



## **Privacy notice for project: North of England Women's Diet and Activity After Breast Cancer (NEW DAY-ABC) pilot Randomised controlled trial**

### **I have questions or want further information. Who do I talk to?**

University of Hull are working in collaboration with the University of Northumbria at Newcastle to deliver this project. The University of Northumbria at Newcastle Research Participant Privacy Notice is available here:

<https://www.northumbria.ac.uk/about-us/leadership-governance/vice-chancellors-office/legal-services-team/gdpr/gdpr---privacy-notices/>

This document focuses on the University of Hull role as data processor for the project.

If you have any questions or concerns about how your data will be processed within this project please contact Hull Health Trials Unit (HHTU) in the first instance:

Email: [hhtuenquiries@hyms.ac.uk](mailto:hhtuenquiries@hyms.ac.uk)

Telephone: 01482 463444

Address: 3<sup>rd</sup> Floor, Allam Medical Building, University of Hull, Hull, HU6 7RX

If you would like further information, please contact the University of Northumbria at Newcastle, Data Protection Officer (DPO):

Email: [dp.officer@northumbria.ac.uk](mailto:dp.officer@northumbria.ac.uk)

Telephone: 0191 243 7357

### **What is this project about?**

Being overweight after hormone-positive breast cancer treatment increases the chance of cancer returning: extra weight (mainly fat) leads to higher levels of oestrogen/harmful substances in the blood. There is a lack of lifestyle support for overweight women after breast cancer.

The first stage of this project consisted of working with patients and clinicians to develop an individually tailored lifestyle support programme to help these women lose weight. The second stage will now test the feasibility of completing a randomised study of the programme. Provided it is found to be feasible, the project will progress on to stage 3, which is a full trial to test the effectiveness of the programme.

### **Who is involved in this project?**



The University of Northumbria at Newcastle are the sponsor of this study. This means they have overall responsibility and control for the study conduct. Under the Data Protection Act (DPA) 2018 and General Data Protection Regulation (GDPR), the University of Northumbria at Newcastle are data controller for NEW DAY ABC.

The University of Hull, Sheffield Hallam University and the University of Newcastle are collaborators on this study.

The University of Hull are inputting to a number of areas within the study including trial and data management. The University of Hull manage the data systems used to collect and store your data in this study.

Sheffield Hallam University are involved in the inputting of data into the research database and conducting the study interviews.

The University of Newcastle are conducting the analysis of pseudonymised information at the end of the study.

Under the DPA 2018 and GDPR, all three collaborators are acting as data processors on behalf of the Sponsor and are therefore operating under their instructions.

### **How will you look after my information and who will have access to it?**

Your data will be managed and stored by the Hull Health Trials Unit (HHTU) using their data capture system REDCap cloud and BOX Governance file storage system. Both systems have high levels of security and all data is stored within the EU. Only staff working on this study will have access to your data. Staff have individual logins and all activity is logged. The HHTU hold an NHS Data Security and Protection Toolkit (DSP) which provides assurance that they are practising good data security and that personal data is handled correctly. More information about the DSP can be found [here](#).

What this means is that if you agree to take part in the trial, the University of Hull will keep your name, contact details and date of birth secure with only staff working on the study having access to your data. The NEW DAY-ABC research team who are based at Northumbria University and Sheffield Hallam University will use this information as needed, to contact you about the research study follow-up and interviews if you agreed and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. At the end of the study pseudonymised data will be provided to the University of Newcastle for the analysis of the information.



### **How long will you keep it?**

At the end of the study, all data collected about you will be securely transferred from the University of Hull to the Sponsor (data controller) at the University of Northumbria. All identifiable information about you with the exception of consent forms will be removed within 6-12 months after the study has finished. Consent forms will be retained until 5 years after closure of the research project.

The only exception to this will be if you have consented to discuss participation in similar research studies in the future. In this case, personal details such as name and contact details will be retained separately from the research data for 5 years after the study has ended by the University of Northumbria at Newcastle (Sponsor) allowing further contact to be made.

### **What is the purpose of the General Data Protection Regulations (GDPR 2018)?**

The University of Northumbria at Newcastle is the data controller of the information it collects and processes as described in this Notice. This means that it has the core legal responsibility to safeguard the information and ensure it is processed lawfully. The law is set out in the EU General Data Protection Regulation (called "GDPR") and a new UK law, the Data Protection Act 2018. In particular UOH must:

- Take steps to ensure that the data it processes is accurate and up to date;
- Give you clear information about its processing of your data, in one or more privacy notices like this one and the participant information sheet (referred to together in this section as a "Privacy Notice");
- Only process your data for specific purposes described to you in a Privacy Notice, and only share your data with third parties as provided for in a Privacy Notice; and
- Keep your data secure.

The law states that we can only process your personal data if the processing meets one of the conditions of processing in Article 6 GDPR. As we are processing your special category data we also must meet one of the conditions in Article 9 GDPR. Special Category data includes personal data which relates to your ethnicity, sex life or sexual orientation, health or disability, biometric or genetic data, religious or philosophical beliefs, political opinions or trade union membership. Under the data protection legislation we need to explain the legal basis for holding your data, i.e. which of these conditions apply.

For our research project the following conditions apply:

- Article 6.1(e) of the GDPR, i.e. our processing is necessary for the performance of a task carried out in the public interest. Research is a task that UoH performs in the public interest, as part of our core function as a university;



- Article 9.2(j) of the GDPR, i.e. our processing is necessary for research purposes or statistical purposes. This condition applies as long as we are applying appropriate protections to keep your data secure and safeguard your interests.

### **Your rights as a data subject**

Under the data protection laws you have a number of rights in relation to the processing of your data. These are limited by the lawful basis under which we hold your data. Your rights are:

- Right to request access to your data as processed by UoH and information about that processing
- Right to rectify any inaccuracies in your data
- Right to place restrictions on our processing of your data

If you would like to exercise any of your rights as outlined above, You can contact the DPO at the University of Northumbria at [dp.officer@northumbria.ac.uk](mailto:dp.officer@northumbria.ac.uk) or visit their Data Protection page on their website:

<https://www.northumbria.ac.uk/about-us/leadership-governance/vice-chancellors-office/legal-services-team/gdpr/>

As Data Processors, the University of Hull would work with the University of Northumbria (the Data Controller) to respond to any requests.

We will always aim to respond clearly and fully to any concerns you have about our processing and requests to exercise the rights set out above. However, as a data subject, if you have concerns about our data processing or consider that we have failed to comply with the data protection legislation, then you have the right to lodge a complaint with the data protection regulator, the Information Commissioner:

Online reporting: <https://ico.org.uk/concerns/>

Email: [casework@ico.org.uk](mailto:casework@ico.org.uk)

Tel: 0303 123 1113

Post: Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF