



## Scorecard for spina bifida research, prevention, and policy – A development process



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### ABSTRACT

Spina bifida is a serious and largely preventable neural tube birth defect and an important cause of mortality and lifelong disability. The People and Organizations United for Spina Bifida and Hydrocephalus (PUSH!) Global Alliance was formed in 2014 to provide a common platform for various organizations worldwide to raise the visibility of spina bifida and hydrocephalus. In its formative phase, the alliance recognized that in order to accelerate surveillance, prevention, and care for these conditions, there was a need to provide an evidence-based assessment of how nations are performing in specific areas. In this paper, we describe the impetus for, and the process of, developing country-level scorecards for spina bifida surveillance, prevention and care. The PUSH! Executive Committee formulated a comprehensive list of six actionable indicators measuring availability of published studies on population-based folate studies; surveillance of prevalence and mortality; prevention-based policies; access to care; and quality of life associated with spina bifida. Rubrics were developed to score each country on the aforementioned indicators. Country scores were pooled across each indicator and the composite scores ranged between zero and three if there was a need for improvement, four and five if they were in good standing, or six for an excellent status. The scorecard included country-specific recommendations assimilated from the literature and published guidelines to aid policy makers in accelerating surveillance and prevention, and improving the care and quality of life indicators. For comparison, country-level scorecards were grouped by WHO-regions. Score cards were made available publicly through the website "[www.pu-sh.org](http://www.pu-sh.org)".

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### 1. Introduction

The proportion of under-five deaths due to birth defects is increasing (WHO, 2016) and it is well-established that birth defects are one of the leading causes of perinatal, neonatal, infant and under-five mortality (WHO, 2016; GBD 2013 Mortality and Causes of Death Collaborators, 2015). Birth defects cannot be overlooked by countries that are aiming to reach the health-related targets under the Year 2030 - Sustainable Development Goals (SDG) (Murray, 2015; Sustainable Development Goals, 2015). Historically, it has been difficult to garner support for national programs on birth defects surveillance and prevention, or for improving care and quality of lives of the affected persons, in low- and middle-income countries due to competing healthcare priorities, limited budgets, and little to no available data on the burden of birth defects

(Christianson et al., 2006; Lawn et al., 2014). The People and Organizations United for Spina Bifida and Hydrocephalus (PUSH!) Global Alliance formed in 2014 to accelerate action to improve spina bifida (the term used in this paper to refer more specifically to myelomeningocele) and hydrocephalus surveillance and prevention, while also advocating for improving care and quality of life for those living with these conditions. Although PUSH!'s work encompasses two conditions, spina bifida and hydrocephalus, in this paper, we only discuss the efforts of PUSH! to measure and publicize country-level efforts related to spina bifida through development and publication of the Spina Bifida Scorecard (SBSC).

Spina bifida is a mostly preventable, life-threatening neural tube birth defect (NTD), associated with severe motor, sensory, and structural malformations that can lead to life-long disability, and a high risk of death among those affected (Botto et al., 1999; Sutton et al., 2008; Flores et al., 2014). Spina bifida is associated with the loss of human potential and with significant economic and social costs (Grosse et al., 2016; Liptak et al., 2011). Worldwide, 300,000 NTD-affected births are

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estimated to occur every year, about half of which constitute spina bifida (Christianson et al., 2006).

A systematic analysis by Zaganjor et al. (2016) on the worldwide prevalence of spina bifida has shown that many countries lack data. Among those that had data, prevalence estimates varied widely by socio-economic status of countries. The review also showed a lack of accurate and timely data to inform policy decisions related to prevention and care, while underestimating the total burden by excluding cases associated with stillbirths, miscarriages, or planned abortions.

There has been unequivocal empirical evidence that the majority of spina bifida cases can be prevented by ensuring optimal intake of folic acid (400 mcg/day) by mothers during the periconceptional period (MRC, 1991; Czeizel and Dudas, 1992; Berry et al., 1999). Folic acid interventions have been shown to significantly reduce the prevalence of spina bifida in several countries (Botto et al., 2006; Bhutta et al., 2013; Castillo-Lancellotti et al., 2013; Bhutta et al., 2014; Atta et al., 2016). Based on the WHO recommendation, most countries recommend 400 mcg/day of folic acid for women of childbearing potential (Gomes et al., 2016). Fortification of staple foods is a cost-effective population-based intervention for prevention of spina bifida. Economic analysis from the United States (US) showed that during the year 2014, mandatory fortification resulted in 767 fewer cases of babies born with spina bifida, averting total medical care costs of 603 million US dollars, and the cost-benefit ratio of prevention achieved through mandatory fortification to be extremely high (~1:150) (Grosse et al., 2016). Despite this knowledge, as of 2015, only 58 countries worldwide had mandatory fortification policies aligning with the WHO recommendations (Arth et al., 2016).

