

## **ENO Breathe Participant Information Sheet**

As a participant on ENO Breathe you will be asked to share with us some of your personal information and will complete important monitoring forms as part of our ongoing evaluation of the programme. Before you decide whether to participate in the programme, it is important for you to understand what data we will collect from you, why we collect it, and how we will use and store it. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

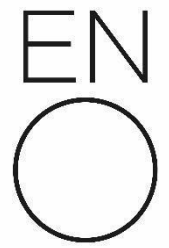
### **Information we hold on you**

ENO will collect information directly from you for participation in the ENO Breathe programme via the following means:

- **Patient sign-up form** (completed via a secured online platform):  
*This includes basic contact details, demographic information, details of which long COVID service you were referred from, emergency contact details and basic questions on your COVID dates.*
- **Pre-programme survey** (completed via a secured online platform):  
*This includes your basic anonymised health info, health survey scores and views on ENO.*
- **End of programme survey** (completed via a secured online platform):  
*This includes your anonymised health survey scores, feedback on the programme and views on ENO.*
- **3 month follow-up survey** (completed via a secured online platform):  
*This includes follow up anonymised health information and further feedback on the programme.*
- **Zoom recordings of ENO Breathe group sessions:**  
*We record all of our group sessions for internal monitoring purposes.*

We will do our best to protect your personal information. However, we cannot guarantee the security of your data transmitted to our site before it reaches us, and any transmission is therefore at your own risk. Once we have received your information, we use strict procedures and security features to prevent access by unauthorised parties.

By providing us with your information, you are giving us permission to use that information to fulfil your participation and evaluation in the ENO Breathe programme. Where you have provided an email address we will contact you by email.



## Data sharing

Very occasionally it can be useful to be able to communicate with the post-COVID service who referred you to ENO Breathe, for example if we need further information to assess your suitability for the programme. In these cases, we would actively seek your consent to name you in our correspondence with the service.

Data collected on registrations to ENO Breathe per month, per post-COVID service, is shared **anonymously** with our partnered clinics, as a percentage of the amount of referrals the clinic has made to ENO Breathe. We will not tell your clinic whether you have signed up for ENO Breathe without your permission.

There is no other scenario in which we will share any of your personal data with the post-COVID service who referred you, and we will never do so without gaining your written consent. We also do not collect any patient data from our partner post-COVID services.

Demographic data collected via your sign-up form is periodically analysed and shared with partners and funders. This data is always anonymised.

Data collected via the programme surveys is anonymised and sent to our external evaluator who conducts periodic analysis and writes up findings in regular impact reports that are shared with our steering group and NHS partners. All data contained within these reports is anonymised.

## How we store your data

- **Data submitted via your registration form:**  
*This information is held on a password protected secure online platform only accessible to the ENO Breathe staff team.*
- **Data submitted via your pre-programme and end-of-programme surveys:**  
*This data is held on a password protected secure online platform only accessible to the ENO Breathe staff team. Data is downloaded from the platform, anonymised and shared anonymously to our ENO Breathe evaluator.*

*Data on the secure online system will be held for a period of 3 years, after which point all data will be deleted.*

- **Data submitted via your 3-month follow up survey:**  
*This data is held on a password protected secure online platform only accessible to the ENO Breathe staff team. Data is downloaded from the platform, anonymised and shared anonymously to our ENO Breathe evaluator.*



*Data on the secure online system will be held for a period of 3 years, after which point all data will be deleted.*

- **Zoom recordings of sessions:**

*These recordings are held on password protected zoom accounts and will not be shared externally without gaining your prior consent. These are deleted 3 months after the date of your final group session.*

## Your rights

Under The General Data Protection Regulation, you have a right to:

- **Ask for a copy of the information we hold about you and to have any inaccuracies in your information corrected.** If you wish to do this or to make any enquiries, please contact [breathe@eno.org](mailto:breathe@eno.org).
- **Make a complaint.** If you have a complaint please contact ENO first by email, post or phone. You also have a right to complain to the ICO. Please visit [ICO.org.uk](https://ico.org.uk).
- **Request that we delete or remove the data we hold about you if:** you think that our purposes for processing the data no longer apply; or have withdrawn your consent to our using it and your consent was our lawful basis for processing it; where you consider that our legitimate interests in processing your data do not or no longer apply; and if you think we have processed your data unlawfully.
- **Request restriction of how we process your personal data, which allows you to suspend our use of your data if you:** want to ensure the accuracy of your data; want to establish the lawfulness of our use of your data but do not want us to delete it; want us to retain your data beyond the point we require it for the purpose we obtained it for; you have requested that we stop processing your data whilst our legitimate interests are balanced against your individual interests.

Please email [breathe@eno.org](mailto:breathe@eno.org) to exercise your rights.

For further information, please refer to [ENO Breathe's privacy policy](#)