Summary Participant Information Sheet

HALO study: **Ha**ematology **L**ived experiences and **O**utcomes

We are keen to improve the support and care we deliver and so would like to know more about what life is like for adults who received a diagnosis of a Sickle Cell Disorder, Acute Leukaemia or Beta Thalassaemia in childhood.

If you have been treated for one of these conditions, we would be grateful if you could answer some questions about you and your life by completing a survey. It is part of a research study called the **HALO study** being conducted across the North of England. It is being run by the University of Leeds in partnership with NHS Hospitals and IQVIA, an NHS approved survey company. Taking part is completely voluntary. If you decide not to, this will not impact on any of the care you receive from the NHS or affect your legal rights.

Some questions in the survey ask about your general health, social issues, and health experiences, or about the disorders we are studying. You do not have to answer all of them if you do not want to. It should take about 20 minutes to complete. You do not have to finish it in one go. You will be able to log back in, change your answers or continue until the point when the complete button on the last page is pressed.

In this research study, we will use information from you, your medical records and routinely collected NHS data sources. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data. We will make sure no-one can work out who you are from the reports we write. The information pack tells you more about this.

To thank you for your help, at the end of the survey you will have the option to enter a free prize draw to win £100 *of Love2shop* vouchers.

To understand as much as possible, we would like to link your answers from the survey with details held about your use of NHS services. You will be able to opt out of linking data if you want, and you will be asked to consent at the start of the questionnaire.

For more information about the study, please read the attached *Full Participant Information Sheet* and how to opt-out please see the HALO study *Opt-Out Policy* link in the Full Participant Information Sheet.