By email – for response

March 2024

Dear Colleagues,

ADDENDUM TO DATA SHARING AGREEMENT (DSA) FOR THE NEWBORN NATIONAL IT SYSTEM (SMaRT4NIPE, S4N)

We are writing to ask you to agree to this addendum to the DSA in relation to the provision by NHS England of the SMaRT4NIPE (S4N) clinical management IT system to your Trust.

The S4N system has been enhanced to provide the functionality to collect additional data items. This functionality is being rolled out to Trusts individually, and with your agreement will be switched on for your Trust.

The DSA that is currently in place between NHS England and your Trust for S4N specifies the individual data fields that support the screening pathway in Schedule 1 (ii). With your agreement, the definitions in Schedule 1 (ii) will include the addition to the dataset, as embedded below.

*The types of Data / data field types that will be transferred from NHSE to the Local Screening Provider and from the Local Screening Provider to NHSE* in the DSA between NHS England and [Local Screening Provider Organisation] are:



This agreement will be in place in the first instance for participating trusts for a period of one year, from April 1st 2024 ending on March 31st 2025, and may be subject to review as required.

**Please indicate your agreement to the enhancement of the S4N functionality for your Trust by responding to:** **jillwalker1@nhs.net** **and copy to Richard Kirk** **Richard.Kirk@liverpool.ac.uk**

**Jill Walker, Lead for Newborn & Infant Physical Examination (NIPE) Screening Programme, NHS England**

**Richard Kirk, Senior Research Coordinator for Children’s Orthopaedic and Trauma Trials, University of Liverpool**

Background

As a result of the 2021 hip expert working group review of hip outcomes, and development of NIPE standard 4, the existing hip pathway was extended to include the assessment of the timeliness of orthopaedic episodes, and post-screen positive referral outcomes. This led to a more recent review in 2023 via an expert sub-working group, with this standard now being designated as a key performance indicator (KPI).

These additional data will offer additional granularity regarding hip risk factors and post-screen positive referral outcomes. This will inform the efficacy of the NIPE hip screening end-to-end pathway, and further inform development of the screening pathway in relation to hip risk factors.

There is a recognised lack of evidence to support the robust assessment of the current screening pathway, and these data will support the further understanding and impact of individual newborn hip screening risk factors and associated outcomes.

To support audit or research in this area, NHS England may release data from the S4N system subject to approval by the Research Innovation and Development Advisory Committee (RIDAC). Such approval will depend on assurance of appropriate ethics approval, legal basis for disclosure and other information governance requirements.

An example of such audit work is being led by Professor Dan Perry (National Institute of Health & Care Research (NIHR) Professor and Professor of Children’s Surgery). This work is part of a project funded by NIHR to support the development of a programme to overcome Unplanned Variation in Children’s Health – the OUCH study programme. The first step of this (for participating sites) is known as the SMARTIE audit.