



EHDI Follow Up Workgroup: WorkPlan

Charge: Develop and Distribute best practice follow-up protocols/practice models for population-based identification of children with heritable disorders.			
Objective	Who	What	When
1. Expand Follow up WG to include representatives of EHDI	MPHI, AG	Identify and recruit members to participate in FWG	February 2008
2. Develop and disseminate follow-up protocols/practice models	FWG	Identify protocols/practice models for providing information at time of identification (positive screen, report, etc.)	March 2008
	MPHI	Compile and distribute list of protocols/practice models	
	FWG	Review, discuss and add samples identified to list of protocols/practice models	
	MPHI	Summarize compare and contrast identified protocols; disseminate summary	April 2008
	FWG	Review and discuss summary	May 2008
	FWG	Develop criteria for determining quality, cost and feasibility of replicating protocols/practice models	
	MPHI	Develop/modify assessment tool	
	FWG	Review and finalize assessment tool	June 2008
	FWG	Assess protocols/practice models using assessment tool	
	MPHI	Compile/summarize reviews	
FWG	Formulate recommendations based on reviews (e.g. adapt protocols/practices, recommend protocols/practice models)	July 2008	

A. Promote the use of care plans specific to the needs of children with heritable disorders			
Objective	Who	What	When
2. Develop and disseminate follow-up protocols/practice models (continued)	MPHI	Summarize recommendations	August 2008
	MPHI	Poll states to determine which practices models they would be willing to pilot	
	TBD	Implement selected practice models	August 2008-Y5
	Evaluate or	Evaluate implementation	Y2-Y5
	FWG	Adapt, refine practice models/protocols based on evaluation findings	Y3-5
	R4 Partners	Disseminate protocols and models	Y2-5