

## **UK Covid-19 Inquiry**

### **Every Story Matters webinar transcript**

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Online

### **Participants**

#### **UK Covid-19 Inquiry**

7 participants from UK Covid-19 Inquiry secretariat

#### **Organisations**

Department of Health and Social Care

Disability Rights UK

Long Covid Kids

Long Covids Kids and Friends

Long Covid SOS

Long Covid Support

Older People's Commissioner for Wales

The Commissioner for Older People for Northern Ireland

Welsh Government

**Member of the Inquiry team:** Hello and welcome everybody, thanks for taking the time to join today. We're going to be talking through our listening exercise, Every Story Matters and will also be taking your questions. Just to make you aware, we won't be discussing the legal process in today's session. So if you have questions because you are Core Participants and you want to ask questions about the legal process of the modules, it's very unlikely that we'll be able to answer those because they actually need to be dealt with via your legal teams. But obviously, if there are things that are confusing to people, then we can take a note and we can make sure they get set back to the legal team. If you're not familiar with the term, essentially Core Participants are people who have a particular status within investigations, and people can apply to be Core Participants. That's for each of the different modules of the Inquiry. And then, if they are granted Core Participant status, they gain access to information about the Inquiry, and the evidence that is being gathered.

I will now introduce my colleague who is going to talk to you about the listening exercise.

**Member of the Inquiry team:** I've been working on the listening exercise, or Every Story Matters as we call it over the last seven months. We've heard from your organisations and your members that people want more clarity on what Every Story Matters involves. So we're going to talk through that today and take questions at the end. One thing to also say is that

we are getting into the detail behind how this listening exercise will be conducted and delivered. It might sound a little bit technical and removed or a little bit cold in some ways to deliver a project and I'm sorry that doesn't necessarily reflect the pain that people have gone through.

Throughout designing Every Story Matters, we've taken a trauma-informed approach and that's something that has been a consistent theme throughout. Obviously we're engaging with people throughout this project and I'm building feedback into all of our such points. I will start off by setting out the purpose of the Every Story Matters listening exercise. It's there to listen to people across the UK, and about their experiences of the pandemic, so that these can be shared with the Inquiry. We're aiming to offer that opportunity in a variety of different ways.

It allows people to share their experience without the formality of giving evidence or attending public hearings and therefore is separate from but very much linked to the process and it's built into the terms of reference for the Inquiry, which set out what the Inquiry is here to do. The terms of reference say that we are going to hear from and listen to people across the UK who have been affected, in particular those who have suffered hardship and loss. The purpose for doing this is that we can use that to inform the Inquiry, understand the impact of the pandemic and inform the lessons to be learned which is what the inquiries is here to do. It's to help learn lessons and ensure that the country is better prepared for the future.

So if we consider the legal process that happens under an Inquiry and this is there to determine what happened and why, Every Story Matters will gather information from the UK public about the impact of what happened on them and turn that into a series of reports. The intention is that this is submitted into the legal process as evidence and therefore, forms a part of the formal Inquiry.

The slide that you can currently see on the screen is showing the combination of the listening exercise's report and the legal process coming together to give us a fuller understanding of the pandemic's impact on the UK. This will mean that the Inquiry's outputs should be stronger and based on a wider evidence base. In an Inquiry, we are working towards a set of reports that have recommendations to prevent the same problems happening in the future and the better evidence those recommendations are based on, the more likely it is that they are taken on board and acted next time. Every Story Matters is very much about creating a source of evidence which reflects the experiences of the UK population and is imported into the legal process as a way of helping us to better evidence what the Inquiry recommends.

If we think about why it's important to have this evidence of what happened to the UK population, recommendations after an Inquiry are handed to central or devolved government and wider parts of the public sector in order to act upon those and to accept them or not and to implement them or not. So making sure that those recommendations are really, really well evidenced is really important for increasing their uptake basically and having that record of what happened previously, so we can prevent similar harm from occurring in the future.

Where this has happened previously is an example is in the Grenfell Tower Inquiry, in which recommendations that they made led quite quickly to some new fire safety regulations in 2020.

How does somebody share their experience? And how is it turned into legal evidence? First of all, we've been thinking about how to hear from people and how to listen to their experiences and we've identified that we've got a huge number of people that might share their experience. Everybody in this country went through the pandemic and it's likely that many people will want to share their experience with us. We've been thinking through about everybody's different needs and preferences and ways to share and have designed specific routes for them to come and talk to the Inquiry.

Our evidence pointed quite early on to the main way that people want to share being online in people's own time and in their own way. We moved relatively quickly to getting an online route, which was launched last November in a pilot and is on our website. You'll find it by clicking 'Share your experience' from the home page. A new version will be coming out later this year. We've had a fair amount of experiences shared through that but we're aware that actually the Web form is not appropriate for everybody and there are many different needs amongst the population.

Where people cannot use a web form, we have got a paper version, which will be available and we're working towards setting up a phone line for people to either share their experience or to get help in using the web form or the paper version. We're also working towards making information about how to engage with the listening exercise, Every Story Matters available in British Sign Language (BSL), video format, easy read, Braille and other languages.

We are looking at how to make sharing these experiences as accessible as possible. So in addition to being able to take those over the phone, we are able to take them in written format, online in other languages and we're exploring how we might receive those in BSL as well. Unfortunately we're not able to take them currently in video format and easy read or Braille.

We've been talking to a number of organisations to cater for people's different needs across the UK. We're piloting community listening events in cities and towns across the UK later on this year to enable people to share their story in person in their community. That was based on feedback that we had from talking to different people and organisations, who identified the need for some people to share in person as being particularly important. So we're mixing up large, open public sessions that are available for anyone to attend, as well as more specific ones that cater to the needs of different groups. These events will be attended by Inquiry staff as well.

The outcome of this will be to produce reports to feed into the Inquiry's modules. If you're not aware, the Inquiry itself has been broken down into a number of modules. We're very mindful of the need for the listening exercise to input into each of those modules in a meaningful way. The reports that summarise people's experiences and offer some analysis need to be as robust and defensible as possible. For that reason, we've been working with a research company called Ipsos, who have identified the need to conduct some additional interviews with particular people in the population that have had specific experiences. That's what we're calling targeted, qualitative research. This will be brought together with what

people share online through the community listing events, through the telephone, through paper submissions and other formats and analysed in order to identify themes and learning that can be written up in these reports that go into each module.

This targeted qualitative research is with relatively low numbers of people. It's about the research company going and finding specific people to talk to. These are people that are going to be selected on the basis of their experience, usually during the pandemic and in response to specific lines of enquiry that have been identified by the Inquiry legal teams. The Inquiry legal team might want to understand the experiences of a particular segment of the population or a particular set of experiences. That's something that the research company will be going away and finding out more information about.

There is a segment of the population that we still haven't got a policy on - our approach to children and young people. It's taking us a little bit longer to work through this because I'm sure you'll appreciate there are a number of issues around engaging with children and young people and some quite high bars to reach in terms of safeguarding and protections. We are working with experts in children and young people's engagement and participation and hopefully will be able to update people shortly on progress with that.

I've talked a little bit about these reports that will be produced. After somebody has shared an experience with the Inquiry we will be analysing and understanding the different themes that might be emerging. We'll be using a mixed method of analysis. Some of that will involve software and artificial intelligence, while some of it will include human review and the scale of responses that we expect means that we do need to mix up these methods. We had 20,000 responses to our terms of reference consultation and therefore mixed up human and artificial intelligence analysis there. If you want to get an idea of what that mixed method approach might look like, you can see our documentation around the terms of reference consultation on our website, which will give you an idea about the reports and how that might end up looking.

I will now move on to talking about the timelines. I talked a little bit about the first part of Every Story Matters that was launched in November, which was the pilot form on our website and I want to reiterate that it's a pilot and we are testing it. Thank you very much to those of you who have fed back on it and submitted your experience through it. To reassure you that even though it's a pilot, if you had shared your experience through that web form, it is being considered as part of Every Story Matters and fundamentally, we're asking for feedback on it as well. We've taken account of that feedback and have done a lot more testing and refinement and further research. A new version of the web form will be coming out later this year.

Some features are going to be added to it based on feedback, including the ability to save and return to your experience. That doesn't exist at the moment. If you want to pause halfway through and take a bit of time to reflect and come back, you'll be able to do that. We will also be adding the ability to more easily withdraw your experience from the process if further down the line you don't want it to remain part of Every Story Matters. We're going to be signposting emotional support a little better and trying to incorporate some feedback we've had about the tone of the form and trying to make it feel more inclusive.

We're looking to launch Every Story Matters formally in the summer and we're really keen to work with you. We would welcome your support in reaching as many people as possible who would like to contribute their experiences to Every Story Matters. We're acutely aware of the need to reach wide segments of the population and have a really diverse set of people contributing, so your support is going to be key to that.