In 2015, the WHO released evidence-based guidelines for optimal serum and red blood cell (RBC) folate concentrations in women of reproductive age for estimating the risk of NTD in the population (Cordero et al., 2015; Crider et al., 2014). Accordingly, population-level RBC folate concentrations need to be >400 ng/mL (906 nmol/L) in women of reproductive age for preventing a majority of spina bifida, and this level can be used to assess folate deficiency (WHO, 2015). However, most low- and middle-income countries do not conduct regular blood folate surveys to determine the nutritional status of women for optimal pregnancy outcomes.

Factors affecting care and quality of life of people living with spina bifida vary widely by country, including the number of neurosurgeons available to provide surgical interventions, the availability of healthcare services and equipment, and a nation's commitment to support the United Nations (UN) Convention on the Rights of Persons with Disabilities. With developments in surgical treatments, it has been possible to reduce spina bifida mortality; however, there is still a lack of parallel progress in efforts to provide optimal healthcare and to improve the quality of life among those living with spina bifida, even in high-income countries (Bakaniene et al., 2016).

PUSH! developed the country-level scorecards to make evidence-based information on spina bifida and hydrocephalus prevention and care easily accessible to policy makers, health care professionals, and advocates to help them translate opportunity into political will and action. In this paper, we describe the impetus for, and process of, development of the spina bifida component of the Score Card (the Spina Bifida Score Card, or SBSC). SBSC provides easily understandable measures of the current status of research and prevention, care and quality of life at both country- and WHO-regional levels, a first-step in filling the information gap to help guide and enable countries to act.

## 2. Impetus and conceptual basis for SBSC

There are many advocates, individuals, and civil society organizations worldwide, who are dedicated to reducing the burden of birth defects generally, and spina bifida specifically, and to ensuring that people living with spina bifida receive the care and quality of life support they need. PUSH! provides a platform to impact change. In its formative

phase, PUSH! Global Alliance founding organizations (Table 1) and its steering committee (Table 2) noted the following major impediments to improving spina bifida prevention and care: 1) lack of current and reliable data on prevalence needed to advocate for prevention and care; 2) lack of cumulative knowledge of national policies, commitments, and interventions to improve prevention and care; and 3) lack of awareness and advocacy efforts about quality of life issues for those who live with spina bifida. These factors provided the rationale to develop a standardized scorecard with benchmarks and data comparable across countries and within regions. Given the high toll of spina bifida in low- and middle-income countries, where limited resources thwart surveillance, research, and prevention, the need to provide an objective assessment tool to initiate and promote dialogue at the national level was apparent. The timeline tracking the formation of the PUSH! Global Alliance, drafting of scorecard framework, and development and dissemination of scorecards is presented in Fig. 1.

## 3. Methods

### 3.1. Objective of SBSC

The SBSC aims to quantify country-level performance in selected indicators for surveillance, prevention, and care, and provides recommendations in a clear and succinct format for actionable responses. It communicates burden and provides a platform for both national and international entities, and compares progress with other countries.

### 3.2. Data and Indicators for SBSC

SBSC was developed by the PUSH! Executive Committee (Table 3) using published data from several peer-reviewed articles and official reports from reputable sources. Comprised of clinicians, public health professionals, and epidemiologists, and representing various reputable non-profit and academic institutions, the committee identified areas for examination and developed six actionable measures to rate country level performance:

1. Availability of published studies on folate status among women of reproductive age

**Table 1**

PUSH! Global Alliance founding organizations (in alphabetical order).

1	Bethany Kids
2	Boston Children's Hospital Department of Neurosurgery & Boston Children's Hospital Global Health Program, Boston, Massachusetts
3	U.S. Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Atlanta, Georgia <sup>a</sup>
4	Center for Spina Bifida Prevention, Department of Epidemiology, Rollins School of Public Health, Emory University, Atlanta, Georgia
5	Cornell University, Division of Nutrition, Ithaca, New York
6	CURE Hydrocephalus – CURE International
7	Food Fortification Initiative, Atlanta, Georgia
8	Foundation for International Education in Neurological Surgery
9	Global Alliance for Improved Nutrition Food Fortification
10	Hydrocephalus Association
11	International Federation for Spina Bifida and Hydrocephalus
12	March of Dimes Foundation
13	Miami Children's Hospital Haiti Healthy Kids
14	Pediatric Hydrocephalus Foundation
15	Penn State University, Center for Neural Engineering, University Park
16	Project Healthy Children
17	Sophie's Voice Foundation
18	Spina Bifida Association
19	Sprinkles Global Health Initiative – The Hospital for Sick Children
20	Sunnybrook Health Sciences Center
21	Tufts University School of Medicine and Department of Child Development Lewis Rhodes Laboratories

<sup>a</sup> U.S. Centers for Disease Control and Prevention, National Center for Birth Defects and Developmental Disabilities serve in an advisory, non-voting capacity.

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