

Participant Information Sheet

Study title: AI-Respire/BreathBot – Establishing personalised health response to air pollution

Principle Investigators: Prof Fan Chung and Prof Christopher Pain

Co-Investigators: Prof Ian Adcock, Prof Marc Chadeau, Dr Fangxin Fang & Prof Alexander Porter

- **Invitation paragraph**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

99% of the world's population breathe indoor and outdoor air which fails to meet WHO guideline limits for air pollution and kills approximately 7 million people each year worldwide. In the UK, it is rated as one of the most serious threats to public health with only cancer, obesity and heart disease eclipsing it. The AI-Respire project therefore aims to help us better understand the link between air quality and our health so that we can develop ways of mitigating the effects of air pollution to our health. This stage of the project is focused on gathering data but eventually we would like to provide guidance to people on how they can change their daily habits to protect their health. We aim to do that in a personalised way which considers people's health condition and their environment.

To do this, we need a lot of data from a wide range of people to improve our models of the relationship between air quality and health and start to develop the capacity to provide information back to users. Smart devices provide us with an amazing opportunity to get an overview of people's health on a day-to-day basis. If you use Garmin, Fitbit, Google Fit/Health Connect or Apple Healthkit, you can contribute to this study by downloading the BreathBot app, consenting to the study requirements, linking your fitness devices and apps, and completing a short questionnaire. We will also need to access your phone's GPS data (with 200m accuracy) to link air quality and weather information to your health data. After that, the app will automatically collect your fitness data and you will be required to do very little. You may receive an occasional notification to re-activate the app if your phone operating system sees that you are not interacting with it and stops it from functioning.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

- **What is the purpose of the study?**

99% of the world's population breathe indoor and outdoor air which fails to meet WHO guideline limits for air pollution. This takes approximately 7 million lives globally each year. Furthermore, climate change can increase air pollution through events such as

heat waves, drought and wildfires. Health risks include the development and exacerbation of respiratory and heart conditions.

We aim to eventually create a personalised analysis tool to empower individuals in monitoring and managing their air pollution exposure. In order to do so, we are seeking volunteers who are willing to share fitness data from their wearable devices (Garmin and Fitbit) and/or apps (Google Fit/Health Connect or Apple Healthkit). We would also like to collect location data so that we can study the air quality and weather conditions where you are. Location data is collected when you change location outside of a 200m area and is accurate to a 200m area. Finally, we ask you to complete a short health questionnaire.

- **Why have I been invited?**

We are seeking users of Garmin, Fitbit, Google Fit/Health Connect or Apple Healthkit to join our study. We have no limit on numbers.

- **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you can access this information sheet via the AI-Respire [website](#) or BreathBot app at any time. We ask that you consent to the study via the BreathBot app via these links [ADD LINKS]. If you decide to take part, you are free to withdraw at any time and without giving a reason. To withdraw, either delete the app from your phone or email BreathBot@imperial.ac.uk directly or generate an email from the app home screen. We will then deactivate your account

from our side which will stop the data collection and you can delete the app from your phone. We will keep the data you have shared with us for our research, until the point at which you withdraw.

- **What will happen to me if I take part?**

Initially, the study will run until 1st January 2025 at which point data collection will stop and you are free to delete the app. However, we hope to extend that study period and will be in touch (if you consent for us to do so in the BreathBot app onboarding process) to ask if you are happy to continue with the study, outlining the new time period for which we plan to collect data. There are no requirements for participants of the study aside from those completed as part of the BreathBot on-boarding process; the BreathBot app will automatically collect the relevant data from your devices.

- **What do I have to do?**

There are no requirements for participants of the study aside from those completed as part of the BreathBot on-boarding process; the BreathBot app will automatically collect the relevant data from your devices. Participants go about their daily lives as normal and do not need to regularly interact with the app. As some phone operating systems deactivate apps which you have not interacted with for a certain time period, you may occasionally receive a notification from the app asking you to open it so that the data collection is reactivated.

- **What are the possible disadvantages and risks of taking part?**

At this stage in the project, we will be analysing the data at an aggregate level, no detailed study of individuals' data will be performed.

- **What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get might help you and others in the future; we aim to get further funding to continue this work and develop ways to provide information back to users.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator Professor Fan Chung (f.chung@imperial.ac.uk). If you are still not satisfied with the response, you may contact the Imperial College Research Governance and Integrity Team (rgitcoordinator@imperial.ac.uk).

- **What will happen to the results of the research study?**

We aim to publish our findings towards the end of the project (1st January 2025), all findings will be published in an open-source manner. We will inform participants of where they can access publications by email (if you consent to us using your email address

in this way). It will not be possible to identify any individual participant through the data and findings published.

- **Who is organising and funding the research?**

The AI for Personalised respiratory health and pollution (AI-Respire) project is funded by UK Research and Innovation (UKRI), Engineering and Physical Sciences Research Council (EPSRC), EPSRC reference EP/Y018680/1. The lead department implementing the project is the National Heart and Lung Institute, Faculty of Medicine, Imperial College London.

- **Who has reviewed the study?**

This study was given favourable opinion by Imperial College London's Research Governance and Integrity Team (RGIT) and approval by Professor Clare Lloyd, Interim Head of the National Heart and Lung Institute, Imperial College London.

