



State Systems Follow-up Workgroup –Work Plan

Charge: Identify model state systems that assure linking/referral to services, facilitate surveillance and support communication among programs for children with genetic conditions and their families.

Outcome: One or more models for follow-up systems that assure linking/referral to services, facilitate surveillance, support communication and increase access to services for children with genetic conditions and their families.

Objective	Who	What	When
1. Develop shared understanding of WG purpose	SSFU WG	Provide input on charge & outcome	Completed
	SSFU WG	Finalize charge & outcome	July 2010
	SSFU WG	Reach consensus on terminology	July 2010
2. Identify outcomes of a model state system	SSFU	Review existing models <ul style="list-style-type: none"> • CDC Outcomes for BDR Surveillance • Other outcomes? 	July 2010
3. Delineate different models	SSFU WG	Identify information needed	July 2010
		Describe what is happening currently <ul style="list-style-type: none"> • Nationally • Within states • Consider electronic systems – what electronic systems are states using? How do they play in integrated follow-up? • How do programs communicate and integrate? <ul style="list-style-type: none"> ○ Benefits, efficiencies ○ Barriers, inefficiencies <ul style="list-style-type: none"> ▪ How work through barriers? Inefficiencies? 	
	MPHI	Develop and disseminate survey	August 2010
	SSFU WG	Complete survey	
	MPHI	Compile and summarize survey responses	
SSFU WG	Discuss state system follow-up models		
	Disseminate summary of state systems in Region 4	September 2010	



4. Identify promising practices	SSFU WG	Identify models/protocols for assuring follow-up, surveillance, and communication	August 2010
	MPHI	Collect protocols (written protocols, databases, etc. Prompt for submission with survey)	September 2010
	SSFU WG	Consider protocols for adaptation	
5. Compare and contrast models	SSFU WG	Select 2 conditions to work through – 1 NBS and one BDR	October 2010
		Identify information needed <ul style="list-style-type: none"> • Service system(s) child and family connected to • Service system role • Data points/data system collects • How programs relate to each other • Outcome indicators in an integrated system 	
	MPHI	Develop template to collect information about surveillance, follow-up, communication; track e-systems	
	SSFU WG	Track practice patients through each state system (Table top exercise) <ul style="list-style-type: none"> • Identify other stakeholders to participate in exercise • Test implementation • Identify strengths, weaknesses, “glitches” <ul style="list-style-type: none"> ○ What have other states done to overcome glitches 	November 2010
		MPHI	
	SSFU WG	Discuss results	December 2010
5. Develop systems model(s)	SSFU WG	Formulate recommendations/select strategies	January 2011
	MPHI	Develop protocol	
	R4 States	Pilot protocol	February 2010