

NBS Stakeholder Group		Ethical and Social Issues Related to the Initiation of Screening	Ethical and Social Issues related to NBS Results				
			True Positive	True Positive (Adult Onset)	False Positive	Carrier	Unclear Result (borderline, age, disease severity)
	Individual Newborn	Benefit/Harms of screening to a newborn?	<ol style="list-style-type: none"> 1. Diagnostic procedures: harms vs benefits? 2. Benefit/Harms of treatment? 3. Psychosocial consequences (label/stigma, insurance, job)? 4. Benefit of early identification 	<ol style="list-style-type: none"> 1. Diagnostic procedures: harms vs benefits? 2. Benefit/Harms of treatment? 3. Psychosocial consequences (label/stigma, insurance, job, uncertain future)? 	<ol style="list-style-type: none"> 1. Diagnostic procedures: harms vs benefits? 2. Benefit/Harms of treatment if started? 3. Psychosocial consequences (label/stigma, insurance, job)? 	<ol style="list-style-type: none"> 1. Diagnostic procedures: harms vs benefits? 2. Benefit/Harms of treatment, if health impacts of heterozygous status 3. Psychosocial consequences (label/stigma, insurance, job)? 4. Reproductive impact of carrier information for the newborn? 	<ol style="list-style-type: none"> 1. Diagnostic procedures: harms vs benefits? 2. Benefit/Harms of treatment if started? 3. Psychosocial consequences (label/stigma, insurance, job, uncertain future)?
	Family	Benefit/Harms of screening to a family?	<ol style="list-style-type: none"> 1. Financial costs and psychosocial benefits/harms of diagnostic procedures? 2. Financial costs and psychosocial harms of treatment? 3. Implications (benefit/Harms) for family of inherited conditions? 	<ol style="list-style-type: none"> 1. Financial costs and psychosocial benefits/harms of diagnostic procedures? 2. Psychosocial consequences (anticipatory interventions, vs anxiety, uncertain future)? 3. Implications (benefit/Harms) for family of inherited conditions? 	<ol style="list-style-type: none"> 1. Financial costs and psychosocial benefits/harms of diagnostic procedures? 2. Psychosocial consequences (anxiety, uncertain future)? 	<ol style="list-style-type: none"> 1. Implications for family of inherited conditions? <ol style="list-style-type: none"> a. Related to future reproductive decisions b. Obligation to inform extended family? 	<ol style="list-style-type: none"> 1. Financial costs and psychosocial benefits/harms of diagnostic procedures? 2. Psychosocial consequences (anticipatory interventions, anxiety, uncertain future)? 3. Implications for family of inherited conditions?
NBS State	1. Resources to implement NBS	1. Resources for short-term	1. Resources for short-term follow-	1. Resources for short-term follow-	1. Should family be informed of carrier	1. Should family be informed of	

	Program	2. Opportunity costs to the state and/or department of health	and long-term follow-up 2. Impact on state services (e.g. Medicaid, public school system)?	up	up	status? a. Gender differences b. Carrier vs. heterozygous with some potential impact 2. Resources for short-term follow-up	unclear results? 2. Resources for short-term follow-up
	Health Care System	1. Additional resources needed as complexity of NBS increases? 2. Opportunity costs for clinical personnel involved in NBS	1. Costs of diagnosis and treatment	1. Costs of diagnosis and (later) treatment	1. Costs of diagnosis and (if started) treatment 2. Opportunity cost to limited number of specialists	1. Costs of diagnosis and (if started) treatment 2. Opportunity cost to limited number of specialists	1. Costs of diagnosis and (if started) treatment 2. Opportunity cost to limited number of specialists
	Population	1. Opportunity costs to society	1. Opportunity costs to society	1. Opportunity costs to society	1. Opportunity costs to society 2. Do excessive false positive results undermine faith in NBS, science, or government?	1. Opportunity costs to society 2. Does knowledge of carrier status affect birth rate and/or incidence of a condition?	1. Opportunity costs to society 2. Do excessive false unclear results undermine faith in NBS, science, or government?