

Initiating Newborn Screening in Developing Countries: Challenges and Opportunities

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Objectives

- Discuss the **challenges** experienced by developing countries in initiating newborn screening as part of the national health system.
- Present **strategies** that developing countries may use in identifying and overcoming barriers to successful newborn screening.

Challenge No 1

Getting Started - Need for Dedicated Team

- One person cannot do this!
- Identify the team players – doctors, nurses, midwives, parents, public health officials....
- Involve all stakeholders

Decide on Strategies as a Team

Challenge No 2

Set short term, medium term and long term goals

As a TEAM, need for a Clear **SMART** End Goal

- **S**pecific
- **M**easurable
- **A**ttainable
- **R**ealistic
- **T**ime-bound

Challenge No 3

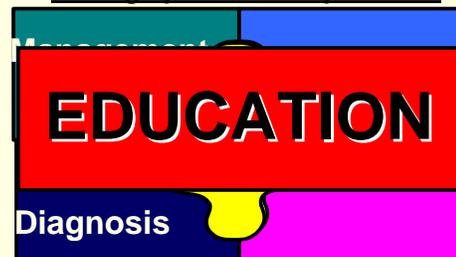
As a TEAM , Choose the Screening Disorder(s) Wisely

- Carefully define the criteria for inclusion– **incidence**, availability of confirmatory tests, availability of treatment, availability of experts, cost of treatment, etc.

NEED FOR PILOT POPULATION STUDIES

Challenge No 4

Setting up Practical Operations



Challenge No 4

As a TEAM, Agree on Flow of Operations

- There are many possible schemes of operations. Learn from other countries and modify to your advantage.
- Responsibilities must be set and agreed upon by key stakeholders.



Define responsibilities and procedures for:

- Advocacy to patients, professionals and to the policy makers
- Collection of samples and transport to laboratory
- Analysis of samples
- Transmittal of results to physicians and parents
- Recall of patients with positive screens
- Treatment of patients
- Monitoring of positives cases



Challenge No 5

Develop sustainable financing

Most Ideal – Government

Main Problem in developing countries – competes with other priorities of the Department/Ministry of Health

Typical Scenario in developing countries – Fee for Service paid by the family



Develop a realistic cost estimate

Costs should include the following:

- Testing (reagents)
- Transmittal of samples (mail/courier service)
- Result reporting
- Immediate Recall/Long term Follow-up (outcome monitoring)
- Advocacy / Public relations
- All associated administrative expenses



Challenge 6

Ensure System Quality (Monitoring and evaluation)

- Laboratory Management
- Recall of patients with positive screens
- Management of patients with a confirmed diagnosis
- Monitoring of saved babies
- Other system components – program administration, data management, etc.



Challenge No 7

Getting Support from the Health Professionals and General Public



Challenge No 8

Reaching the Remote Areas



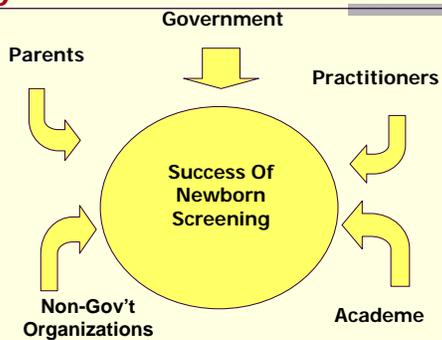
Challenge No 9

Work with the Government

- Solicit government support from the very beginning of planning and implementation.



Challenge No 10 System wide Communication



Message

Be Patient!

- Do not expect miracles. Success comes after hard work and patience.



Summary of Challenges

1. Getting Started - Need for Dedicated Team
2. Set short term, medium term and long term goals
3. As a TEAM, choose the screening disorder(s) wisely
4. As a TEAM, agree on flow of operations
5. Develop sustainable financing



Summary of Challenges

6. Ensure System Quality (Monitoring and evaluation)
7. Getting Support from the Health Professionals and General Public
8. Reaching the Remote Areas
9. Work with the Government
10. System wide Communication



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