

# **INFORMED CONSENT: COVID-19 Oral History Project**

## **STUDY PURPOSE:**

The COVID-19 Oral History Project is a rapid response oral history focused on archiving the lived experience of the covid-19 epidemic.

We have designed this project so that professional researchers and the broader public can create and upload their oral histories to the database.

The dataset will serve as

- a historical archive that compiles oral histories about the experience of living through the covid-19 pandemic.
- a tool to allow individuals and communities to express their understandings, hopes, beliefs, and values about the covid-19 pandemic.
- a resource to help researchers, policy makers, activists, artists, and communities interpret and respond to current and future pandemics.

These oral histories will create a permanent record of participants reflections and insights about the covid-19 pandemic for scholars, health care professionals, planners, and the public

The digital video and/or audio recordings, demographic information, and the verbatim transcripts will be deposited in The Covid-19 Archive (Indiana University); The Journal of the Plague Year: A Covid-19 Archive (Arizona State University and George Mason University); and the Indiana University Library system for the use of researchers and the general public.

## **ARCHIVAL DETAILS:**

(1) Option to transcribe: Project Staff may have the recordings transcribed in order to create a verbatim transcript. If you wish to add anything substantial to what you have said, you may do so in the form of an Addendum, which will be deposited in The Covid-19 Archive; The Journal of the Plague Year: A Covid-19 Archive; and the Indiana University Library system.

(2) Supplementary Documents and Photographs: Project staff may ask you for supplementary documents or photographs that we may deposit in The Covid-19 Archive; The Journal of the Plague Year: A Covid-19 Archive; and the Indiana University

Library system along with your recording(s) and transcript(s). You are under no obligation to provide supplementary documents or photographs.

(3) Deposit of oral history materials in The Covid-19 Archive; The Journal of the Plague Year: A Covid-19 Archive; and the Indiana University Library system: Project staff will deposit the recording(s), demographic data, signed Informed Consent documentation, transcript(s), and any relevant supplementary information in The Covid-19 Archive; The Journal of the Plague Year: A Covid-19 Archive; and the Indiana University Library system.

(4) Curation: Project staff will review all materials before providing them to the public. Project staff has the right to decide which materials become available to the public.

(4) Open Source/Open Access: Any or all of materials that you submit may be available for use by researchers and the general public via The Covid-19 Archive; The Journal of the Plague Year: A Covid-19 Archive; and the Indiana University Library system.

(5) License: By uploading materials to The COVID-19 Oral History Project, you will be making them available for public use by selecting one of the two licensing options below.

a) The first license is a Creative Commons

Attribution-NonCommercial-ShareAlike 4.0 International (CC BY-NC-SA 4.0) license that allows you to retain copyright of your oral history but grants permissions to The COVID-19 Oral History Project, researchers, and the public-at-large to distribute, remix, and adapt the oral history for non-commercial purposes. The terms of this license are as follows:

“This license requires that reusers give credit to the creator. It allows reusers to distribute, remix, adapt, and build upon the material in any medium or format, for noncommercial purposes only. If others modify or adapt the material, they must license the modified material under identical terms.”

b) The second license grants permissions to the research and archiving teams associated with The COVID-19 Oral History Project, the Journal of the Plague Year: A Covid-19 Archive, and Indiana University that allows them to distribute, remix, and adapt the oral history and associated materials (this includes providing access to researchers and the public-at-large through online databases and exhibitions). It also grants researchers the right to use

the materials under the terms of fair use (for example, in articles and books). The terms of this license are as follows:

“The COVID-19 Oral History Project; the Journal of the Plague Year: A Covid-19 Archive; and The Trustees of Indiana University (“IU”), acting through its agents, employees, or representatives has an unlimited right to reproduce, use, exhibit, display, perform, broadcast, create derivative works from, and distribute the oral history materials in any manner or media now existing or hereafter developed, in perpetuity, throughout the world. I agree that the oral history materials may be used by The COVID-19 Oral History Project; the Journal of the Plague Year: A Covid-19 Archive; and IU, including its assigns and transferees, for any purpose, including but not limited to, marketing, advertising, publicity, or other promotional purposes. I agree that IU will have final editorial authority over the use of the oral history materials, and I waive any right to inspect or approve of any future use of the oral history materials. Moreover, I agree that the public has the right to use the materials under the terms of fair use (U.S. copyright law Section 107 of the U.S. Copyright Act).”

