

CAH Proposed Registry Data Elements – Demographics Review

	Measure	Answer Type	Measure Answer	Comments
2	Unique Registry ID	Free Text	Proposed Units (2digFIPS/2digBirth Year/1digCenter/3digAscension)	<p>If use the same formula for CAH as IBEM-IS</p> <ol style="list-style-type: none"> <li>1. Would need a way to know the next available Ascension number. Is this feature built into the platform?</li> <li>2. Is 999 patients enough? Or should we go to 4 digit Ascension</li> <li>3. If leave at 3 digit ascension, should CAH patient numbers begin with 400, leaving IBEM-IS patients to go up to 399</li> <li>4. What about changing the 3 digit ascension to an alpha-numeric or numeric only code that delineates IBEM or CAH, for example I### for IBEM, C### for CAH?</li> <li>5. Is there any added value to establishing an institution number and a clinic number; so U of MN would have a number, followed by a separate number for the IBEM-clinic or a different number for the CAH clinic? This would allow data to be looked at by clinics within an institution, e.g. CAH vs IBEM?</li> </ol>
4	Who consented enrollment in registry?	Pick List	Missing/unknown data, both parents, mother only, father only, guardian	Proposing removing Missing/unknown. Written consent must be available. Proposed adding both guardians (in keeping with both parents, one parent)
	Was assent obtained?	Yes/No		Suggest adding this element
7	Patient is enrolled in other research studies	Pick List	Missing/unknown data, no yes-other Region 4 emergency study, yes – other Region 4 clinical/medication studies, yes – other Region 4 psychosocial studies, yes – studies related to this disorder not conducted through Region 4, yes – other research.	<p>Suggestions</p> <ol style="list-style-type: none"> <li>1. Change “disorder” to “condition”, here and throughout</li> <li>2. Delete other from all of the options, except the final “other”. Having other precede the type of study implies that this registry is one of those studies.</li> <li>3. Delete Region 4 – intent is to go national, and Region 4 does not have any currently active studies</li> <li>4. Change Pick List to Check Box, to allow for multiple response</li> <li>5. To last item yes – Other; add Specify and free text</li> </ol>
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	<p>Issues</p> <p>This item seems to refer to a specific center.</p> <p>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</p>

	Measure	Answer Type	Measure Answer	Comments
			follow up; Inactive – Treatment deemed not necessary	accurate – shows under old center, while follow-up is occurring at new center
9	Has patient been followed by >1 center for this disorder?	Pick List	Missing/unknown data, Yes, No	<p>Group discussed these items together</p> <p>Issues/Questions</p> <ol style="list-style-type: none"> <li>1. What is the purpose of this question?</li> <li>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</li> </ol>
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>	<p>Issues/Questions :</p> <ol style="list-style-type: none"> <li>1. Does center in items 9, 10, 12, refer to centers participating in the registry and 13 non participating centers and all other providers?</li> <li>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 &gt;1 center for this disorder, who was the primary care provider treating the patient?”</li> </ol>
13	Other health services received by patient	Check Boxes	Missing/unknown data, <list of providers>	