

2017 PUSH! Global Alliance – Country Report Card: UNITED KINGDOM OF GREAT BRITAIN AND NORTHERN IRELAND

Spina Bifida Score: 4 ★

Hydrocephalus Score: 3 ★

Spina Bifida - SCORE KEY

Excellent = 6 stars

Good = 4-5 stars

Improvements needed = 0-3 stars

Hydrocephalus - SCORE KEY

Excellent = 5 stars

Good = 3-4 stars

Improvements needed = 0-2 stars

UNITED KINGDOM OF GREAT BRITAIN AND NORTHERN IRELAND	Folate studies	Prevalence Data	Mortality Data	Prevention	Access to Care	Quality of Life
SPINA BIFIDA	X	★ ¹	X	★	★	★
HYDROCEPHALUS	N/A	★ ¹	X	NO DATA	★	★
RECOMMENDATIONS	Develop surveillance capacity to periodically monitor blood folate status in women of reproductive age	Continue surveillance and monitoring of spina bifida and hydrocephalus prevalence and mortality, over time and by population clusters (i.e., high risk groups). Create prevention targets and benchmarks for trends, and report progress	Create surveillance systems in multiple local and regional hospitals, and publish prevalence and mortality rates for spina bifida and hydrocephalus	Spina Bifida: Periodically evaluate coverage and effectiveness in mandatory fortification, and implement required remedial measures to address gaps	Improve evidence-based treatment and post-surgical community-based support and follow-up, with quality control protocols	Ensure that programs and policies supporting the rights of persons with disabilities are implemented and enforced

Additional Information:

United Kingdom is a Full Member of the European network of population-based registries for the epidemiologic surveillance of congenital anomalies (EUROCAT) and a member of the International Clearinghouse for Birth Defects Surveillance and Research

¹ Regional population-based surveillance (South west England, Northern England, Thames Valley, East Midlands and South Yorkshire, Wales, Wessex)



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TECHNICAL NOTES

PUSH! Research Methodology

The purpose of PUSH! Global Alliance Report Card Project is to provide a summary report of status of spina bifida and hydrocephalus at country-level, and by WHO-defined regions, with the best available and most current information by following indicators: a) availability of data (e.g., prevalence, mortality, folate studies); b) prevention; c) access to care; d) quality of life. Members of PUSH! Executive Committee and other expert advisors contributed in formulating credible, actionable indicators for exploration in each of the content areas. For each indicator, three levels of benchmarks were identified to help stratify progress into three scoring criteria (full star, half star, no star). Two independent searches per indicator per data source were conducted. Data sources included published studies retrieved through PubMed search engine, Food Fortification Initiative, WHO Global Database on the Implementation of Nutrition Action, and USAID, Millennium Development Goals Track, Neurology Atlas (WHO, 2004), and United Nations Convention on the Rights of Persons with Disabilities. PubMed searches for research studies on prevalence and mortality for spina bifida and hydrocephalus were conducted from 2000 onwards, and folate studies from 1990 onwards. The report cards deliver comprehensive information to Ministries of Health or other national level organizations on current status and need for spina bifida and hydrocephalus research, prevention, and policy in their countries.

Scoring Criteria

Folate Studies Data

1 Star = WHO data OR published population-based or large hospital-based data on RBC or serum folate levels (Publication Year: 1990 or upwards); **1/2 Star** = Small studies on RBC or folate levels (Publication Year: 1990 or upwards); **X** = No studies on RBC or serum folate levels studies (Publication Year: 1990 or upwards)

Prevalence Data

1 Star = Published population-based or large hospital-based prevalence data on live births, still births, elective terminations (Publication Year 2000 or upwards) OR existing birth defects surveillance system; **1/2 Star** = smaller hospital-based prevalence studies on live births, still births, elective terminations (Publication Year 2000 or upwards) OR small regional surveillance / official reporting; **X** = No published prevalence studies (Publication Year 2000 or upwards).

Mortality Data

1 Star = Published population-based or large hospital-based mortality data (Publication Year 2000 or upwards); **1/2 Star** = Published smaller hospital-based mortality studies, small regional surveillance / official reporting (Publication Year 2000 or upwards); **X** = No published mortality studies (Publication Year 2000 or upwards).

