

Every Story Matters - how it will work

Every Story Matters is an opportunity for everyone who wishes to to contribute to the UK Covid-19 Inquiry.

The Inquiry's Chair, Baroness Hallett, has directed that a comprehensive update should be published to set out how Every Story Matters - the Inquiry's way of listening to people's experiences across the UK - will work in practice and how it is integral to the Inquiry's investigations. Every Story Matters was formerly known as the Inquiry's 'listening exercise'.

The Inquiry team will continue to consult with organisations and individuals, test and adjust its approach to ensure that Every Story Matters works well for the Inquiry and for those sharing their experiences with the Inquiry. This page will be updated regularly over the Inquiry's lifetime as Every Story Matters develops.

The pandemic affected every single person in the UK and, in many cases, continues to have a lasting impact on lives. Every experience is unique and this is an opportunity for people to share the personal impact it had on them, their life and their loved ones. Every story shared will be valuable in shaping the Inquiry's recommendations and help us to learn lessons for the future.

Over 120 organisations and individuals have fed into the design of Every Story Matters and we would like to thank them for their invaluable contribution.

We will formally launch Every Story Matters in June. This will give everyone the opportunity to tell the Inquiry how the pandemic has affected their lives.

What is the purpose of Every Story Matters?

- Every Story Matters will provide an opportunity for everyone in England, Northern Ireland, Scotland and Wales to tell the UK Covid-19 Inquiry about their pandemic experiences. The <u>Inquiry's Terms of Reference</u> includes a requirement to listen to and carefully consider the experiences of bereaved families and others who have suffered loss as a result of the pandemic and to learn lessons from the pandemic.
- Every Story Matters will support the Inquiry's investigations by adding insight about the human impact of the pandemic on the UK population. In this way, Every Story Matters is integral to the Inquiry and ensures that it is informed by people's experiences.
- Experiences shared will feed into each investigation from Module 3 onwards. Module 3 is the Inquiry's third investigation looking into the impact of the pandemic on healthcare systems in the four nations of the UK. For example, if an experience is shared which highlights issues relating to hospitals, this will be analysed and fed into the Inquiry, for consideration, in this module. It may highlight an issue of which the Inquiry was not previously aware, which can then be investigated further.

- Every story matters, so every story shared with us will be analysed and will form the
 basis of themed reports. These will be anonymised, disclosed to the Inquiry's Core
 Participants and used in evidence. These will identify trends and themes, and identify
 particular experiences which may illustrate systemic failures.
- The Inquiry will base its findings and recommendations on the totality of the evidence before it, including what is provided by Every Story Matters, on the impact of the pandemic on the UK population. This will ensure that its recommendations are as robust and well-evidenced as possible and should mean they are more likely to be implemented.

How will the Inquiry make sure it has what it needs?

- The Inquiry's legal team develops key lines of enquiry based on the module's scope and issues to be investigated. A research plan is developed to ensure that those key lines of enquiry are properly looked into, and information from targeted research and the experiences already gathered are brought together into the reports. That is shared with CPs for them to review and consider as part of evidence disclosure.
- We must choose a diverse range of people to speak with, to ensure that we are hearing from people across the UK, representing the whole of the UK population in terms of gender, age, ethnicity, location and other characteristics.
- So far the Inquiry team has developed the key lines of enquiry into healthcare for Module 3. A research plan has been developed to gather information on areas where evidence of the human impact of the pandemic may be helpful to answer those lines of enquiry. People are then interviewed by trained research professionals to gather these experiences, which are recorded and transcribed. The research plan will evolve as the research company holds interviews and analyses the information to start to identify themes and gaps.
- When we look further at the information collected through the Every Story Matters online form, gaps in the key lines of enquiry might be identified, which will further evolve the research plan. The analysis of information gathered through the online form, community events and interviews will be brought together in Every Story Matters reports.
- As we launch future investigations (modules) we will develop key lines of enquiry and
 the corresponding research plan for each module. This approach has been
 developed with the research company, Ipsos, to ensure a robust methodology, and to
 ensure the widest range of experiences and insights are gathered as possible. A
 peer review process is being established and the Inquiry's Ethical Advisory Group is
 ensuring the research aligns with the highest standards of research ethics.

