

*MGH Center for Child and Adolescent Health Policy*

*Evidence Review Group*

*Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children*

***DRAFT – August 27, 2007***  
***Definition of Terms for Evidence Reviews***

<b>Term</b>	<b>Definitions, mainly from Nomination Form</b>
<b><i>Severity</i></b>	Morbidity, disability, mortality Burden of illness (family perspective) Vulnerability to morbidity, disability, mortality
<b><i>Urgency</i></b>	How soon after birth treatment needs to be initiated to be effective (to prevent complications or irreversible damage). Spectrum from life-threatening to immediate to priority.
<b><i>Efficacy</i></b>	Benefit: Extent of prevention of mortality, morbidity, disability. What are the treatment issues that may limit child or family acceptance or adherence?
<b><i>Risks (of screening)</i></b>	False positives, carrier detection, phenotypes with no or little morbidity. Detection or suggestion of other disorders? Association – How strong is the reported relationship between a test result and a disease?
<b><i>Risks (of treatment)</i></b>	Potential medical or other ill effects from treatment
<b><i>Acceptability (Invasiveness)</i></b>	What tests/procedures are required? How acceptable are these tests? Primary newborn screening and confirmatory testing.
<b><i>Availability</i></b>	What is the availability of the (confirmatory) test in clinical practice?