July 2021

Privacy Notice: STOP-ADENOMA

What is the purpose of this document?

This Privacy Notice describes how the STOP-ADENOMA study is using patient data and is intended to demonstrate how we comply with the 2018 Data Protection Act. It describes how we create the STOP-ADENOMA dataset and use any personal data within it so you are aware of how and why we are using your information. The policy may be updated at any time.

Glossary

The term 'personal data' when used in this document means any recorded information that is about you and from which you can be identified. It does not include data where your identity has been removed. These are called de-identified data.

The term 'processing' of your personal data means anything that is done with that information including collecting, use, storage, disclosure or retention.

The 'Data Controller' is the organisation that determines the purposes for which ('why') and the means by which ('how') personal data is processed.

What is the purpose of the STOP-ADENOMA Study?

An earlier study, the seAFOod polyp prevention trial was a clinical trial funded by the National Institute for Health Research (NIHR). It tested whether the omega-3 polyunsaturated fatty acid EPA (a natural substance found in high quantities in fish) and aspirin, alone or together, prevent bowel polyps (benign precursor growths that can progress to cancer) in individuals who underwent a lower bowel camera test (colonoscopy) in the Bowel Cancer Screening Programme (BCSP) in England.

The results were published in a medical journal (The Lancet – Lancet 2018 Dec 15;392(10164):2583-2594. doi: 10.1016/S0140-6736(18)31775-6) and a Plain English Summary of the results is available here. The study showed that both EPA and aspirin prevented recurrence of polyps when taken for 12 months but it couldn't determine any longer-term impact. The STOP-ADENOMA study was, therefore, funded by NIHR to look at the long-term effects of EPA and aspirin on polyp formation.

What types of data will STOP-ADENOMA use?

This particular question will be answered by analysing the results of check-up colonoscopies that were carried out routinely in the Bowel Cancer Screening Programme after trial participation. seAFOod trial participants will be identified in the Bowel Cancer Screening Programme dataset and additional information on colonoscopy findings extracted. These will then be linked to the original seAFOod dataset, patient identifiers removed and a pseudonymised dataset provided to the STOP-

ADENOMA team. They will keep it in a secure data repository and use it for their research. They will not be able to identify any individuals within the dataset. The Data Controller for the STOP-ADENOMA study is the University of Leeds.

Is STOP-ADENOMA using your personal data?

The StopAdenoma dataset only contains information on people who consented to participate in the seAFOod study but the research team will not have access to any personal information.

How the University of Leeds uses your data

The data captured as part of the seAFOod trial were done so with consent from all participants and this included permission to link to follow-up colonoscopy data. The combined trial and follow-up information forms the STOP-ADENOMA dataset. This is being used for the purpose of performing scientific (medical) research being carried out in the public interest. This is known under data protection law as our "legal basis" for processing personal data. The STOP-ADENOMA team only process your personal data for these purposes under approval granted from the London – Surrey Borders Research Ethics Committee (19/LO/1655).

Please note that we may process your data without your knowledge or consent, in compliance with the above rules, where this is required or permitted by law.

The University of Leeds Policy on Data Protection can be accessed via the following link: https://dataprotection.leeds.ac.uk/

Who has access to your data?

Access to your personal data is limited to the small STOP-ADENOMA team and is accessed in a strictly controlled data environment. All the individuals who have access to the information have undergone special training in handling confidential data and the data system they use is highly secure.

Transfer of STOP-ADENOMA data outside of the European Economic Area (EEA)

No StopAdenoma data will be transferred outside of the EEA.

Retention period

The STOP-ADENOMA data resource has been created from a three-year grant funded by National Institute of Health Research and is due to end in March 2022. To ensure all research undertaking using the study data is completed and published, the data will be retained until March 2026. At that point they will be destroyed.

Security

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All STOP-ADENOMA data will be held securely in accordance with University of Leeds policies and procedures. Further information is available at the University's Information Security website: https://it.leeds.ac.uk/it?id=kb_category&kb_category=7950ab68db7ffbc48b6583305b9619e0

Your rights

Under certain circumstances and by law you have certain rights with respect to your data. A summary of these rights is available here: https://ico.org.uk/your-data-matters/

If you want to exercise any of these rights or you are dissatisfied with the way we have used your data, please contact the University's Information Compliance Team at dpo@leeds.ac.uk. The same address can be used to contact the University's Data Protection Officer. If you remain dissatisfied, you have the right to lodge a complaint with the Information Commissioner's Office at https://ico.org.uk/make-a-complaint/

Contact

If you wish to raise any queries or concerns about this Privacy Notice please write to Professor Mark Hull, Leeds Institute of Medical Research, St James's University Hospital, Leeds LS9 7TF or email him at m.a.hull@leeds.ac.uk