Prevention

Spina Bifida: **1 Star** = Mandatory folic acid fortification policy is implemented and is aligned with WHO standards; **1/2 Star** = Voluntary folic acid fortification policy is implemented and is aligned with WHO standards; **X** = No mandatory or voluntary folic acid fortification policies.

Hydrocephalus: **1 Star** = On track to, or has achieved MDG 4 AND MDG 5 targets; **1/2 Star** = On track to, or achieved MDG 4 OR MDG 5 targets; **X** = MDG 4 and 5 targets not met or on track.

Access to Care

1 Star = Minimum of more than 1 neurosurgeon per 1,000,000 population; **1/2 Star** = 0.2-1 neurosurgeons per 1,000,000 population; **X** = 0-0.2 neurosurgeons per 1,000,000 population.

Quality of Life

1 Star = Signed AND ratified the UN Convention on the Rights of Persons with Disabilities; **1/2 Star** = Signed only the UN Convention on the Rights of Persons with Disabilities; **X** = Neither signed nor ratified the UN Convention on the Rights of Persons with Disabilities.

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Recommendations for Indicators

The Global Report Cards reflect specific recommendations based on how individual countries scored and different recommendations were given depending on how countries scored in each area. Below is a complete list of the recommendations for each indicator. Please note: The recommendations provided for each individual country are for information purposes only and are not meant to be definitive or exclusive of other actions. PUSH! recognizes the specific circumstances of each individual country may vary.

Recommendations for FOLATE STUDIES (spina bifida)

- **No star:** Develop surveillance capacity to periodically monitor blood folate status in women of reproductive age
- **Half star:** Enhance surveillance to assess blood folate status among women of reproductive age at national levels
- **Full star:** Continue national surveillance of blood folate status among women of reproductive age

Recommendations for DATA for Prevalence & Mortality (Spina Bifida and Hydrocephalus)

- **No star:** Create surveillance systems in multiple local and regional hospitals, and publish prevalence and mortality rates for spina bifida and hydrocephalus
- **Half star:** Enhance surveillance efforts and conduct population- or large hospital-based studies, and publish prevalence and mortality rates for spina bifida and hydrocephalus at national levels
- **Full star:** Continue surveillance and monitoring of spina bifida and hydrocephalus prevalence and mortality, over time and by population clusters (i.e., high risk groups). Create prevention targets and benchmarks for trends, and report progress

Recommendations for PREVENTION (Spina Bifida)

- **No star:** Explore opportunities for mandatory fortification policies for staple foods, and implement or enhance supplementation programs in the interim to reach reproductive aged women
- **Half star:** Undertake coverage and effectiveness studies for existing programs (voluntary fortification / supplementation), and explore opportunities for mandatory fortification policy of staple foods
- **Full star:** Periodically evaluate coverage and effectiveness in mandatory fortification, and implement required remedial measures to address gaps

Recommendations for PREVENTION (Hydrocephalus)

- **No star:** Improve access to peripartum and neonatal care
- **Half star:** Improve access to antenatal care
- **Full star:** Improve management of pre-term labor, including identification of women at risk

Recommendations for ACCESS TO CARE

- **No star:** Increase the number of neurosurgeons in country who can provide care to children and adults with spina bifida and hydrocephalus
- **Half star:** Improve global neurosurgical education and practice (e.g., training, residency, traveling fellowships, supportive partnerships, disease-specific development)
- **Full star:** Improve evidence-based treatment and post-surgical community-based support and follow-up, with quality control protocols

Recommendations for QUALITY OF LIFE

- **No star:** Take the first step to recognize the rights of persons with disabilities. Sign and ratify the UN Convention
- **Half star:** Take the next step to ratify the UN Convention and actively implement and enforce programs and policies supporting the rights of persons with disabilities
- **Full star:** Ensure that programs and policies supporting the rights of persons with disabilities are implemented and enforced

For additional inquiries please contact: push.global.alliance@gmail.com