

Video Explaining the NNRD

A link to the animation can be found here: <https://youtu.be/fWgLR03AhPE>

In this short animation, we'd like to explain the NNRD

Narrator: "Meet Mona and her partner David; their baby, Indi, was born twelve weeks early. Indi is in the Neonatal Unit, receiving the extra care she needs"

Mona (thoughts): "I feel so helpless seeing Indi so small, I just want to be able to take her home. I wish I could do something to help Indi and all the other babies here."

Narrator: "While Indi receives care in the neonatal unit, doctors and nurses enter information about her and her treatments onto her electronic patient record. These notes are linked to a large database called the National Neonatal Research Database, or NNRD in short. Mona is given a leaflet about the NNRD."

Visual: Infographic showing data flow from the neonatal unit to the NNRD.

Nurse (talking to Mona and David): "I'd like to tell you about the NNRD and give you this leaflet to read."

Narrator: "The NNRD holds information from a baby's medical records about for example how early they were born, their weight and sex, if they were ill, and what treatments they received. Babies' names are not recorded which means that those who have access to the data, will not know the identities of the babies. The NNRD is fully approved by UK regulatory authorities."

David: "How is all this information about babies in the NNRD used?"

Nurse: "The NNRD is used to improve the care of newborn babies and their families in many ways. The information in the NNRD is used for research studies to find out which treatments work best, in audits that measure how well neonatal units are practising, and to support legislative change. For example, information from the NNRD helped change the law so that parents of babies in neonatal care can now get up to 12 extra weeks of paid leave"

Visual: Information on the Neonatal Care Leave and Pay Bill

Mona: "But what if we don't want our baby's information in the NNRD?"

Nurse: "That's absolutely fine. If you don't want your baby's data included in the NNRD, just let me or one of the other doctors or nurses know"

Narrator: "All babies admitted to NHS neonatal units are included in the NNRD unless parents choose to opt out. Including all babies in the NNRD means that the information is a fair representation of the diversity of babies that require extra care. Less than 3 in a thousand parents choose not to have their baby's information in the NNRD."

David, looking at Mona who nods: "I think we both happy for Indi's data to be in the NNRD. We understand the information is used to help improve the care babies receive."

Narrator: "You can find out more about the NNRD and the ways in which it is used to help improve the care of sick and preterm babies here:"

The NNRD is supported by BLISS, the Charity for babies who are born premature or sick.

We'd like to thank Alima, Louise and Rafika. Parents of babies born either preterm or sick for helping make this video.