

## ***SWEET: Your Data***

This leaflet tells you more about your data within the SWEET study, who will have access to it and how we will keep it secure.

### **How will we use information about you?**

We will need to use information from you and from your medical records, your GP and central NHS Databases for this research project.

This information will include your:

- Initials
- Name
- NHS (or CHI, or HSCN) number depending on where you live
- Date of Birth
- Ethnicity
- Contact details (Email address and Telephone Number)

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

**Newcastle Upon Tyne Hospitals NHS Foundation Trust (NuTH)** is the sponsor of this research and it will be coordinated by the University of Warwick.

**NuTH and the University of Warwick are jointly** responsible for looking after your information. We will share your information related to this research project with the following types of organisations:

- **UK Universities where colleagues involved in this research are located - Newcastle University, Oxford Brookes University, Oxford University, Imperial College London and University College London**
- **Central databases held by NHS England (or their equivalents in Scotland, Northern Ireland & Wales)**
- **Text and email messaging services**
- **Breast Cancer Now**
- **Your GP**

We will keep all information about you safe and secure by:

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## Supporting Women with adherence to hormone Therapy following breast cancer

- Holding your information securely on University of Warwick systems that comply with strict data protection standards. When we share data with other organisations (like those listed above) they will also hold it securely.
- Limiting access to your data to authorised members of the research team, the study sponsor, and approved third-party collaborators, all of whom are bound by confidentiality agreements and data protection obligations.
- Using a range of technical and organisational measures, including but not limited to:
  - Encryption of data during storage and transfer.
  - Multi-factor authentication for system access.
  - Access restrictions based on user roles.
  - Monitoring and audit logging to detect and respond to any unauthorised access.

Your personal data will not be shared outside the UK.

### How will we use information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your study data for 15 years after the end of the study. The study data will then be fully anonymised and securely archived or destroyed.

### What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- If you choose to stop taking part in the study, we would like to continue collecting information about your health from:
  - Central records/databases
  - Your hospital
  - Your GP.
- If you do not want this to happen, tell us and we will stop.
- you have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this. You can also object to our processing of your data.
- If you agree to take part in this study, you will have the option of also being included in future research studies. We would contact you about these new studies using the contact details you gave us for this study.

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## Where can you find out more about how your information is used?

You can find out more about how we use your information:

- [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch) and <https://www.newcastle-hospitals.nhs.uk/help/privacy/privacy-notice-for-patients/> and <https://warwick.ac.uk/services/legalandcomplianceservices/dataprotection/otherprivacynotices/research>
- By asking one of the hospital site study team.
- By sending an email to [nuth.dpo@nhs.net](mailto:nuth.dpo@nhs.net)

## Why are we linking your information with other datasets?

As part of the SWEET study we will share your name, date of birth and NHS Number (or CHI, or HSC number depending on where you live) with relevant organisations in your country to access your prescription data. We do this to enable us to answer the research question and to see if the HT&Me Intervention being tested is helpful in helping women to take their hormone therapy as prescribed.

*For example, if you are in Northern Ireland, the prescribing data is collected in the Enhanced Prescribing Dataset. This is held by the Family Practitioner Services (FPS) in Health and Social Care (HSC) Business Service Organisation (BSO) and processed on behalf of the Strategic Planning and Performance Group (SPPG) in the Department of Health Northern Ireland.*

The table listed below shows by nation the databases we will be gathering information from and who currently holds this data.

| Nation           | Database Name:   | Data held by:   |
|------------------|--|---|
| Scotland         | Prescribing Information System   | Public Health Scotland  |
| England          | Medicines Prescribed in Primary Care Product<br>NHS Business Services Authority (NHSBSA) | NHS England   |
| Northern Ireland | Enhanced Prescribing Dataset   | Family Practitioner Services (FPS) in Health and Social Care (HSC) Business Services Organisation (BSO) |
| Wales            | NHS Wales Prescribing Dataset  | NHS Wales Shared Service Partnership – Primary Care Services  |

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**What if I misplace this leaflet or if any of your plans change during the study?**

You can always find the latest versions of the Patient Information Sheet and this data leaflet on the SWEET project website: <https://www.sweetstudy.co.uk/>. This website also tells you how the study is progressing.

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