

CAH Proposed Registry Data Elements – Demographics Review

	Measure	Answer Type	Measure Answer	Comments from October Meeting	Comments from 11.11.10 Telemeeting
7a	Research studies patient is enrolled	Free text			Measure needs to be in proper English – <b>research studies patient is enrolled in</b>
8	Follow-up Status	Pick List	Active, Inactive-Deceased; Inactive – Lost to follow up; Inactive – Moved to another state not participating in registry; Inactive – Refused follow up; Inactive – Treatment deemed not necessary	Issues This item seems to refer to a specific center. If moves to another center, does center assign new unique ID? How do the two patient records then tie together? Or does new center use old ID? Data complications – patient appears as two unique patients, center specific data is not accurate – shows under old center, while follow-up is occurring at new center	<b>Still needs resolution</b>
9	Has patient been followed by >1 center for this disorder?	Pick List	Missing/unknown data, Yes, No	Group discussed these items together Issues/Questions 1. What is the purpose of this question? 2. Could they be combined? Measure Answers would then be: Missing/Unknown Data, No, Yes with drop down of State and participating centers within state	Kiki – intent of this question is to know where services were provided. Kupper – does obtaining the only the state get at this information? Nancy – what about MN where they are seen by other physicians between visits with Kiki? Kiki suggested keeping it state only so it stays manageable. Linda noted that 1 in 4 patients undergoing reconstructive plasty come through the IU. Those patients could be captured in registry at IU. Linda suggested using the state by state assessment conducted with the workgroup this past spring to list the clinics we know about and have a free text for those we don't. <b>Consensus was to operationalize Linda's suggestion</b>
10	If Patient has been followed by >1 center for this disorder, note in which state these centers were located (enter 99999 if N/A, 88888 if unknown)	Free Text			
12	If patient has been followed by > 1 center for this disorder, what type of provider was treating the patient?	Check Boxes	Missing/unknown data, <list of providers>	Issues/Questions for items 9 through 13: 1. Does center in items 9, 10, 12, refer to centers participating in the registry and 13 non participating centers and all other providers? 2. Is item 12 really about who the primary care provider is/was at the other center? If so, reword "If patient has been followed by >1 center for this disorder, who	
13	Other health services	Check	Missing/unknown data,		Kiki – this is intended to be a broader

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	received by patient	Boxes	<list of providers>	<p>was the primary care provider treating the patient?</p> <p>3. Add other specialists to list of providers: urologist, gynecologist, reproductive endocrinologist, psychologist, psychiatrist, other, specify _____</p> <p>4. Should a question be added to the consent, and the response listed here (Yes/No) granting permission to share within the “consortium (i.e., users of the Information System) without having to specify which centers can share information</p>	<p>health question. Linda – would help to think about where the information will come from. Will the family provide via a form or through the consent process? How will the clinician know? Also, terminology is not patient friendly. <b>Need to reach consensus on addressing this issues.</b></p>

Other: **Change disorder to condition throughout.**