**The impact of chemotherapy dose intensity on survival in Teenage and Young Adult Cancer Patients. Privacy Statement and Data Opt-Out policy.**

This statement explains how we use the personal information we have obtained for use in this research project.

***What data is being used?***

The data items being used in this research project relate to details of an individual’s cancer, the treatment that they had received and whether or not the patient was still alive at the time of the request. The data is non-identifiable patient data which means that no personal identifiers are held by the research team.

***Where did the data come from?***

The data was originally received from Public Health England via the Office for Data Release but is now under the control of NHS digital. We store the data securely at the University of Leeds in order to analyse it for this project.

***What is the legal basis for using and storing this information?***

As set out under the General Data Protection Regulation (GDPR), our lawful basis for processing your data under Article 6(e) and special category data under Article 9(2)(j) is “Public Task”. This means the processing of your/ your child’s data is necessary for us to perform a task in the public interest. This task has a clear basis in law in terms of relating to cancer registration.

Furthermore, ethical approval for this project has been granted by the Yorkshire & The Humber - Bradford Leeds Research Ethics Committee (reference 19/YH/0121).

***What is the data being used for?***

The purpose of this research is to investigate whether the amount of chemotherapy received by TYA cancer patients and over what time, effects the amount of time that they survive. In addition, we will explore whether there are any patient factors that influence the treatment received including sociodemographic factors such as ethnicity. This data will not be shared by us with any other organisations or research groups.

***Where are the data held and for how long?***

Microsoft Ireland Operations Limited is our data processor providing cloud storage services. The University of Leeds instruct Microsoft to securely store all data in the Microsoft Azure (Cloud) UK datacentres in the UK region only. Microsoft will not process this data outside of the UK and/or the EEA, without the explicit instruction of the University of Leeds. We will hold this data for a further 3 years inline with our data sharing agreement with NHS digital.

***What rights do I have over my/my child’s data?***

You have the right of access, the right of rectification, the right to restriction of processing and the right to object to processing. If you wish to enact any of these rights, please contact the National Disease Registration Service (NDRS). They are in charge of collecting cancer data and storing it on a register. They hold special permissions which enable them to collect data related to cancer. You do however have the right to ‘opt out’ if you do not want your data to be held on the cancer register. You can also request your child’s data be removed if they are aged 13 or younger or you can show they have competency issues.

For more information about this please visit the NDRS website:

<https://digital.nhs.uk/ndrs/patients/opting-out>

or email the team at: [NDRSoptout@nhs.net](mailto:NDRSoptout@nhs.net)

***National data opt-out.***

Opting out of the national cancer register is different from the National data opt-out. The registers are not included in the National data opt out scheme as it is considered important to public health, so you need to contact the NDRS separately.

More details on the National opt-out scheme can be found here:

<https://digital.nhs.uk/services/national-data-opt-out>

***What if I have any questions relating to data use in this particular project?***

Please contact the principle investigator via the details below:

**Contact details:**

Dr Nicola Hughes

NIHR Doctoral Research Fellow

School of Medicine

Worsley Building

Clarendon Way

University of Leeds

LS2 9JT

**Email:** [n.f.hughes@leeds.ac.uk](mailto:n.f.hughes@leeds.ac.uk)

***Who is responsible for the data we hold at the University of Leeds and who processes it?***

The Data Controller and Data Processor for data collected is:

University of Leeds

Woodhouse Lane

Leeds

LS2 9JT

Data Protection Officer: Alice Temple

***What if I have any other concerns about the way my personal data are processed at the University of Leeds?***

If you have any concerns with regard to the way your personal data are being processed or have a query with regard to this Notice, please contact our Data Protection Officer, Alice Temple via email at a.c.temple@leeds.ac.uk.

Our general postal address is University of Leeds, Woodhouse Lane, Leeds LS2 9JT, UK.

Our postal address for data protection issues is University of Leeds, Room 11.72 EC Stoner Building, Leeds, LS2 9JT. Our telephone number is +44 (0)113 2431751.

Our data controller registration number provided by the Information Commissioner's Office is Z553814X.

If you are unhappy with the way you or your child’s data are being processed you have the right to complain to the Information Commissioner’s Office (ICO). <https://ico.org.uk/>