I'm now going to hand over to my colleague, who is going to talk about the Every Story Matters campaign.

**Member of the Inquiry team:** I'm going to talk about the Episode Matters campaign and the aim of the campaign is to help make sure people across the UK know about Every Story Matters, that they understand the value of sharing their experience, that they understand how the information they share will be used and they have both the reassurance and the practical information they need to take part. We're working with a creative agency, M&C Saatchi to design the campaign. To be clear, M&C Saatchi will not be directly collecting experiences, nor will they have any access to experiences that are shared with the Inquiry. Their role has been to help us with the look of Every Story Matters and help us to understand the barriers facing different audiences, as well as to create the messages to help people feel motivated to take part. As part of the development process so far, we've sought input from those most affected by the pandemic and we've had focus groups to understand directly from people, with lived experience, the barriers they face in sharing their experience.

We've held a number of roundtables and insight sessions as well to shape the name and logo. We've also tested messages with different communities and individuals. We held sessions with disabled people and the bereaved frontline workers, just to name a couple. You can see the logo that's coming up on screen shortly. It's a series of words around the outside. That is a design feature, and it represents a number of names and family labels that organisations and individuals have submitted to us. The finished result is a collection of those names and family teams in different languages to really show the diversity of the UK and also to demonstrate that everyone's story does matter. In the summer, we'll be launching a national advertising campaign to promote the opportunity and that will be at the same time as the redeveloped form that my colleague talked about earlier as well as the advertising campaign.

We're working with a range of organisations to make sure we reach different communities across the UK and really help us speak to those affected by the pandemic. We're conscious that the relationships that many of you have with these groups will be really valuable and powerful in helping us to make sure that we reach these people. We're very keen to hear from anyone that's willing to help us share Every Story Matters messaging and we would like to request representatives of these organisations to get in touch with us. If you'd like to help us engage with your members, we're going to be producing a partners' toolkit that will include assets like written copy or some social media graphics. We're keen to work with you and see how you can help us reach people within your communities and your networks. And I think that's it in terms of an overview of the campaign, but very welcome, any questions?

**Member of the Inquiry team:** It's now time for the question and answer section that I referred to in the chat. I'm going to go first to those who've submitted questions in the chat. If you have a question, please pop it in the chat and I will then come to you and invite you to

come off mute and you can speak about your questions, give a little bit of context and then I'll invite one of our panel members to answer.

So the first question that we had was from the Welsh Government, 'Will the community listening events mentioned happen across the whole of the UK?' Did you want to add any further comments?

**Welsh government:** I'm from Wales and have a particular interest in the engagement within Wales. So that's where this question came from.

**Member of the Inquiry team:** The short answer is yes, they will be across the UK and as my colleague said the community listening events are being planned in response to people's direct feedback that they want to be able to share their experiences in their local community. We are at a very early stage and we will be procuring a community engagement specialist to help us design the event. The intention is that they will be across all four nations and that we will hopefully be able to target the local authority areas. We are planning on doing a pilot and hoping in September to start that and we will come back to you with more detail. The idea is that we will have some larger events for the general public and then some smaller more targeted events for specific groups who have been especially impacted by the pandemic. While we're on the topic of community listening events, I've seen a question come through from Disability Rights UK about the locations of the community listening events. Our answer at this stage is very similar in that we're in the initial planning stages. We don't yet know where the locations are, but we can be across the UK.

I'm going to go on to the second question that we've received now, which is from the Long Covid SOS team on how we will ensure proportionality. It would be really useful to hear a bit of context behind this.

**Long Covid SOS Team:** There's a lot of competing interests here around the Inquiry. A lot of groups who may feel that their needs are more important. You've got a hugely diverse range of views and experiences and I suppose where we're coming from, of course, is that we are in many respects representing a couple of million people who've been impacted health-wise and who have not really been listened to until now.

There are so many competing voices. We would be very disappointed if we were drowned out. What my question is, is, how are you going to establish some kind of priority, some kind of proportionality? Because if this is going to be used as evidence in the Inquiry, it's really important that you get it right. I don't expect that you're going to be able to give me a formula that you're going to use right now. I'm just interested to know how you're going to make sure this doesn't go wrong.

