartley, Director of Policy, Research and Analysis, and Deputy Secretary to the Inquiry and I just facilitated a really helpful discussion. I cannot do it in one line, I'm afraid, Ben, but I will try and put a few brief points together on behalf of the group. I should first say thank you to everybody that participated in a really constructive and positive discussion as well.

I think the few points that I took away immediately, although I've got about seven pages of notes, and we have the transcript, as you said, to come – first of all, the one point that comes across not just the work of the Inquiry so far, but how it will act and how the Terms of Reference will be framed in the future is about the accessibility of it. And so there were some very well-made points about our start, and website, and the consultation itself that I promised and committed to take away in relation to the accessibility of what we've done so far. And learn from, and indeed set that sort of trend of how we're going to work with the Inquiry in the future. And there were some really good points made about some of the issues that people with disabilities had faced in terms of accessing, not just services, but simple things like shopping, and websites, and support and care and all those sorts of things as well.

So accessibility was a sort of – the first point that cuts across both what we're looking at and how we're going to operate and in the future. And there were some really good, specific points about the Terms of Reference, the detail and the specificity within them. So rather than just looking at the particular characteristics, looking at actually specifying people with disabilities, as well, and other people who have suffered other types of harm over and above medical harm or bereavement, social harm as well being – being one of them. And a lot of discussion about the sort of medical model of the Terms of Reference in the investigations versus the – the social model, and sort of framing all that was the issue of human rights and the rights based approach that the Inquiry will – will look at and use and whether or not that should be explicit in the Terms of Reference itself. And there were some good discussions about that, which obviously Baroness Hallett will consider fully.

And then just moving on to the other question, I mean, there was lots of other stuff about the Terms of Reference themselves and the scope of it. And there's some really good points about – not quite prioritisation, whether it was priorities or not is another matter, but what we should look at, what the Inquiry should look at first and the trade-off between depth and breadth and speed and making an impact first, when the interim report was generally seemed to be welcomed.

And then finally on the fourth question about how people can tell their stories and how people can participate in what can be an intimidating process and a very legal process. And there were some good ideas that I hope will be followed up with responses to the consultation about storytelling, about the way in which we can think innovatively about how people can participate and submit their views to Baroness Hallett over and above the legal process and legal framework. I think I'll stop there. So they've got lots and lots of good points. I'm sure I've missed some really good points as well in the feedback, but I'll leave it there.

Ben: [01:34:22] Brilliant. Sam, thank you very much. And huge thanks to the people who participated in that group. I sat in for bits of it, and it was clearly a very full and lively discussion. Can I come to Sabah now who was within the room that was covering the issues around ethnic minority, asylum and immigration. Sabah?

Sabah: [01:34:44] Thank you, Ben. So yes, our group had a bit of a rocky start. And again, apologies for that. But once we got started, just as Sam has said, very valuable information came through, wonderful insights. There's a transcript and of course, myself and my colleagues were also taking notes.

I am going to do my best to kind of give some key terms that we'll use to make sure that we've covered all four questions. But please bear in mind, there was so much, and I won't be able to say it all in just a few moments.

So human focus, that was something that was said; that this Inquiry needs to have a human focus, it needs to build trust, really important, through its practices, that it shows that it has listened, that it's got serious intent. And that it offers feedback. So once it's gone to communities, it's engaged with various sectors, that those groups hear back from the Inquiry about what they've heard and what they're going to do.

We heard comments about interim reports, because this was in relation to an end date. Covid, we spoke about in our group, is a live ongoing current situation. And so an end date is important, it's vital. But what we were hearing in the group was that everything must be covered but people need to hear as and when the Inquiry learns of something so that people can be protected if further strains are identified.

We heard a lot about cross-cutting services, cultures, groups, and various diverse sectors, having that intersectionality and making sure that the approach is cross-cutting. Racism, human rights, key issues that must be at the heart of the Inquiry and looked at. We heard about a chronology as well, and how, through the lifetime of the Inquiry, because this is an ongoing situation, people's experiences will change.

There's so much more for me to say, but I'm really mindful of the time so I'm going to pass it back to Ben. Thank you.

Ben: [01:37:02] Fantastic. Thank you, Sabah. And thanks, everybody that participated in that group too, finally I'm going to ask Samantha, who was in the gender and LGBTQI plus group.

