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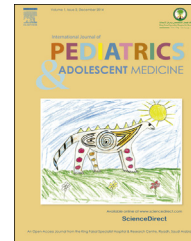


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INVITED REVIEW

Barriers to implementing sustainable national newborn screening in developing health systems[☆]



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Abstract Newborn screening is a comprehensive public health prevention system that seeks to identify newborns at increased risk for certain inherited congenital conditions. Institutionalizing and sustaining this system presents a formidable challenge within developing public health systems often competing with other healthcare priorities and political agendas. We review some of our experiences in overcoming newborn screening implementation challenges and discuss recent efforts to encourage increased newborn screening through support networking and information exchange activities in the Middle East/North Africa and in the Asia Pacific Regions.

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1. Introduction

The term 'newborn screening' generally describes various tests that can occur during the first few hours or days of a newborn's life. These screening tests have the potential for preventing catastrophic health outcomes to newborns and their family when they are properly timed and performed. Newborn dried bloodspot screening (NDBS) is one type of

screening that uses blood collected from the baby's heel, placed onto special absorbent paper, air dried, and transported to a screening laboratory for analysis. The presence of abnormal concentrations of certain biochemical markers can indicate increased risks for the condition of interest and must be confirmed through further diagnostic testing. Other types of NBS include hearing loss and congenital heart defects, among others, but this manuscript focuses on NDBS screening.

To provide national uniformity and equality, NDBS programs are generally part of the national public health prevention system. While in their initial phase, NDBS programs may exist in academic or private settings, and their institutionalization and sustainability at the national level require recognition by the health ministry and integration into the public health system. This recognition can take different forms in different settings ranging from simple recognition statements to full-scale program implementation and support. Although government financing is ideal and assures sustainability, there are successful programs in which full or partial payment is made by the family obtaining the screening service.

NDBS programs function within a comprehensive system that includes education, screening, short-term follow-up, diagnosis, treatment/management, and long-term follow-up/evaluation [1]. The NDBS system is often challenged by economic, political, and cultural considerations. The initiation of NBS in developing health systems, such as many in the Middle East and North Africa (MENA) and the Asia Pacific (AP) regions, has been slow for various reasons, including lack of understanding by the individual as well as family, societal, and financial benefits. All countries with NDBS either have faced or will face challenges in implementing NBS; however, many developing health systems face additional challenges related to the economy, government stability, culture/religion, geography, and health/political priorities [2–6].

The countries in the MENA and AP regions vary widely in size from small countries (e.g., Bahrain, Lebanon, Qatar, Kuwait, New Zealand, and Singapore) to large countries (e.g., Saudi Arabia, Egypt, Iran, Libya, Algeria, China, and Mongolia). Some countries are economically advanced (e.g., Saudi Arabia, United Arab Emirates, Qatar, Kuwait, Australia, Japan, New Zealand, and Singapore), whereas others are economically developing (e.g., Iraq, Iran, Syria, Jordan, Morocco, Libya, Algeria, Yemen, Philippines, Indonesia, Sri Lanka, and Vietnam). Out-of-hospital births remain a challenge in Bangladesh (80%), India (61%), Philippines (62%), Pakistan (80%), Laos (85.7%), Iran (34.4%), Palestine (38.8%) and Yemen (50%) [3,4,6]. Written languages that use character sets not readily understood by outsiders (e.g., Arabic, Chinese, and Thai) also present special challenges, particularly to experts on developed programs who cannot easily communicate their experiences or share educational materials. Despite these variabilities and challenges, NDBS champions continue to press for progress in the more progressive developing health systems in both regions [2–6].

Historically, successful NDBS has developed from the efforts of an interested individual or group of individuals concerned with improving the health outcomes for newborns and their families. In limited cases (usually in small

countries, such as Singapore and Hong Kong), the NDBS program has developed as a government service. However, academic and hospital initiatives have become more common. Without recognition of the importance of NDBS by the health ministry, these initiatives have often remained isolated and have exhibited slow progress. Their institutionalization at the national level invariably requires intersection with government public health activities. Sometimes, these efforts have taken years to develop into a comprehensive system that adequately serves all newborns. Success in the development and institutionalization of NDBS has typically resulted from the perseverance of dedicated leaders who work to gain the required expertise in NDBS medical and laboratory science and whose perseverance results in overcoming the political, cultural and economic challenges [7].

Through our efforts in working with individuals and groups seeking to begin and improve NDBS in both developed and developing health systems, we have identified four strategic elements useful for developing a successful and sustainable NDBS program. These include the following: (1) identifying and nurturing strong leadership with the goal of educating others, designing and carrying out pilot studies to obtain data for health policy development, and gathering program support from potential stakeholders (parents, professionals, and policymakers); (2) initiating strategic advocacy initiatives targeted at providing policymakers, health professionals and the general public with a basic understanding of the operation and value of NDBS; (3) developing and maintaining strong collaborations between NDBS stakeholder groups (government organizations, non-government organizations, and individuals) in planning and implementation; and (4) developing innovative and sustainable financing strategies.

In this manuscript, we briefly summarize the current status of NBS efforts in a large part of the developing world (MENA and AP), review some of the challenges associated with implementing and sustaining NDBS in a developing healthcare environment, and discuss some example approaches and experiences in overcoming internal barriers to NBS implementation. Whenever possible, we provide examples of successful NDBS program activities, acknowledging that there are many other examples of success that are not noted here.

2. Screening in the Middle East/North Africa and the Asia Pacific regions

Table 1 summarizes selected demographic data for the countries in the MENA and AP regions with developing NDBS systems. These data are the latest available from the World Health Organization (WHO) and provide comparisons of population totals, annual births, gross national income, fertility rates, infant mortality rates and percentages of government budgets allocated for health [8–10]. A summary of published NDBS screening data in the two regions is also given. Accurate data from developing programs are sparse, and the data listed may not be current, particularly that for MENA [2–4,6].

It is interesting to compare the percentages of government expenditures for health in 2000 and 2008 because this

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