

## Privacy Notice

The SIPS study is using routinely collected NHS data (routine data) to meet a number of its key objectives. This routine data will allow the study team at the University of Bristol to describe the patient characteristics of those who are admitted to hospital with a severe, full skin thickness pressure ulcer. It will also enable the study team to compare outcomes for groups of similar patients who do and do not have surgical reconstruction following their admission to hospital with a severe, full skin thickness pressure ulcer. Surgical reconstruction of pressure ulcers is not common in the United Kingdom, and at the moment it is not clear which patients with pressure ulcers may benefit from an operation and which of the different ways of doing surgery is best. The SIPS study aims to find out more about how best to conduct research in this area.

NHS England, who are the holders of routine data in England, will be asked to create a cohort of patients who are known to have been admitted to hospital with a severe pressure ulcer from 2011-2019. NHS England will then provide the study team at the University of Bristol with pseudonymised information on these patients relating to outpatient visits, hospital admissions and deaths. In pseudonymisation, something in the data which identifies an individual is replaced with an artificial identifier, for example a reference number. At no point will identifiable information be provided to NHS England by the University of Bristol, or by NHS England to the University of Bristol. No attempt will be made to identify anyone from this data. The transfer of data will be secure and only necessary data will be transferred. Data will be stored on secure University of Bristol managed servers for 5 years from the end of the study, as is required in clinical trials. This period will be from November 2023 to November 2028. These processes will be overseen by two joint Data Controllers – the University of Bristol and the University of Manchester.

If you wish, you can contact the Data Protection Officer at these organisations:

University of Bristol: [data-protection@bristol.ac.uk](mailto:data-protection@bristol.ac.uk)

University of Manchester: [dataprotection@manchester.ac.uk](mailto:dataprotection@manchester.ac.uk)

Your data is being processed under General Data Protection Regulation Article 6(1)(e), processing for a task in the public interest, and Article 9(2)(j), processing for scientific research purposes.

The General Data Protection Regulation provides rights for individuals which we need to make you aware of; the right to be informed, the right of access, the right to rectification, the right to erasure, the right to restrict processing, the right to data portability, the right to object to processing and rights in relation to automated decision making and profiling. There is no automated decision making (making a decision solely by automated means without any human involvement) or profiling (automated processing of personal data to evaluate certain things about an individual) involved in this study. The rights available to you depend on the reasons why we are processing your data. As this study is only using pseudonymised data, if you were to contact us regarding your data we would have no way of knowing if we are using your data. As such, the only right available to you in relation to this study is the NHS data opt-out. For more information on this, please visit <https://www.nhs.uk/your-nhs-data-matters/>. If you have any queries, you can contact the Study Manager via email at [sips-study@bristol.ac.uk](mailto:sips-study@bristol.ac.uk).

If you have concerns about how an organisation has handled your information, you have the right to lodge a complaint to the Information Commissioner's Office. Their helpline number is

0303 123 1113 and their email address is [dataprotectionfee@ico.org.uk](mailto:dataprotectionfee@ico.org.uk). You can also contact them in writing at:

Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

You can also contact the Study Manager or the relevant Data Protection Officer in the first instance (contact details above).