Aim

To investigate if newborn babies with Down syndrome require different management strategies in neonatal units compared with unaffected babies of similar gestations and to compare their outcomes on discharge.

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Objectives

1. To determine the proportion of babies with Down syndrome that are admitted to a neonatal unit in England from 2009-2011 according to gestational age.
2. To describe the occurrence of common neonatal events in babies with Down syndrome and the treatments they receive.
3. To compare the occurrence of common neonatal events in babies with Down syndrome with babies without Down syndrome, adjusted for gestational age.
4. To evaluate the length of stay on a neonatal unit, the need for home oxygen, mode of feeding and weight at discharge for babies with Down syndrome.

The National Neonatal Research Database (NNRD)

The National Data Analysis Unit (NDAU) is an independent academic unit based at the Chelsea & Westminster campus of Imperial College London. NDAU receives electronic data from contributing neonatal units and has permission to hold these in a National Neonatal Research Database (NNRD). The NNRD is a resource for research and service evaluations to improve newborn care. Contributing neonatal units form the UK Neonatal Collaborative. The National Research Ethics Service (ref 10/H0803/151) and the Ethics & Confidentiality Committee of the National Information Governance Board (ref ECC 8-05(f)/2010) have approved the use of the NNRD for NHS service evaluations and research.

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The National Down Syndrome Cytogenetic Register (NDSCR)

The NDSCR contains basic information on all postnatal and prenatal diagnoses of Down syndrome in England and Wales. As a member of BINOCAR (British Isles Network of Congenital Anomaly Registers) the National Research Ethics Service (ref 09/H0405/48) and the Ethics & Confidentiality Committee of the National Information Governance Board (ref 2-08(e)/2012) have approved the use of the NDSCR for surveillance and research.

Methods

Babies with Down syndrome will be identified in the NNRD by examining the fields recording diagnoses. Anonymous data on all babies with Down syndrome born between 01/01/2009 and 31/12/2011 will be extracted and in addition data for a control set of 5 “unaffected” babies per case born during the same period will be extracted. Cases will be matched on gestational age in completed weeks, neonatal unit and month of admission.

Individual specific information will be extracted on daily events, level and location of neonatal care, and neonatal care characteristics. We will also identify specific procedures and interventions and identify the risk of additional complications in the neonatal period. Trends in care from the point of identifying a need, if there is one, for additional neonatal care in a newborn child with Down syndrome will be examined. Patient specific details of important discharge criteria such as the need for home oxygen, mode of feeding and weight at discharge will be evaluated. A full list of variables being extracted are available upon request.

Unidentifiable grouped data on the numbers of babies born according to gestational age and weight from the NDSCR will be used with the data from the NNRD to enable the proportion of admissions to be estimated and also to evaluate the importance of birth weight in the admission to a neonatal unit.

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Sample size

On the assumption that information on around 200 babies with Down syndrome will be available in the NNRD there will be sufficient power to compare if babies with Down syndrome are twice as likely as unaffected babies to develop any specific clinical events that occur in around 10% of babies. The power will also be sufficient to determine if babies with Down syndrome stay 50% longer on neonatal units.

Impact on Clinical Practice

This study will quantify the problems that children with Down syndrome may face in the first few weeks of life. Such information is important for both parents and health professionals caring for these children.

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Further Information

If you require further information on the DIN Project please email Professor Joan Morris (j.k.morris@qmul.ac.uk)

NDSCR

NDAU
Neonatal Data Analysis Unit

The DIN Project

“Down syndrome In Neonatal units”

A national case-control study of the treatment received and the outcome of babies with Down syndrome compared to babies without Down syndrome who are admitted to a neonatal unit.

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