Data Protection Statement for the TrueNTH Global Registry Study - Prostate Cancer Outcomes Protocol

Study Short Title: TrueNTH Global Registry Study
IRAS Number: 214153

This information is being made available to all participants in the TrueNTH Global Registry study in order to fulfil transparency requirements under the General Data Protection Regulation for health and care research.

The TrueNTH Global Registry study is being run in UK by the Macmillan Survivorship Research Group (MSRG), with funding provided by Movember and the University of Southampton acting as sponsor. We will be using information from you and 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. The University of Southampton will keep identifiable information about you for 10 years after the study has finished.

As this study is being conducted on behalf of the University of Southampton 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. Your rights to access, change or move your information may be 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 TrueNTH Global Registry 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 to achieve our research objective.

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 appropriate organisational policies and procedures (e.g. UK Policy Framework for Health and Social Care Research).

What legal basis do we have to process this information?

The TrueNTH Global Registry study requires ethically approved, voluntary, explicit written consent for you to participate. Information given to you is included within the relevant participant information sheets and consent forms, created and supplied by those running the trials. Processing your information for trials is necessary for the performance of a task carried out in the public interest (GDPR Article 6(1)(e)) and under Article 9(2)(j) necessary for archiving purposes in the public interest, scientific or historical research purposes in accordance with Article 89 (1).

How we use your data

Your hospital will collect information from you or your medical records for this research in accordance with our instructions. Your hospital will use your name, NHS number 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 the University of Southampton and regulatory organisations may look at your medical and research records to check the accuracy of the research study.

Your hospital will pass these details to the University of Southampton along with the information collected from you and your medical records. The only people in the University of Southampton who will have access to information that identifies you will be people who need to contact you to send or request questionnaires, process and analyse your data or audit the data collection process. Where this information could identify you, the information will be held securely with strict arrangements about who can access the information.

Your hospital 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. 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.

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 affect your care. It will not be used to make decisions about future services available to you, such as insurance.

Your information collected in this research will be anonymised and then transferred securely to Monash University in Australia. Your anonymised information will be added to the global

TrueNTH Global Registry database for comparison with other countries. Anonymisation of your information means that anything that identifies you personally will have been removed.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer at data.protection@soton.ac.uk. The University's data protection policy is available at: https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page.

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 is the UK data protection regulator/supervisory authority. For further information on your rights and how to complain to the ICO, please refer to the ICO website: https://ico.org.uk/.

Rights to withdraw

Your participation is voluntary and we very much hope that you will continue to participate in our research and let us use your data. However, you are free to withdraw at any time and without giving a reason. A decision to withdraw at any time will not affect the standard of care you receive. These are the options if you choose to withdraw:

- You may choose not to receive further questionnaires but are happy for us to use the answers you have given us so far and for us to continue to collect routine clinical data.

Or

- You may prefer for the researchers to no longer contact you or use the information collected previously