**Member of the Inquiry team:** Completely, thank you very much for that question about these really well expressed points about some of the challenges that we face in our work, running such a large and wide reaching public inquiry. Thanks for asking the question. As you recognise it is a big challenge and something we're really mindful of is there are lots of very different experiences and views that we need to be understanding and working through and working out how to talk about in the reports that are produced. I think the fact that the Inquiry itself has been broken down into a number of modules will help us to focus. Specific groups and their experiences will align to specific modules. Some groups walk across lots of different modules and will be in multiple reports from the listening exercise. It's hard to say at

this point because we've only gathered a limited amount of experiences through the existing web form. Once we launch later in the year and we start to get more and more experiences through, I think we'll get a better sense of the range of those experiences that are coming in.

We're hoping that they're as broad as possible as we want to understand what the experience of the UK population has been like. It will come down in part to the analysis that is done and we are finding specialist companies to help us with the analysis and the report writing. It will come down to their ability to process the information, understand the experiences and write these up into meaningful reports and conclusions that are going to be useful as evidence. I'm confident that, even though this is a huge amount of information that we are going to be gathering, there are companies that have dealt with this kind of thing before, and should be able to produce those methods of logically robust reports. At this stage, I haven't got a magic formula to give you and I'm sorry about that. It's something that you're right to point out, we need to navigate that complexity and present the experiences in a way which is both useful to the Inquiry, but also recognises the huge impact that different groups have felt through them.

**Disability Rights UK:** I just wanted to ask a question, linked to the former question, which is when you fill in a web form, do you ask for any demographic data like whether someone's got long covid?

**Member of the Inquiry team:** Thank you for mentioning this, absolutely that is built into both our pilot web form which is currently available on the website and we are evolving that for the future web form as well, so that we can understand who is responding and how many of those specific responses represent the UK population. I'm going to hand over to my colleague now, who is also thinking really hard about that data that we're gathering through that process and how it's used in the communications work.

**Member of the Inquiry team:** The aim with the campaign in the summer is to reach as many people as we can across the UK. So regardless of whether they are a Core Participant or whether they're a member of an organised group, we want to reach as many people as possible on individual levels. The advertising will be online, probably some radio as well just so we can kind of use different media touch points but also working with them, with partners who are willing to help us, to share some of our campaign materials and our messages with our members as well. So that we can use that direct access as well. In terms of the demographic information this is absolutely key. We're going to be tracking that on a weekly basis within the campaign team so that we can look at the diversity that we're getting through. If we are spotting gaps, we can change our approach accordingly and I think demographic information is optional on the form. So again if there's anything you can do to help us encourage people to share that insight with us so that we can keep an eye on it, as well as demographic diversity, we're going to be monitoring the themes that are coming through in terms of the experiences shared because you know, we didn't want to overburden people with capturing too many demographic details. If there are particular themes that are feeling like they're underrepresented, again we aim to be as agile as we can in terms of looking at the data, spotting gaps and finding routes to those individuals. The campaign is aiming to be national so it's very focused on reaching individuals rather than single groups.

**Member of the Inquiry team:** I'm going to now go to a question from Long Covid Kids, 'Given that Baroness Hallett has recognised the importance of collecting the experiences of

children before their memory fades, can you confirm when you'll be able to confirm a timeline for announcing, how they'll be collected?' Long Covid Kids, do you want to speak about this question?

**Long Covid Kids:** I'm just really conscious that for children, still living with long covid at that time. I know that Baroness Hallett has already stated very clearly that she's aware of this but I was just picking up on the point. I think some months ago we discussed this and I just wanted to know if you're able to provide any further information. Thank you.

**Member of the Inquiry team:** Thanks for asking it because you're absolutely right about the time that's elapsed since the pandemic and this very specific experience of children and young people, we are very much aware of both of those things. And Baroness Hallett you have rightly pointed out, mentioned this a few weeks ago in a preliminary hearing that we need to get on and look at this. I'm afraid I haven't got any information at this stage to share about when we can confirm a timeline for it. I hope that we can come back to you relatively soon and provide some information on that because we all do recognise how important this is. I apologise at this point that I can't give anything more specific.

**Member of the Inquiry team:** I'm going to come onto a question from the Older People's Commissioner for Wales now. The question is, 'Is there a specific engagement plan for engaging with older people living in care homes?'

**Older People's Commissioner for Wales:** We have experience of being able to engage effectively with older people in Wales. In June 2020, we produced a report of the lived experiences of older people living in care homes which gave a snapshot of life in care homes in Wales. We know the specific needs of individuals living in care homes and how an engagement plan needs to be very different, to be able to capture those voices, so I was wondering if you've got a thought process in relation to that.