Samantha Edwards: [01:37:14] Thanks very much, Ben. And, equally, we had a few teething problems. So my massive thanks to Katie and Jemima, for bearing with us, and pivoting smoothly onto a Google Meet platform. So we had a brilliant conversation. And I think one of those virtues of being a really small group is that actually it was very free flowing and hugely productive.

I've got four things that I think really kind of stand in my mind. So the first is in terms of decision making, how much were whether it was women, or whether it was people from other diverse backgrounds, but how much of the impact on them was in our decision making? And when I say 'our', the UK decision making – did we bear in mind the impacts and the things that people would have to pick up as a result of decisions that were taken, but also, who was making the decisions at the top? And were they a representative group? And what can we learn from that?

Equality runs throughout the Inquiry; it is not something that we look at once, it's not something that we look at as one topic, it has to be a lens through which we look at every single area of the Inquiry. So really, keep in mind, we built that in.

We talked a little bit about the impenetrability of the legal process. And actually, the intimidation of it, whether or not there are things that we could do. And we talked a lot about making sure that it is safe, accessible, but also something that that hadn't occurred to me was, is there a way of making sure that parts of that legal process are truly representative so that, for example, if you're in a public hearing, that the people who are in that public hearing are actually representative of the person that you are, who's giving evidence, and whether or not you can create those sorts of environments, which I've never thought about it that way, personally.

And the other thing I'm sure came out a lot was transparency of process, appreciating that this is a how long was a piece of string sort of thing in terms of timing, but making sure that you've got real clarity of what's happening, when it's happening and why is it happening? What have we learned from there?

Ben: [01:39:24] Samantha, thank you very much. And thank you to the colleagues that were in that group as well. So my thanks to everyone who's participated today. I'm really, really sorry that at the start of this session, we had some technical issues that meant that some of our conversation was curtailed. This is one of the downsides of being the first of our consultation exercises. This is among the most cross-cutting and therefore important of the issues and we wanted it to be first. But I'm sorry that you had to work through some of those teething troubles – problems.

Because we've lost some time, we're going to make sure that the chat on the Zoom call is kept. And we will maintain a record of that. We'll also see whether we can keep the call open for the next 20 minutes or half an hour to ensure that people who perhaps didn't get the chance because of lost time, can add any comments to the chat before we download that and keep that for our – for consideration by the Chair when – when the time comes.

There are far too many points that came out there for me to try and summarise. And so I won't insult your intelligence by doing so, but what I heard, as I walked around the rooms was a real impatience for this Inquiry to begin its business and to get on with making some findings and recommendations. The very final line of the Terms of Reference, if that is included in the final version, does require the Chair to make timely recommendations, and indeed envisages an interim report or reports. Of course, that will be for the Chair to consider. But I can assure you that we welcome that impatience. And we take seriously our mission to deliver an inquiry in a timely fashion.

I heard a lot about the need for us to listen throughout the Inquiry’s process in all sorts of ways and reaching all sorts of communities using different languages to make sure that we can talk to those people that want and need to give us their views. And I heard a lot about the importance of being absolutely clear that we are independent of Government. And that's something that we will make as clear as we can at every point that we are out and about and that we're doing our work. Thank you very, very much for emphasising that and for – for helping us to, to set the tone for this consultation and also for the Inquiry.

Just a reminder that Martin Hogg, our counsellor, is available today and afterwards, if you wish to speak to him about anything that has come up today. And he, of course, provides confidential support. If you're able to, please do this in the chat if you're online. And please let us know if you're happy for us to contact you in the future for any further engagement or sessions like this that we might run. We will try to make sure that those technical issues are ironed out before the next ones take place.

But you know, I'll finish by saying how incredibly grateful I am to all of you for sparing the time this morning. And I hope that you will see in due course, the issues that were raised and the views raised, reflected in the recommendations that go back to the Prime Minister. So thank you very much indeed. Whether you were joining us virtually or in the room. I'm very, very grateful.

Speaker: [01:43:03] Ben, sorry. Just Jabeer has a quick question for you.

Jabeer Butt, Race Equality Foundation: Ben, could I just say, are there other consultation events taking place? And would you be able to share those details with us?

Ben: [01:43:15] Jabeer, yes. There are other consultation events taking place over the next four weeks. As I said at the start, we're doing different sectors on different days. But yes, I think we must have a timetable that we can share. Thanks very much indeed. Bye bye.

[END OF TRANSCRIPT]