How can I share my experience with the Inquiry as part of Every Story Matters?

- More elements of Every Story Matters will launch at the same time as the public hearings in June.
- There are a number of ways for an individual to feed their experiences into the Inquiry and people across the UK can submit their experiences in a way that suits them best.
- The main way will be via our <u>Share Your Experience</u> online form. This form has been available since November 2022 and over 5,800 people have already shared their stories with us.
- A new online Every Story Matters form will go live in May. We have made a number of changes to the form after consulting with over 120 organisations. These organisations represented people working in healthcare, equalities, social care, children and education organisations, faith groups, business, trade unions and those offering bereavement support. We have also tested the new online form with more than 100 individuals including people who have been bereaved or have Long Covid and are taking on board their feedback.
- If you decide to use the form, you will be asked about your experience, including its
 effect on you and people around you and any lessons you think could be learned for
 the future. These are large text boxes, and you can write as much or as little as you
 wish.
- We are adding a 'save and come back' feature, giving you more space to write in the
 free text boxes, the ability to withdraw your experience, improved signposting to
 support organisations and other design features to make the form easier to use.
 More details on how we have responded to organisations and individuals' feedback
 can be found on our You Said We Did feedback page on our website.
- For those who cannot go online, there will be paper versions available. Later this summer we plan to open a phone line to help people who wish to share their stories but find it harder to do so online. We will offer information about how to share your experience in British Sign Language, video, Easy Read, braille and other languages. We will be able to receive submissions in other languages, including over the phone via our 'language line.' These accessible versions will be launched throughout the summer. Paper versions of the online form are available from the Inquiry directly (email contact@covid19.public-inquiry.uk or write to FREEPOST, UK Covid-19 Public Inquiry).
- We are keen to ensure that Every Story Matters is accessible to those whose voices are not always heard and some people can get help in filling out the form from friends, family and people they trust.
- We will ask for some information, about things like gender, age, ethnicity and postcode. This information will help us understand more about the impact the pandemic had on every part of the UK and on people from different backgrounds or with different characteristics. For example, the Inquiry will be able to see whether

experiences differed by gender. You do not need to complete this part of the form if you do not wish to do so.

- In response to feedback from organisations that we need to 'come and meet people where they live', we will be piloting community listening events across the UK, enabling people to share their story in person with members of the Inquiry team in their own communities. These will be a mixture of open public sessions that anyone can attend, as well as smaller, targeted events for particular groups that have suffered hardship or loss as a result of the pandemic.
- We are consulting with experts in children and young people's engagement and participation to ensure the Inquiry can understand the experience of children as well as adults. We have been advised that to ensure the proper support and safeguarding of children is in place when they share their experiences, those under 18 cannot use our online form. We will find a different way to ensure we can understand the experiences of children and young people during the pandemic and share this via the Inquiry's newsletter when we have more information.
- There are no citizenship or residency requirements to participate. We want to hear the experiences of everyone in the UK during the pandemic so that we can understand and learn lessons from what happened.
- If you are sharing an experience that happened in Scotland, the Scottish COVID-19 Inquiry is also gathering people's experiences. You can share with the UK Inquiry, the Scottish Inquiry, or both. We have listened carefully to feedback from bereaved families in Scotland and want to make sharing your experience with both Inquiries straightforward. We have agreed with the Scottish COVID-19 Inquiry that their listening exercise for people living in Scotland will launch first. They will still have plenty of time to share their experience with the UK Inquiry later in the year.
- You do not need to have had Covid-19, or an experience that is directly related to the virus, to share your perspective of the pandemic. The pandemic affected every single person in the UK in a wide variety of ways, and in many cases continues to have a lasting impact.
- Every Story Matters will remain open throughout the Inquiry, so you can share your experience when you are ready. You can share now or later, your experience counts no matter when you tell us. There will be a final report submitted into evidence to ensure all stories matter.