**Member of the Inquiry team:** I can speak in response to part of that question, then I'll pass it on to my colleagues. I think part of the engagement plan for engaging with old people living in care homes is to work through organisations that are already working with them. So, if that is your organisation, then it would be great to get half an hour or so for a call with you to speak about that, knowing that you're the experts in this field. When we're talking about older people living in care homes, one thing that we definitely recognise is that this isn't one homogeneous group. Therefore we're going to be looking to engage with lots of different organisations that represent different people with different needs in and within that group. For example, we're working with Alzheimer's charities, at the moment, and recognising that people need specific training to be able to engage with these groups and support them to express themselves and tell their stories. I don't know if other panel members want to speak on this about the community listening events and speaking to older people.

**Member of the Inquiry team:** We recognise that people living in care homes were amongst the most impacted by the pandemic, and they are definitely a group that we will be looking to engage with at community listening events. Again, we'll be working with community engagement experts and you've got networks and partners who can then deliver these events, most likely in care homes. I would imagine that we would need to go to them but we're at an early stage and will be coming back out and updating you on what these events will look like.



**Disability Rights UK:** Could I ask if groups like the older people or people with Long Covid will be able to submit audio recordings of their experiences? And can we start to prepare our audiences for sharing their experiences? Also, can we submit organisational findings to the listening exercise?

**Member of the Inquiry team:** The way that we are receiving people's experiences unfortunately does not involve audio or video formats, pre-recorded audio and the reasons for that are largely technological actually. But also there are some legal issues around it and transcribing those, so unfortunately that isn't a format that we're able to accept. However, you've raised a really good point about preparing people to start sharing their experiences and yes, I think getting people to start thinking about that is a really good idea. Now people can already submit an experience through the web form, which is the pilot form. So it's not like the most perfect version but it will be considered as part of the work. If you wait for the later version, we're looking at summertime for that to become available and the alternative ways of contributing including telephone and potentially BSL. Video relay is likely to be coming later in the summer as well. So if people need to wait for those alternative formats, starting to prepare them to share is a really good thing to be doing.

If you have pre-existing research or stories that your organisation has collected, we aren't including those as part of the listening exercise. Some organisations have asked us, 'if we've already spoken to our members and collected their experiences or their stories, or their views, can we submit them to the listening exercise?' However, if you've got something to share from an organisational collection perspective, you are very welcome to send it through to [contact@covid19.public-inquiry.uk](mailto:contact@covid19.public-inquiry.uk) and that gets looked at by our research team and potentially goes through directly to the legal teams. That doesn't come through to Every Story Matters which is very much focused on hearing directly from individuals on their individual experience.

**Member of the Inquiry team:** The next question is about the Welsh language. So the question is, 'How will individuals be able to engage in their language of choice? For example, in the Welsh language in Wales.' Did you want to add anything here?

**Older People Wales:** Quite a straightforward question I think in relation to individuals being able to engage in their language of choice but specifically in Wales obviously as Welsh is an official language.

**Member of the Inquiry team:** We are making Every Story Matters, the web form, available in Welsh as indeed our website largely is as people are also able to access that in Welsh. People are able to respond in any language via the web form and that will get translated and included as part of the analysis. For people taking part in other ways of contributing, we've got the telephone line which we're working towards later in the summer. That will be able to take people's experiences in different languages as well, including Welsh and anything that is sent through on paper, we'll have the same treatment, with Welsh also available there. I'm making a big assumption here, but looking at the community listening events, I think if we are holding those in Wales, it's fair to say that we would provide Welsh language support and translation there as well.

**Older People Wales:** Just a follow up actually, in relation to the toolkits that you were talking about when you are providing toolkits to organisations, will they be provided in

different languages or will it be expected for the organisation to be able to translate in whatever language they want to be able to and disseminate the information?

**Member of the Inquiry team:** We'll have bilingual campaign materials and we are working with partners who have a specific need for their communities. If they can translate in house, then fine and if not, then we are looking to provide them with access to in-house resources so they can communicate with their members in the way that works and just to clarify that goes beyond translation. If there's a way to better communicate with your network or the people that you represent we can speak about how we can support that.

The next question is from Long Covid Support, 'If people wish to give evidence in person how can they apply to do so?' So we really hope you can give some context to that question.

