Consent for Newborn Blood Spot Screening

Consent for Newborn Blood Spot Screening for Congenital Hypothyroidism (CHT), Cystic Fibrosis (CF), Sickle Cell Disorders (SCD) and 6 Inherited Metabolic Disorders (IMDs) - *Phenylketonuria (PKU), Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD), Maple Syrup Urine Disease (MSUD,* Homocystinuria (HCU), *Isovaleric Acidaemia (IVA) and Glutaric aciduria type 1 (GA1)*

I have received and read the national patient information leaflet and have had an opportunity to discuss the tests I am being offered with a health professional. I understand the reasons for the tests and the consequences of the results. I also understand the significance of not having these tests performed. I am aware that my decision whether or not to have these tests will not affect the quality of care delivered by healthcare professionals.

Baby's Name……………………………………………. Date of birth …/…/…

CHI Number…………………………………………………

I wish   **I do not wish** my baby to be tested for Congenital Hypothyroidism

I wish   **I do not wish** my baby to be tested for Cystic Fibrosis

I wish   **I do not wish** my baby to be tested for Sickle Cell Disorders

I wish   **I do not wish** my baby to be tested for the 6 IMDs

I understand that the Newborn Blood Spot Screening Programme needs to obtain my permission to store the newborn blood spot card beyond the initial 12 month testing period and to use any of the blood spots left over after testing is complete for anonymised research, such as the development of new screening tests. If any research was proposed in which the researcher would be able to identify me or my baby, a member of staff from the Newborn Bloodspot Screening Programme would always contact me again to seek my approval.

I agree   **I do not agree** for the storage of my baby's blood spot sample beyond the initial 12 month testing period.

I agree   **I do not agree** to the use of any leftover blood spots for anonymised research.

Signature:………………………………………… (Parent/Guardian)   Date …/…/…

Signature:…………………………………………(Witness: Healthcare professional)

Print:…………………………………………………

Designation: …………………………………………..   Date …/…/…