



BOSS Study c/o BOSS Trial Office Chestnut House Gloucestershire Royal Hospital Great Western Road Gloucester GL1 3NN 0300 422 5475

Email: ghn-tr.BOSS@nhs.net

December 2022

Re: BOSS (Barrett's Oesophagus Surveillance Study) General Data Protection Regulation

Dear Participant

The BOSS trial is nearing the point where we will be able to publish our results. It is anticipated that this should be ready by early summer 2023.

As we close the BOSS trial, we are required to ensure that all our systems are in place and that we continue to follow correct processes with regards to collection, storage, and use of data.

Before we started our research, we had to demonstrate that patient data and privacy would be protected. An NHS research ethics committee reviewed this and was satisfied that we met all the requirements.

Therefore, when you entered the BOSS trial between 2009 and 2011 you gave consent to staff across the UK using the ethically approved consent form and accompanying patient information sheet relevant during that period. The information you would have received during the recruitment period would have included:

The purpose of the study? Why you have been invited? What will happen if you take part? What you have to do? What are the possible benefits of taking part? What if you don't want to take part? What happens when the research study stops? Will your taking part in this study be kept confidential? What will happen to the results of the research study?

In reviewing our systems, it has come to light that when the **General Data Protection Regulation** legislation **(GDPR)** came into law in 2018 we should have informed you of this. On 25 May 2018, GDPR came into force across the EU. The UK introduced a new Data Protection Act (DPA) on the same date, which replaced our old DPA and implemented GDPR. The new regulation introduced more stringent requirements for protection and accountability, and gave individuals more control over their personal data.



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Please tell the receptionist if you would like a copy of letters sent between health professionals about your care.

For further information, please visit www.gloshospitals.nhs.uk

Chair: Deborah Evans **Chief Executive:** Deborah Lee



The principles of data protection under the GDPR are similar to those under the DPA, in summary, these are that personal data shall be:

- processed in a lawful, fair and transparent manner
- collected for specified, explicit and legitimate purposes, and that there will be no further
 processing that is incompatible with those purposes (there are some exceptions to this for
 processing for research, statistical or archiving purposes)
- adequate, relevant and limited to what is necessary
- accurate and kept up to date
- kept in a form allowing identification of data subjects for no longer than is necessary (there are some exceptions to this for processing for research, statistical or archiving purposes)
- processed in a secure manner

We have reviewed our original patient information sheets that you would have received a copy of and are satisfied that we are still able to demonstrate our need to use patient data for the BOSS research. In legal terms this means that we have a 'legitimate interest' in using patient data.

We have not changed our reasons to collect your data. Please be assured that your data remains anonymised and is only to be used for the purposes of the BOSS trial. No one outside of the trial management team will have access to any portion of your data.

Further information on the use of patient data in research which is compatible with the new General Data Protection Regulation (GDPR) guidelines can be found on the Health Research Authority (hra.nhs.uk) website Patient Data and Research leaflet.

The data protection officer is Thelma Turner ghn-tr.dataprotection.officer@nhs.net or Phone: 0300 422 2222

The sponsor for the BOSS trial is Gloucestershire Hospitals NHS Foundation trust.

If you have any concerns, please contact the main BOSS trial team on 0300 422 5477.

Yours sincerely

Professor Hugh Barr MD, ChM, FRCS, FRCSE, FHEA. (Chief Investigator BOSS)