**Long Covid Support:** I'm a senior hospital doctor. I retired from NHS Wales in 2019. I'm quite experienced in doing this sort of thing, giving evidence, I advise the World Health Organisation on cancer as it runs in families. That's my usual subject. And I feel that I've got a duty to advocate. For all those who cannot, who can't say what I might be able to and I'd be quite happy to turn up in person and talk to people face to face about what happened and the specific questions that I would like answers to, which, because of the way they were dealt with at the time actually caused me severe pain as a doctor that I offered my help to my government and they never ever got back to me. I almost died from one of the complications of Long Covid and it was only by a fluke because I gave evidence online to the Senedd Health and Social Care Committee that I got to see a consultant who frankly saved my life. So we're not talking trivial stuff here. I'd like to confront the people and give evidence. I also provide the occasional report, but medico-legal expertise. So that's why I was asking that I'm happy to give evidence in person, I've written up my experiences.

For my organisation of which I'm the president, I'm currently one of the 38 presidents of pathology in the world. I speak with some about the mechanism of diseases and I've written up my experiences in a 30 page article before I forgot it or wasn't able to tell it and so I can submit that. I've got online talks that I'd give in other countries that are recorded, so I've got a fair bit of material, but I'd like to help people further. That's why I was asking, or do you select who comes up and gives evidence?

**Member of the Inquiry team:** Thanks and I'm going to pass that question to my colleague as a legal question.

**Member of the Inquiry team:** Thank you for sharing that experience, it very much sounds like you're talking here about how people can participate in the in the legal investigation so in actual evidentiary hearings rather than in Every Story Matters, but just to be clear, anyone can share information with the Inquiry at any time and so you can just submit that as an individual to the contact mailbox.

There isn't a process as such to apply to give evidence, but of course we do, welcome any information that anyone wishes to share including of the type that you've just spoken about, your articles, etc.

**Long Covid Support:** Is there any mechanism for ordinary individuals affected by the ongoing pandemic to make a point?

**Member of the Inquiry team:** Any individual who has been affected by the pandemic can share information with the Inquiry via our contact mailbox.

**Long Covid Support:** Okay, okay. Thanks.

**Member of the Inquiry team:** We've done a range of insights, including in roundtables. We've also done polling more broadly and in focus groups. I'd have to check the full list of the focus groups to see who attended. We also put an open offer to help shape the logo through our Inquiry newsletter as well. So we are definitely keen to bring anyone on board with the journey with us. For any further kind offers of help, do get in touch with us.

**Member of the Inquiry team:** The next question that I've got in the chat is from Long Covid Kids, 'will the reports be punctuated throughout by the experiences of children and young people?' Did you want to speak about that question?

**Long Covid Kids:** Thank you, yes. Just to really make sure that children and young people are reflected throughout all of the stages of all of the reports because often they are put into a specific section and then their experiences are missing from some of the wider experiences, which obviously, they're affected from directly and indirectly. If their parents are affected or their school environment is infected or anything else. So I was just asking really that they're not just referred to as people with Long Covid.

**Member of the Inquiry team:** Thanks very much for raising this. I'm sort of apologising again for not being able to say much more on how we're approaching children, just because we're not quite at that point yet of having a decision on how best to understand their experiences of the pandemic. But I've definitely noted what you said and you're right. It is really important that we recognise that their experiences are wide ranging and they're not to be grouped in with adults and that their experience is very specific. That's something that I'll definitely be feeling into the team that's considering this and we hope to get back to you on this.

**Member of the Inquiry team:** The next question is from Long Covid Support and this is about Patient-led initiatives. They have gathered contemporaneous stories. We spoke about this a little bit earlier, about the ways that people could submit research. That's already been done earlier and the question asks, 'Could we have a follow-up discussion after the call about how they might be able to be included?' Did you want to speak about this question?

**Long Covid Support:** I think what I've said is probably sufficient, I think it's about recognising that individual stories give individual accounts of what's happened to individuals, but the long covid studies have been done in the past in such a way that people have really been moved and related to the studies that were shared. Shouldn't be capturing some of these points but most importantly, for me, the fact they were done a year ago and two years ago. We can't replicate this by asking people to try and remember back to 2020. I'm really open to having a conversation with the right person in the team as to how it would work because I'm noticing what you're saying about it not being video based and we have good contributions that have been collected in various ways. I think it would be a good addition to the public archive if nothing else for some of those to be included, thank you.

