



eNewborn


International Neonatal Research Database

Reunião do Grupo do Registo Nacional do Recém-nascido de Muito Baixo Peso
Coimbra, 13 de outubro de 2021




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eNewborn



In 2014, Professor Dominique Haumont (Saint Pierre University, Brussels) established eNewborn to support benchmarking across Europe.

This platform obtained anonymised data on admissions of newborns less than 32 weeks gestation to neonatal units.

Primarily but not exclusively across Europe – 300 neonatal units from 10 countries.

Professor Neena Modi (Imperial College London) subsequently joined her as a co-director.

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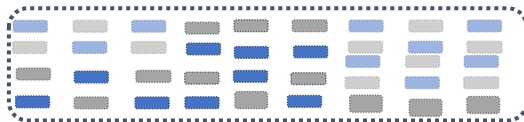


Professor Dominique Haumont has retired from clinical practice and eNewborn has moved to Imperial College London, managed by Professor Neena Modi (Director of Neonatal Data Analysis Unit, Imperial College London).

Legacy data has been safely transferred from Belgium to Imperial College London, including portuguese data from 2010 to 2017.

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Neonatal units across the world



International outputs



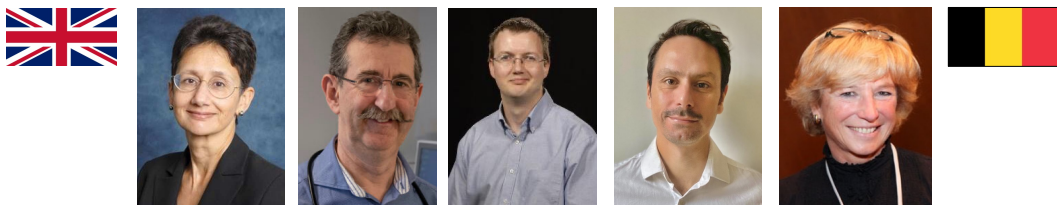
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Management Group:

Data quality assurance, curation and general management



Neena Modi, Mark Turner, Alex Bottle, Ricardo Ribas, Dominique Haumont

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International Investigator Group:

Access agreement, governance and research

Meetings every 3-6 months.

1st meeting at December 8th 2020 (online).

- Mark Adams, Switzerland.
- Ana Cristina Freitas, Portugal.
- Janusz Gadzinowski, Poland.
- Georgios Mavrogeorgos, Greece.
- Mohammadbagher Hosseini, Iran.
- Jan Smisek, Czech Republic.
- Jacques Sizun, France.
- Wolfgang Boehm, Luxembourg.
- Fermín García Muñoz, Spain.
- Gunnar Naulaers, Belgium.



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International Advisory Group:

Independent group that provides horizon scanning, advice and guidance.

Does not dictate the way in which eNewborn operates

Do not have privileged access to eNewborn data

Ms. Silke Mader, CEO of EFCNI.
 Professor Charles Roehr, President of the ESPR
 Professor William Tarnow-Mordi, Clinical Trials Unit of the University of Sydney;
 Professor Vincent Jaddoe, Director of the Generation R Longitudinal Cohort Study, Erasmus University;
 Technical and corporate representatives from Bayer International



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Established as a UK National Research Ethics Service approved database.

Individual data sharing agreement with Imperial College London.

Secure data storage and processing location at Big Data and Analytical Unit (BDAU) at Imperial College London (ISO 27001 accredited).

No data can leave BDAU.

Approval to anonymized data analyses held by International Investigator Group.

Any contributor has the right to refuse data use for specific research.

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Anonymised data. Protocol with core dataset of variables is being made.

Bulk upload by Secure File Transfer or data entry directly through eNewborn portal.

Regular data upload, ideally monthly or quarterly

Can we move towards this goal...?

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Interactive benchmarking outputs in a public online platform.

Each country will be able to compare itself with global data.

Country identification is confidential.

Parent information in different European languages.



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No charges for participation in benchmarking.

Resourced through cost-recovery from research projects by external investigators.

Start-up funding has been received from UK National Institute for Health Research, European Health Data Network, Bayer International and Chiesi Pharmaceuticals.

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Real-world data for real patient benefit

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