Who will be doing the listening?

The Inquiry's Chair, Baroness Hallett, wants to make sure that the widest possible range of people across the UK have the opportunity to share their experiences. That means finding ways for people to share their stories through methods that suit them. We expect most people to share their story online, in a written format when they want to, through the Inquiry's website. For those who cannot use the website to share their story there will be a range of alternatives - including paper and telephone. The Chair and members of the Inquiry team will also be travelling across the UK so individuals can share their experiences in person at community events.

- The Inquiry team will be working with specialist researchers to listen and capture people's experiences directly on its behalf. This will be in addition to the stories people come forward to share online or at events. The research company will conduct a small number of interviews over the next couple of years. This company will then bring together the stories from the online form and events, with the stories they gather directly through interviews, to produce the Every Story Matters Reports for each module.
- The Inquiry will ensure that the researchers and Inquiry staff involved in listening to and analysing experiences shared have appropriate training in supporting those who have experienced trauma.
- Our communications specialists, who will be helping the Inquiry to encourage
 participation in Every Story Matters, will not be doing any listening, nor will they have
 access to any of the experiences shared with the Inquiry. Listening will be done only
 by the Inquiry team and its professional research partners.

How will you help me to share a traumatic experience?

- We try to ensure that everything we do is trauma-informed, and recognise the
 particular need to take a trauma-informed approach to Every Story Matters.
 Trauma-informed practice refers to behaving and working in ways that acknowledge
 that trauma can affect individuals, groups and communities, recognising the signs,
 symptoms and widespread impact of trauma, to prevent re-traumatisation.
- The Inquiry will provide free emotional support (face-to-face and virtual) at all in-person events. People taking part in 1-2-1 interviews can also access before and after interview emotional support. Our online form signposts to a <u>list of free emotional</u> support services on our website.
- Recognising how challenging it can be to share your story, we have consulted with a
 range of experts in trauma-informed practice to develop every aspect of Every Story
 Matters. This includes experts such as Changing Minds and Hestia Life Beyond
 Crisis as well as a number of bereavement support organisations including Inquest.
 This expertise has shaped the different ways people can share their stories, the
 name 'Every Story Matters', and the communications and images people will see as
 part of the public information campaign to help encourage people to participate. We
 will signpost to emotional support from our online form and provide emotional support
 for all in-person events or interviews.
- We will ensure there is specialist training for all interviewers and staff. Phone line operators will also be trained in trauma informed practice.
- We will be clear when communicating with participants which topics will be discussed in advance, and provide emotional support via the phone, video call, in person and offline.

Who is the Inquiry working with to deliver Every Story Matters?

- Hearing from as many people as possible, up and down the country, including those
 people whose voices were not heard during the pandemic, is a huge and important
 task. To do it properly we need expertise that does not exist within the Inquiry team:
 expertise in large-scale social research, and in engagement with people and
 communities who might have been most affected by the pandemic, but who are not
 yet working with us.
- To help us to design the listening exercise we have been working with Ipsos, a world-leading research company, and with M&C Saatchi, a communications company. Both companies have led consortiums of other organisations, including 23red, WSA, Just Ideas, Criteria Fieldwork, NatCen and Changing Minds. The contracts with Ipsos and M&C Saatchi, including their contracts with subcontractors, were short-term, to design and test the listening exercise. We will shortly be seeking new partners to help us deliver the next phase of Every Story Matters. These will replace the Inquiry's current contracts.
- M&C Saatchi have advised on communications activity that can expand our reach and encourage people to share their stories. When we launch Every Story Matters, you will see the adverts that we are developing which have been extensively tested in focus groups, including with people who have been bereaved.

What happens to the information I share?