**Member of the Inquiry team:** Thank you. I'm happy to respond to that and you're absolutely right that people sharing experiences closest to the time of them happening, is lending

something very different to the sort of the insights that are gathered and the conclusions to be drawn. Similarly, you know, something that's reflected on later brings a completely different perspective as well. I think it's important for us to recognise that throughout the research that's done across being Inquiry and through the listening exercise as well. I really noted the points about limited energy levels and abilities to take part. That is a really good point. I guess that I would, I would say, you know, no one, no one has to take part in the listening exercise. It's obviously everyone's choice. We are, however, asking that organisations that have done their own research and where conclusions or analysis has been done, that could be insightful and whether this has happened, that this comes through a different route than through the listening exercise. We need to have that sort of consistent way of gathering information and then analysing it. So we're asking organisations that have done that themselves, that they send that directly to the Inquiry. It will be considered, whether that is passed on to the lawyers as a separate piece of research or evidence rather than coming through the listening exercise, to then get mixed up with our data and then end up in a report. I hope that wasn't too confusing. If you've got that kind of research or gathering of experiences or analysis that you've already done, please do send it through to our contact mailbox and that'll be looked at and reviewed but the listening exercise is much more about people and contributing their experiences.

**Long Covid Support:** Thank you.

**Member of the Inquiry team:** We've got a question from Claire which is about conflating lockdown with the pandemic. We've had a couple of comments about the lack of audio and video format being a key barrier to many people's cognitive or energy issues.

**Long Covid SOS:** Quite, it would exclude them quite a lot if they had to just put things in writing and quite often, they're happier to be in front of the phone just quickly recording something on camera. That surely in this day and age has got to be a way that you can accept people's evidence by other technological means.

**Member of the Inquiry team:** Thank you. And I've just realised that the Welsh government has asked quite a similar question which is, 'Why is a phone line acceptable? But not other means of submitting audio or video?' and so I think if we deal with those questions as one if that's okay.

**Member of the Inquiry team:** I'm definitely hearing what you're saying about the very specific needs and sort of groups that audio and video would cater to and making that available and also talk you through some of the sort of points around why we have designed the next version of our web form in a way that doesn't receive audio and video and the technology that's required at the back end. I'm not a web specialist but I have been working with colleagues who are and the technology that is required at the back end of the website to receive such large files imposed some quite difficult burdens on the Inquiry and the website, it had to be a lot bigger and and designed in a very specific way that this was felt to be prohibitive to delivery essentially. So it was a technological constraint and that meant that we were essentially ruled out audio and video alongside a couple of other points. If I cast my mind back, there's something around data protection and third parties being caught in audio and video which we had to be really, really careful about. We're very much aware of needing to conform to GDPR and the Data Protection Act.

Then just to talk through the way that the audio-video technology would work, we did explore this. It is essentially that it would be transcribed and then analysed alongside the responses that that we receive from everybody else. So already, I'm thinking, there's people that would find audio and video easier, but that we are making the phone line that we've talked about available. It is a huge endeavour to set up a phone line as well as audio-video. It is simpler to offer the phone line as a stand-in for the audio option. There's also the listening events. Although I also take the point that, you know, the events might be held on very specific times and days, we might not see everybody, particularly if you've got limited energy levels, and I'm just wondering, though, that sort of point about and how audio and video would be used by the Inquiry's analysis in producing these listening exercise reports. Whether there's something around, you know, people self transcribing, it's something we could explore. And I wonder if we could have a follow up discussion on that point just to make sure that we are logging and capturing that need for audio and video, even if we can't directly deliver this through the existing website, the audio and video files. I'd be really keen to continue our conversation.

**Member of the Inquiry team:** Thanks very much and I think the next question that we have is about the community listening and events. Older People Wales said, 'I understand community engagement, visits, initial planning stages, but has there been thought about travel expenses being available for people to attend?'

**Older People Wales:** I understand the enormous amount of work involved in relation to making community events. I absolutely sympathise in relation to how that is going to work. I know there are a number of barriers in relation to people being able to attend in person and access transport. Some of the barriers that we hear of when we do, our engagement is purely financial in relation to being able to have the means to be able to get to the location. Even if there is transport available, it can come down to being a financial consideration as well. I'm just wondering if there has been that thought process in relation to the barriers to community engagement and specifically the financial barriers included in that.

