



## Participant Privacy Notification

### Who are we?

END-VOC is a research consortium of 20 partners from around the world. The consortium is coordinated and managed by researchers at the University College London (UCL).

### What is this project about?

The Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) has continued to evolve since the beginning of the Coronavirus disease (COVID-19) pandemic, which involved millions of deaths and impacted lives around the world with the closure of schools, workplaces, and limitations on freedom of movement. The emergence of new SARS-CoV-2 variants poses potentially new risks and challenges the current management of COVID-19.

To tackle these issues and to reduce the risk of further pandemics, the END-VOC consortium of 20 partners was financed by the European Commission Horizon 2020 programme (<https://endvoc.eu/>) to support a united global response to the COVID-19 pandemic and Variants of Concern (VOC) by using well-characterised cohorts across the world and exploiting ongoing international collaborations.

END-VOC aims to describe the global circulation of current and emerging SARS-CoV-2 VOCs and their characteristics, including transmissibility, pathogenicity and propensity to cause reinfection. In addition, END-VOC will investigate the impact of VOCs on vaccine effectiveness and treatment options, how VOCs alter long COVID and how new VOCs evolve. Ultimately, END-VOC will inform future pandemic preparedness and response.

### The data used in this project

This project includes pooling datasets held by END-VOC consortium partners. *The sources of pooled data include but are not limited to:*

- National surveillance data
- Secondary (hospital) care data
- Primary data from cohort studies

This study will curate, pool, and harmonise anonymised or pseudo-anonymised data collected by various END-VOC consortium partners in a trusted research environment (UCL Data Safe Haven).

No identifiable details (name, address, email, phone numbers) would be used in the data pooling and harmonisation. Where possible, we will pool and harmonise details from the cohorts on



END-VOC has received funding from the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency. Neither the European Union nor the granting authority can be held responsible for them.

demographics (month and year of birth, sex at birth), social demographics (ethnicity, education), clinically relevant variables (e. g. comorbidities, hospital visits), vaccination & treatment data , infection data (SARs-CoV-2 infections) and biological test results data (e.g. PCR, genomic data (SARs-CoV-2 virus) , serology data).

### Data controller/processors

Where UCL receives anonymous data from the END-VOC partners, GDPR terminology of determining controller & processor does not apply as personal data is not being handled.

Where UCL receives pseudonymised data from END-VOC partners, UCL and that partner will be **joint data controllers**.

### Confidentiality

We are undertaking a range of steps to minimise risks to privacy, including:

- Personal data is either anonymised or pseudonymised before being transferred to UCL Data Safe Haven, further checks are in place once data have been transferred to ensure that they do not contain any data that could identify an individual
- Encryption is used in transfers
- Research is not being used to make decisions directly affecting individuals
- Restricted access controls are in place
- Rights to export data is limited to named individuals who have statistical disclosure control training
- The full dataset will be stored and processed in the SLMS Data Safe Haven (DSH), which is a trusted research environment that complies to both ISO27001 and the NHS Digital Data Security and Protection Toolkit. Access is only available to authorised personnel who have completed the National Health Service Digital's (NHSD) Data Security Awareness Training course as well as a DSH Training Course.

### Patient Notification/Fair Processing Notice

The data to be shared by the END-VOC consortium will be anonymised or pseudonymised and as such, no identifiable details (name, address, email, phone numbers) would be shared with UCL and processed. Where possible, we will pool and harmonise details from the cohorts on demographics (month and year of birth, sex at birth), social demographics (ethnicity, education), clinically relevant variables (e. g. comorbidities, hospital visits), vaccination & treatment data , infection data (SARs-CoV-2 infections) and biological test results data (e.g. PCR, genomic data (SARs-CoV-2 virus) , serology data).

All staff working on this project have a legal duty of confidentiality to protect any personal information about individuals. All staff working with the data have had special training in keeping data confidential and secure.

### Where to find the results

ENDVOC results will be published in open access journals so that they can be read online and downloaded for free. We will provide a list of these publications on our project website (<https://endvoc.eu/resources>), as well as lay summaries of our progress and results (<https://endvoc.eu/news>), which we will share via our social media platforms using the project hashtag #ENDVOC

### Legal and ethical permissions

The legal basis for processing personal data for this purpose falls under Article 6(1)(e) of the General Data Protection Regulations (GDPR), i.e. *“processing is necessary for the performance of a task carried out in the public interest”*. It also falls under Article 9(2)(j), *“processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purpose”*.

Prior to uploading any data to the data sharing platform, each END-VOC partner is responsible for ensuring that ethical approval / legal basis for sharing data is in place. The consortium documents & records all ethical approvals as part of our research governance procedures.

### Data storage and retention

Retention of data is necessary to ensure that analyses can be checked and to adhere to guidelines on reproducibility of research. END-VOC data shall be retained for 5 years after the last payment from the funding body has been made.

### Your options

If you would like to know more about the project and how we are using the data, please contact us via our website <https://endvoc.eu/contact/>.

University College London is the coordinator of this project. UCL is Joint Data Controller in cases where project partners are transferring pseudonymised data to UCL. If you have any questions about how UCL uses personal data, you can contact the Data Protection Officer: [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

You also have the right to complain directly to the [Information Commissioner’s Office](#), which is an independent regulatory authority set up to uphold information rights. We will also refer you to the equivalent body in the country where your data were collected (via the joint data controller).