Global Birth Defects App for Description and Coding of Birth Defects

OVERVIEW

Background
Surveillance systems and pregnancy cohort studies working in low resource environments have difficulty in obtaining accurate information about congenital anomalies (birth defects). The Zika epidemic has further emphasised the need for better birth defects surveillance systems in these settings. In response to this problem, the International Committee for Congenital Anomaly Surveillance Tools (comprising members from Europe, Latin America, Africa, Asia and the USA: https://globalbirthdefects.tghn.org/about-us/steering-committee/) is developing an App to facilitate the accurate description and coding of birth defects. Funding is provided from the EU H2020 funded ZikaPLAN project grant agreement No 734584. Access to the App will be managed via https://globalbirthdefects.tghn.org/download-birth-defects-surveillance-app/

Main Purpose of the App
To provide a companion tool that can be used by a wide range of health professionals contributing to birth defect surveillance and research in low resource environments. It will assist with the description and coding of externally visible birth defects during the neonatal period. It is not intended to replace referral of the baby for clinical diagnosis, or to inform care options requiring clinical input.

Target Audience
Healthcare professionals including doctors, nurses and midwives working in hospitals contributing to birth defect surveillance and pregnancy cohort studies. The main target is low resource environments lacking diagnostic capability, but wider use is possible particularly for training purposes.

Description of the App and how it functions
The App, for mobile phones and tablet devices, will function in both Android and iPhone operating systems. It will be available for download in the Android Play Store and Apple App Store. Internet access will be needed for downloading and registration of the user, but not operation of the App.

The App contains images of major externally visible birth defects, with definition and ICD10 code with RCPCH extension. The App also contains existing video material on the newborn examination (provided by WHO-TDR), information on Congenital Zika Syndrome and limited other syndromes. The App will be made available in English, Spanish and Portuguese initially. The App is compatible with the WHO Atlas of Selected Congenital Anomalies, but the App contains a wider range of major anomalies and also guides the exclusion of minor anomalies.

As the user taps the screen, the App takes him/her through a series of body regions and images of major externally visible birth defects, to identify the most likely correct description and ICD code. Please see the illustration of the Congenital Complete Absence of Upper Limb Pathway - four Screens.

The App exists in two versions:
The Basic Version designed for use by persons with an interest in understanding/improving birth defect diagnosis or coding, including for training purposes. This version does not allow for recording of data. A registration code will be available on the Global Birth Defects website.

The Surveillance Version is an extension of the basic version to allow recording of anonymous data for each baby. A unique registration code for each surveillance system operating the App will be issued. After a choice of congenital anomaly has been made, the user can use the “Record Defect” button to keep a record of the text description, code, and limited other information. These data can be uploaded from the phone/tablet to a secure server, and downloaded by the surveillance system data centre. For the purpose of field testing, the surveillance version has been modified to have photo taking ability.

Current state of App development process
The beta version of the App is ready for testing. Phase 1 of testing will be expert review of the Basic Version. Phase 2 will be field testing of the Surveillance version. The Basic Version will be launched in September 2019 and the Surveillance version soon thereafter.

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