**Member of the Inquiry team:** I think that's something we can certainly take away. We are committed to making them as inclusive and accessible as possible. At the same time, balancing that with the value to the taxpayer because we are publicly funded. The idea is that we go to people where they are and that we make them as local as possible to minimise travel costs. I think with some of the smaller and more targeted events, if there were specific communities where costs were a barrier, that is something that we could consider.

**Member of the Inquiry team:** The next question is from Long Covid Kids and Friends about using specialist youth advocates to assist children and young people in giving their stories. Did you want to speak about that point?

**Long Covid Kids and Friends:** Yeah, thank you. Just obviously working with children and young people is different to working with adults, and to ensure their voices are heard accurately, and they get full opportunity to give their stories. Will there be people that are used to working with children helping them?

**Member of the Inquiry team:** I really understand the desire for more information on what we're doing with children and young people. I can't give any more details on how this works. But I think you've hit the nail on the head by saying that we're going to need to work with

specialists. I think we all need to somehow access that specialism when we are able to go out there and talk to children and young people. I think all options are on the table at the moment and that specialism is something we're going to need to engage.

**Long Covid Kids and Friends:** Okay, thank you.

**Member of the Inquiry team:** I see the Older People's Commissioner for Wales has put another point into the chat about the need for audio and video submission. I think we've spoken on this point and we'll definitely note down your concerns. There's not much more that we can add on that at this stage other than just to say that I've heard it and it's coming through really, really loud and clear in this meeting. I'm really keen to continue the conversation on how we can respond to that specific need and come up with something that supports people to do so.

Can I just talk very briefly about an area that we've not covered at all and I just wanted to touch on the the point that some of you will have heard me speak or others speak before about the fact that we are we are developing the Every Story Matters program from a trauma-informed approach and emotional support and psychological safety are absolutely paramount to everything that we do. That will come in different guises, depending on people's different interactions with us. But I wanted to reassure you that we take our safeguarding and support responsibilities extremely seriously.

For example, if people do feel that they need some support after interacting with Every Story Matters, for example, in a face-to-face event that we might hold, we would have, for example, a number that they could call where they could talk to somebody just about things and emotions that may have arisen for them during that experience of hearing from others and perhaps sharing their own story. If they're using our web form, we have designed it from a trauma-informed perspective, we've heavily collaborated with different users and we've tested it, countless times in fact. We've looked to make sure that it's as trauma informed as possible and making sure that there are prompts for people when the next iteration launches for checking in on people, if they've been still for quite a long time, making sure that they know that they could go to the help pages, and that there are a lot of different organisations that might be able to provide support if they so wish.

It will be a multimodal offering because depending on people's interaction, it will be pre-dependent on how much we can offer. We are very mindful of public money, but we do want to make sure that people have support that they need when they are interacting and sharing what happened or what happens to them during this pandemic. So I just wanted to touch on that while we had a sort of brief pause in questions.

**Member of the Inquiry team:** Thanks very much, really, really important to speak about. We've had one final question from Long Covid Kids and we've got four minutes to go. 'What about engaging with schools and universities to get children and young people's voices heard?' I don't know if you want to use any of the final four minutes to speak about that question.

**Long Covid Kids:** I used to be an early years teacher. I worked in primary schools and universities and I just think it's a really good way to build people's awareness and also especially with the younger children and get the engagement and work alongside the teachers.

**Member of the Inquiry team:** It's a really good suggestion and we know that there's a huge body of research out there already that has involved children and young people as well. So this is a really important area and there is some work that we need to do to precisely set out what we think we can do both for the Inquiry as a whole to be able to make sure that children's voices are heard as well as the Every Story Matters aspect as well. We have heard your messages absolutely loud and clear and we promise to come back and share more information as the Inquiry firms up its approach and thank you very much.

I will end by saying, first of all, thank you very much for participating, and I appreciate that 90 minutes is a long session. So thank you for sticking with us and I apologise if it does feel a little bit long. If you have any feedback for us about this, maybe you'd prefer shorter sessions, we'd be really happy to take that on board, but also if you have a desire to have more webinars like this, we'd equally be happy to keep talking to different organisations and individuals about how we can keep building relationships and making sure that Every Story Matters works for every part of society.

I hope that this has been useful for you. We will invite you to more events and please do come along to them. If you do have further questions, we will happily answer them as well. Please let us know if there are other topics that we've not raised today. We will give you access to the notes, the transcript and the questions. My best wishes for the rest of the day and I hope that you go into the weekend on a good note, and thank you very much for your time today.

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