#### RISKS OF TAKING PART IN THE STUDY:

There is a slight possibility that some questions may make you feel uncomfortable. You do not have to answer any question with which you are uncomfortable.

By uploading your name and oral history to the database, what you say will become public information and the materials will be freely available.

#### BENEFITS OF TAKING PART IN THE STUDY:

There is no direct benefit to you for participating in this research. However, the recorded and transcribed interview(s) will provide important source materials that will allow researchers and other users to better understand the lived experience of pandemics in the modern world.

#### ALTERNATIVES TO TAKING PART IN THE STUDY:

The alternative to participating in this study is to elect not to participate.

## PAYMENT:

You will not receive payment for taking part in this study.

## CONFIDENTIALITY:

Your name and the material in your interview(s) will not be confidential. Materials associated with your interview(s) will be deposited in The Covid-19 Archive; The Journal of the Plague Year: A Covid-19 Archive; and the Indiana University Library system.

The credibility and significance of oral history is directly related to knowing who the narrator is, so your name and demographic information will be associated with your interview(s).

## CONTACTS FOR QUESTIONS OR PROBLEMS:

For questions about the study, contact the project director, Dr. Jason M. Kelly, at [iahi@iupui.edu](mailto:iahi@iupui.edu).

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (317) 278-3458 or [for Indianapolis] or (812) 856-4242 [for Bloomington] or (800) 696-2949.

## VOLUNTARY NATURE OF STUDY:

Taking part in this study is voluntary. You may choose not to take part, or you may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Indiana University, IUPUI, or the IUPUI Arts and Humanities Institute.

## **SUBJECT'S CONSENT AND DEED OF GIFT:**

I have read and understand the above informed consent document.

I agree to participate in this study with the following conditions:

- My name and other means of identification will not be confidential.
- My interview(s) will be recorded in digital video and/or audio format and may be transcribed.
- The recordings and possible transcriptions of my interview(s); copies of any supplementary documents or additional photos that I wish to share; and Informed Consent may be deposited in The Covid-19 Archive; The Journal of the Plague Year: A Covid-19 Archive; and the Indiana University Library system.

I understand that the following items may be created from my interview:

- an audio and/or video recording
- an edited transcript and summary
- copies of any supplementary documents or additional photos that I wish to share

I understand that my interview (and other items above) may be distributed to the public for educational purposes, including formats such as print, public programming, and the internet.

I agree to freely share my interview (and other items above) under the terms of the following license (check one):

Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International (CC BY-NC-SA 4.0)

The COVID-19 Oral History Project; the Journal of the Plague Year: A Covid-19 Archive; and The Trustees of Indiana University ("IU"), acting through its agents, employees, or representatives has an unlimited right to reproduce, use, exhibit, display, perform, broadcast, create derivative works from, and distribute the oral history materials in any manner or media now existing or hereafter developed, in perpetuity, throughout the world. I agree that the oral history materials may be used by The COVID-19 Oral History Project; the Journal of the Plague Year: A Covid-19 Archive; and IU, including its assigns and transferees, for any purpose, including but not limited to, marketing, advertising, publicity, or other promotional

purposes. I agree that IU will have final editorial authority over the use of the oral history materials, and I waive any right to inspect or approve of any future use of the oral history materials. Moreover, I agree that the public has the right to use the materials under the terms of fair use (U.S. copyright law Section 107 of the U.S. Copyright Act).

I acknowledge that I am not expecting to receive compensation for participating in this project or for any future use of the oral history materials.

I request that my interview be made available (check one):

- immediately
- on 1 January 2021
- on 1 January 2024

I release and fully discharge IU; The Covid-19 Archive; The Journal of the Plague Year: A Covid-19 Archive; Arizona State University; and George Mason University and their employees, agents, and representatives, from any claim, damages, or liability arising from or related to my participation in this project or future use of the oral history materials.

**SIGNATURE:**

*Sandra R. Smith*

[Sandra R. Smith \(May 23, 2020 09:16 CDT\)](#)

**PRINT NAME:** Sandra R. Smith

**DATE:** 05/23/2020