

## **Transparency Information**

### **Study title: Idiopathic Pulmonary Fibrosis Job Exposure Study (IPFJES)**

**IRAS number 203355**

Imperial College London is the sponsor for this study based in the United Kingdom. We will be using information from you and/or your medical records in order to undertake 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 properly. Imperial College London, will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

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

Dr Carl Reynolds / [carl.reynolds@imperial.ac.uk](mailto:carl.reynolds@imperial.ac.uk) / 0207 594 6847

National Heart and Lung Institute, Room G39 Emmanuel Kaye Building, 1b Manresa Road, London, SW3 6LR.

NHS sites will collect information from you and/or your medical records for this research study in accordance with our instructions.

NHS sites will use your name, clinic attendance details, and contact details, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from Imperial College London and regulatory organisations may look at your medical and research records to check the accuracy of the research study. NHS sites will pass these details to Imperial College London along with the information collected from you and/or your medical records. The only people in Imperial College London who will have access to information that identifies you will be people who need to contact you to interview you or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number, or contact details.

NHS sites will keep identifiable information about you from this study for 10 years after the study has finished.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information

will only be used by organisations and researchers to conduct research in accordance with the [UK Policy Framework for Health and Social Care Research](#).

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance.

Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.