

News release

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A global roadmap to address birth defects at the local level

A pioneering resource to help tackle birth defects, particularly in low and middle income countries (LMICs), is now fully available free and online to health and policy professionals and patient groups across the globe.

The PHG Foundation Health Needs Assessment Toolkit for Congenital Disorders (also known as birth defects), is a comprehensive database, information resource and roadmap to creating essential services in this neglected area. For the first time, health professionals in LMICs have access to a systematic approach to help them demonstrate the need in their regions and to make the evidence based case to build effective and equitable services to address that need.

Throughout the first part of 2012, the PHG Foundation has been releasing the Toolkit topic areas updated with feedback from pilot users. In July, they released the final four of the 17 topics areas.

The full topic list is:

- Down's syndrome
- Neural tube defects
- Orofacial clefts
- Health services
- Preconception care and screening
- Prenatal services
- Newborn screening
- Congenital heart disease
- Congenital hypothyroidism
- Sickle cell disease
- Thalassaemias
- Rhesus haemolytic disease of the newborn
- Glucose-6-phosphate dehydrogenase deficiency
- Fetal alcohol spectrum disorder
- Teratogens
- Congenital rubella
- Congenital syphilis

Access to the Toolkit is at www.bornhealthy.org/toolkit, where users are asked to register for this free resource.

The PHG Foundation Toolkit Development Team has been working closely with pilot groups in three countries in South America – Brazil, Argentina and Uruguay – to improve the usability of the Toolkit. The latest iteration was demonstrated at the recent Brazilian Congress of Medical Genetics 2012 in Porto Alegre, Brazil.

Dr Luis Nacul, who led the early development of the Toolkit, said after the conference, *"The space given to the Toolkit at the conference was extraordinary and demonstrates it is very much part of the agenda in Brazil and in some neighbouring countries, with the potential of high impact growing."*

Dr Maria Teresa Sanseverino, from the Servico de Genetica Medica Hospital de Clinicas de Porto Alegre, who was part of the Brazilian pilot and is continuing to use the Toolkit to develop preconception services in Porto Alegre, said at the conference *"I do not think people realise the huge impact the Toolkit is having in Brazil. Already it is going long way to bring about improvements in services for the care and prevention of birth defects."*

The PHG Foundation is now working to extend adoption of this innovative resource to other countries. The Foundation has recently been awarded UKIERI funding to work with Dr Anita Kar, Director at the Interdisciplinary School of Health Sciences at the University of Pune, India. Using the Toolkit, they plan to carry out a health needs assessment for birth defects in an urban population in Maharashtra state.

Dr Kar said *"With the Toolkit, data regarding India has been brought together to show the enormous, but largely invisible problem of birth defects. Every year, thousands of children are born in India with birth defects. The Toolkit is helping us get to the heart of how to review existing services and prioritise the implementation of new services in order to improve population health in the region."*

ENDS

Notes:

The Health Needs Assessment Toolkit for Congenital Disorders is completely free to use and is available to use at www.bornhealthy.org/toolkit

The Toolkit was developed by the PHG Foundation, an independent, international, non-profit organisation working to achieve the responsible and evidence-based application of biomedical science for health. The Foundation recognises the invaluable support of Costello Medical Consulting in the development of the Toolkit.

Members of the Toolkit Development Team are available for interview. Please contact Rebecca Bazeley rebecca.bazeley@phgfoundation.org or +44 (0)7505092081