- Every story shared with us will be collated, analysed and turned into themed reports, which will be submitted into each relevant investigation. These will be anonymised, disclosed to the Inquiry's Core Participants and used in evidence. The reports will identify trends and themes and include illustrative case studies which may demonstrate systemic failures.
- In analysing people's experiences, specialist researchers and analysts will make use of a range of techniques. This will combine teams reading or hearing accounts first-hand as well as using computing software, such as artificial intelligence, to make sure we are not missing trends or key insights. These techniques will work together to produce strong analysis and conclusions, and reduce human bias. We used some of these techniques when analysing the 20,000 responses to the Terms of Reference consultation. You can find the reports from this consultation on our website (summary Terms of Reference Consultation report) and full Terms of Reference consultation report) to understand more.
- Each report produced will be disclosed to Core Participants at least three months in advance of a module's first hearing, so that they can see it before any evidence in that module is heard and are able to make submissions on it.
- We also plan to produce a final report of Every Story Matters at the end of the Inquiry.
 This means that participants can share experiences relating to a module that has
 passed, and they will still be included as evidence. This is important, as we know not
 everyone will feel able to share their experience at a specific time.

We will preserve individuals' anonymity by not collecting personal data through the
webform except for where it's needed to enable features like 'save and return'.
 Personal data used to find and speak to participants will not be stored alongside the
record of their session, and will be destroyed after a certain amount of time.

How can I be sure that the Inquiry will handle and safeguard my data appropriately?

- The Every Story Matters Reports need to be of the highest quality with a robust methodology to be used as evidence. Working with research and analysis experts is key to this. Ipsos have helped us to design the approach and tested different research methods. We have also appointed an Ethical Advisory Group to ensure that Every Story Matters maintains the highest research ethical standards. Every Story Matters Reports will be peer reviewed to assure quality.
- The Inquiry has a legal basis under data protection legislation to use personal data for the purpose of fulfilling the Inquiry's Terms of Reference. This ensures that:
 - o the collection of data is covered by the Inquiry's privacy policy
 - o the data is processed and retained in a GDPR-compliant manner
 - the Inquiry identifies an appropriate legal basis to justify the processing of data in the first place.
- When certain types of information are shared with us about people at risk, we may take action to safeguard that person's safety. We may need to tell the police and other relevant authorities if you share certain types of information. Examples are:
 - o a vulnerable adult being exploited or abused harm
 - o abuse to a child
 - o abuse carried out by someone in a position of power
 - o modern slavery or human trafficking
 - o risk of harm to life.

How will I know when to share my experience via Every Story Matters?

- A public information campaign to encourage participation in Every Story Matters will begin in June. This will include radio advertising, print advertising, printed and digital billboards, social media, selected websites, and partnerships with other organisations such as charities to help us reach particular audiences (e.g. on parenting blogs and faith news sites) that will allow us to communicate with seldom heard communities.
- We are going to provide a communications toolkit with a range of materials to help organisations and groups speak to their networks about Every Story Matters and to encourage them to take part. We would really welcome your support in encouraging others to share their experiences.

How else will you hear from the people most harmed by the pandemic?

- We have been working hard with Core Participants and organisations to make sure we recognise and acknowledge the human impact of the pandemic as part of the Inquiry's proceedings.
- One of the ways we are working with organisations to represent the human impact of the pandemic, is via a commemorative art installation in the form of a tapestry. Each panel is being designed by a different artist, working in collaboration with a particular group or community of individuals.
- A number of tapestry panels will be unveiled at the hearing centre in June in time for the first public hearings. The thread and linen making up the tapestry will be sourced from all four nations of the UK to help acknowledge the UK-wide remit of this inquiry.
- Digital access to the tapestry will be provided later in the summer, to enable those not present at the hearings to both view and read the stories behind the tapestry panels.
- Filming has now begun on human impact films to be played at the start of the public hearings. These filming sessions are taking place across the UK.
- We have two further filming days in May 10 May in London and 15 May in the Midlands. We would ask interested CPs to submit volunteer interviewees and they can do this by emailing the inquiry's engagement email address engagement@covid19.public-inquiry.uk. We will also plan more filming in June, July and August across the UK.
- A different video will be played at the start of the public hearings for each of the subsequent modules and will feature people talking about their experiences and the emotional impact the pandemic has had on them. Thank you to those individuals who have taken part.