**Fair Data Processing statement (06/09/2017)**

Thank you for taking part in the **Randomised Controlled Trial of Home Mechanical Ventilation in Hypercapnic Chronic Obstructive Pulmonary Disease Patients Post acute Hypercapnic Exacerbation.**

Currently 116 people have taken part in this study.

The HOT HMV trial is funded by two commercial partners (Phillips-Respironics & ResMed) as well as charitable sources (Guy’s and St Thomas’ Charity and the ResMed Foundation).The Data Controller for the HOT HMV trial is Guy’s and St Thomas NHS Foundation Trust.

The HOT HMV collects information (data) about you and we wish to clarify what we do with the data. Identifiable information about you is held by the HOT HMV Research team at Guy’s and St Thomas’ NHS Foundation Trust, where the data is entered by the HOT HMV Research team (such as date of birth, NHS hospital number and postcode) and is kept separately in password protected databases.

Researchers analysing your data in Guy’s and St Thomas NHS Foundation Trust know only your unique study number.

Information held by NHS Digital and other UK NHS bodies such as the Office for National Statistics (ONS) may be given to the researchers and be used to provide information about your current status. To obtain information from NHS Digital we will need to provide them with your NHS number, date of birth and your unique study ID number.

For patients in the trial, your date of birth and NHS number and patient ID number will be provided to NHS Digital in a spreadsheet format.

NHS Digital will then link these identifiers to national death records and send back a spreadsheet confirming the latest status for each patient, and if relevant, date of death.

Updated data will then be added to the secure HOT HMV trial database to ensure no contact is attempted with patients who have passed away.

We will only obtain information from these organisations if you have agreed to do so at the start of the study by ticking the relevant boxes on the consent form.

However, you can always withdraw if you no longer wish that we link your data obtained for the HOT HMVwith data held by these organisations. If you wish to withdraw consent please contact the team, details are listed below.

In general, data are kept indefinitely or until we stop the HOT HMV. When presenting information in research articles your personal information is never revealed. These published articles can be found at <http://jamanetwork.com/journals/jama/fullarticle/2627985>

More information about HOT HMV including the patient information sheet and consent form can be found on the GSTT Research Trial Website which shows HOT HMV website <http://www.guysandstthomas.nhs.uk/research/studies/>

If you have any other questions, please contact: Dr Patrick Murphy, Consultant, GSTT, London, SE1 7EH (Tel.: 0207 188 53807 or Email: patrick.murphy@gstt.nhs.uk) or Gill Arbane, Trials Coordinator, GSTT, London, SE1 7EH (Tel.: 0207 188 8070 or Email: gill.arbane@gstt.nhs.uk).