Contact for Further Information

Please contact Claire Dilliway (c.dilliway@imperial.ac.uk), 020 7594 2921 should you have any questions.

Thank you for your consideration of this study.

TRANSPARENCY NOTICE

How will we use Information about you?

Research Study Title: AI-Respire/BreathBot – Establishing personalised health response to air pollution (EPSRC reference EP/Y018680/1)

Imperial College London is the sponsor for this study and will act as the Data Controller for this study. This means that we are responsible for looking after your information and using it appropriately. Imperial College London will keep your personal data for:

- 10 year after the study has finished in relation to data subject consent forms.
- 10 years after the study has completed in relation to primary research data.

The study is expected to finish on 31st January 2025.

For more information / confirmation regarding the end date please contact the study team, see **'WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED'** for contact information.

We will need to use information (including personal data and data created as part of the study) from you for this research project. This information will include your email address, GPS location (with 200 meters accuracy), fitness data, health history, year of birth, height, weight). People within the College and study team (see section 'Sharing your information with others') will use this information to do the research or to check your records (see

information to be collected) to make sure that the research is being done properly and the information held (such as contact details) is accurate.

People who do not need to know who you are or where you have been (to include data on the air quality in your environment) will not be able to see your email address or GPS location. Your data will have a unique study number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

LEGAL BASIS

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Our legal basis for using your information under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, is as follows:

- Imperial College London - “performance of a task carried out in the public interest”; Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research
- Core Blue Limited (Company Registration: 10290102), app

developer— legitimate interests held by the data controller or a third party;

Where special category personal information is involved (most commonly health data, biometric data and genetic data, racial and ethnic data etc.), both organisations rely on “scientific or historical research purposes or statistical purposes.

INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the United Kingdom (for example, to a research partner, either within the European Economic Area (EEA) or to other countries outside the EEA. Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a UK adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient research partner that incorporates UK approved standard contractual clauses or utilise another transfer mechanism that safeguards how your personal data is processed.

SHARING YOUR INFORMATION WITH OTHERS

We will only share your personal data with certain third parties for the purposes referred to in this participant information sheet and by relying on the legal basis for processing your data as set out above.

- Other Imperial College London employees (including staff involved directly with the research study or as part of certain

secondary activities which may include support functions, internal audits, ensuring accuracy of contact details etc.), Imperial College London agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

- the following Research Collaborators / Partners in the study;
 - i. CoreBlue Limited (Company Registration: 10290102) - App developer requires access to the back end of the app and database for maintenance purposes.

YOUR DATA AND THIRD PARTIES BEYOND THE PROJECT

Note that being part of this study and sharing your data from Garmin, Fitbit, Google Fit/Health Connect or Apple Healthkit, does not affect how those companies handle your data. Whilst we are the data controller for the data we collect from these devices/apps, the aforementioned companies are also data controllers for that data according to any agreements you have with them. We will follow the principles in the Good Data Processing Agreement in our dealings with Garmin, Fitbit, Google Fit/Health Connect and Apple Healthkit and encourage them to adhere to these principles in their handling of the data, where possible.

POTENTIAL USE OF STUDY DATA FOR FUTURE RESEARCH

When you agree to take part in a research study, the information collected either as part of the study or in preparation for the study

(such as contact details) may, if you consent, be provided to researchers running other research studies at Imperial College London and in other organisations which may be universities or organisations involved in research in this country or abroad. Your information will only be used to conduct research in accordance with legislation including the GDPR and the [UK Policy Framework for Health and Social Care Research](#).

This information will not identify you and will not be combined with other information in a way that could identify you, used against you or used to make decisions about you.

COMMERCIALISATION

Samples / data from the study may also be provided to organisations not named in this participant information sheet, e.g. commercial organisations or non-commercial organisations for the purposes of undertaking the current study, future research studies or commercial purposes such as development by a company of a new test, product or treatment. We will ensure your name and any identifying details will NOT be given to these third parties, instead you will be identified by a unique study number with any sample analysis having the potential to generate 'personal data'.

Aggregated (combined) or anonymised data sets (all identifying information is removed) may also be created using your data (in a way which does not identify you individually) and be used for such research or commercial purposes where the purposes align to relevant legislation (including the GDPR) and wider aims of the study. Your data will not be shared with a commercial organisation for marketing purposes.

WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have because some research using your data may have already taken place and this cannot be undone.

- We need to manage your records in specific ways for the research to be reliable. This means that we may not be able to let you see or change the data we hold about you if this could affect the wider study or the accuracy of data collected.
- **OPTION if data will be used for future research:** If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

You can find out more about how we use your information:

- by asking one of the research team
- by sending an email to Claire Dilliway (c.dilliway@imperial.ac.uk), or
- by ringing us on 020 7594 2921.

COMPLAINT

If you wish to raise a complaint about how we have handled your personal data, please contact the research team first by sending an email to Claire Dilliway, AI-Respire Programme Manager (c.dilliway@imperial.ac.uk), or by ringing us on 020 7594 2921.

Imperial College London

Following our response, if you are not satisfied please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you remain unsatisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO)- via www.ico.org.uk. Please note the ICO does recommend that you seek to resolve matters with the data controller (us) first before involving them.