Imperial College London

Department of Medicine,
Imperial College London,
Section of Neonatal Medicine
4th Floor, Chelsea & Westminster Hospital,
369 Fulham Road,
London SW10 9NH

Tel: +44 (0) 20 3315 5102; Fax: +44 (020) 3315 8050
n.modi@imperial.ac.uk

Neena Modi MB ChB MD FRCP FRCPCH FRCPE
Professor of Neonatal Medicine / Honorary Consultant

Dear Colleague

European Neonatal Benchmarking and Evaluation Programme (eNewborn®)

We are writing to you in your capacity as UK Neonatal Collaborative Lead for your Neonatal Unit, to invite you to participate in an exciting benchmarking and evaluation programme across Europe (eNewborn®) led by Professor Dominique Haumont, University of Brussels. The initial phase will focus on babies ≤32 weeks' gestation.

With your agreement anonymised Neonatal Dataset variables from the National Neonatal Research Database will be forwarded to the new Belgian platform, eNewborn®, at info@enewborn.org. The list of variables is shown in the attachment to this letter. No patient, neonatal unit or neonatal network identifiers will be included. Neonatal Units and Networks will be assigned a unique "eNewborn®" code. You will be able to view benchmarking outputs and access your anonymous patient list and data items on a dedicated web platform (https://www.enewborn.org).

You may choose to participate in benchmarking at the level of Neonatal Unit, Neonatal Operational Delivery Network, Nation (Scotland, Wales, England), or country (UK). Benchmarking at Neonatal Operational Delivery Network level will require participation by all Neonatal Units within the Network.
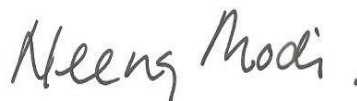
UK Research Ethics approval is currently being sought. Please note that under National Research Ethics regulations NHS Research and Development Office approval is not required. Any publications arising from this initiative will be authored *"on behalf of the eNewborn® European Neonatal Benchmarking and Evaluation Programme". Y*ou and your Neonatal Unit and Network (if applicable), will be listed in all outputs.

Please complete and return the attached form by post or scanned email whether or not you wish to participate so that we have a clear response. Do not hesitate to get back to us if you have any queries.

With kind regards

Mark Turner
Senior Lecturer in Neonatal Medicine
University of Liverpool
Chair, European Network of Paediatric
Research at the EMA
mark.turner@liv.ac.uk

Neena Modi
Professor of Neonatal Medicine
Imperial College London
Director, Neonatal Data Analysis Unit

n.modi@imperial.ac.uk

Dominique Haumont
Professor of Neonatal Medicine
St Pierre University Hospital Brussels
Lead, eNewborn®

dominique_haumont@stpierre-bru.be

European Neonatal Benchmarking and Evaluation Programme (eNewborn®)

I agree as indicated below to the data variables shown in Appendix A being included in the UK and European Neonatal Benchmarking and Evaluation Programme (eNewborn®):

- at Neonatal Unit level   Yes   No

- at Neonatal Network level*   Yes   No

- at National Level   Yes   No

- at UK level   Yes   No

*Neonatal Networks will only be included in bench-marking if all Neonatal Units within a UK Operational Delivery Network indicate they wish to participate.

I understand that

- Data will be included on an annual basis commencing with all neonatal unit admissions of infants born ≤32 weeks gestation in 2014
- No patient, neonatal unit or neonatal network identifiers will be included
- Neonatal Units and Networks will be identified by unique "eNewborn®" codes assigned by the Neonatal Data Analysis Unit
- Data submitted will not be utilised for any purpose other than benchmarking and associated publications
- Data submitted will not be transmitted to any other party
- Data submitted to the eNewborn® Benchmarking Programme will be destroyed should the Programme be terminated
- Data submission to the eNewborn® Benchmarking Programme will only commence following approval by the UK Research Ethics Service

Neonatal Unit Name   _____

Neonatal Unit Postcode   _____

Neonatal Network   _____

Name (UK Neonatal Collaborative Lead) _____

Signature   _____

Date   _____

Please return by post or scanned email to Richard Colquhoun, Manager, Neonatal Data Analysis Unit, Imperial College London, Chelsea and Westminster Hospital, 369 Fulham Road, London SW10 9NH (r.colquhoun@imperial.ac.uk)