

**PARTICIPANT PRIVACY INFORMATION – FOCUS GROUPS**

**Research Study Title:** SHINE

ICREC no: 22IC7687

Imperial College Londonis the sponsor for this study based in the United Kingdom. We will be using information from you 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 in relation to data subject consent statements.
* 10 years after the study has completed in relation to primary research data.

Further information on Imperial College London’s retention periods may be found at

<https://www.imperial.ac.uk/media/imperial-college/administration-and-support-services/records-and-archives/public/Retention-Schedule-February-2022.pdf>

A link to Imperial College London’s data protection webpage may be found at <https://www.imperial.ac.uk/admin-services/legal-services-office/data-protection/> but this is the notice most applicable to the information provided by participants and therefore takes precedence for all purposes described hereunder.

**YOUR RIGHTS**

Your usual statutory rights to access, change or move your information are limited, because of exceptions applicable to some types of research, and also because we need to manage your information in specific, lawful 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.

**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.

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.

**THE TYPES OF INFORMATION WE COLLECT**

We will ask questions about your experiences being involved in clinical trial research.

We will collect the following types of personal data about you

* Age
* Education
* Employment status
* Gender

We will also collect special category data about you including the following:

* Ethnicity
* Type of disability

We collect personal data and special category data to ensure there is a mix of people from different backgrounds for the focus groups.

People who do not need to know who you are will not be able to see your personal or special category information. Your data will have a unique study number instead.

We will keep all information about you safe and secure.

**INTERNATIONAL TRANSFERS**

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). 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 European Commission (**EC**) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

**CONTACT US**

If you wish to raise a complaint on how we have handled your personal data or if you want to find out more about how we use your information, please contact Imperial College London’s Data Protection Officer via email at [dpo@imperial.ac.uk](mailto:dpo@imperial.ac.uk) , via telephone on 020 7594 3502 and via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you are not satisfied 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). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.

Imperial College London will collect information from you for this research study in accordance with our instructions.

If you provide your name and contact details for Imperial College to contact you to send a paper version of the survey or carry out the survey by telephone we will use this data for this purpose only.

If you provide your name and contact details for Imperial College to contact you regarding taking part in the focus groups we will use this data for this purpose only.

Individuals from Imperial College London and regulatory organisations may look at your data collected to check the accuracy of the research study. 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 for participation in the focus groups 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 or contact details.

Imperial College London will keep identifiable information about you from this study for 10 years after the study has finished.

**FUTURE RESEARCH**

When you agree to take part in a research study, the information about your health 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 (<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/> ).

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.