

CAH Proposed Registry Data Elements – Demographics Review

	Measure	Answer Type	Measure Answer	Comments (11.11.10)
17	Racial Category			<b>Consensus – Add mixed race</b>
21	Is primary caregiver proficient in written English?			<p>Linda – how will we assess this? Is this something you are asking to know what materials they need? Should we collect data on primary language instead? Linda – we can’t consent them to participate unless we provide written consent in their primary language. Hmong, Russian, Somali, Spanish in MN, IN Spanish, KY Spanish. Track at refusal point, otherwise we won’t get this information. If we collect it at refusal point, it can be that they are not in the registry because we don’t have written materials to give them in their language.</p> <p>There was discussion about IRB allowing/not allowing enrollment of subjects when English is not the primary language spoken in the home. Sally clarified that the project protocols must spell out how this will be handled – written materials in their primary language, via a translator, etc. Whatever the IRB approves is allowable.</p> <p><b>Consensus – need to know why is this asked. May need to follow up with what the primary caregiver’s primary language is to know what is needed – materials in what language? Translator, etc.</b></p>
24	Primary insurance at birth	Free Text		<p><b>Consensus –</b></p> <ul style="list-style-type: none"> <li>• <b>change to pick list (Private, Public, Other, none, self-pay</b></li> <li>• <b>Change at birth to at time of enrollment</b></li> </ul>
25	Marital Status at birth			<p>Kiki – would it be useful to know if there is a partner? Linda – do we care at birth, at time of diagnosis, or at time of enrollment? Does it matter at all? Kupper – we need to decide what we are doing with the information.</p> <p><b>Consensus – change at birth to at time of enrollment.</b></p> <p>Kiki – do we want to know if the disorder was the cause of the divorce? Kupper – we shouldn’t even go there. Linda – this really isn’t clear whose marital status we are asking about. Linda - “Subject, subject’s parent or legal guardian” are those authorized to consent. Primary care provider may not be any of these.</p> <p><b>Consensus – change to Marital Status of subject’s Primary Caregiver at time of enrollment</b></p>
26	Family members (number of siblings, half-siblings, adopted); enter 88888 if unknown	Free Text		<p><b>Consensus – change free text to check boxes with blanks. Checkbox options should include: Children under 18, specify # of siblings; # of half siblings, # adopted, # of other children, total number of children; and Adults 18 and over, specify # of siblings, of half siblings, # of parents, # of other adults, Total # of adults. Total # household.</b></p>

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27 & 28	Mother's height... Father's height...			<b>Consensus - enter in inches, to nearest half inch, have the computer registry program translate to centimeters</b>
29	Are parents affected with CAH?	Pick list		Kupper – do we need to be able to show both affected (what are the odds)? <b>Consensus - Change to check box so that can choose more than one.</b> Kiki – should we gather data on carriers? Linda – how many parents would know that? Kiki – we test our parents so they would know. <b>Consensus – Add a question. Ask if the parent's have had genetic testing?</b> <b>If yes, are they are carrier?</b>
30	Select Family History			Linda – we need to be careful that the terms are appropriate for whoever is providing the information. In other words, if we are getting this through a patient self-report questionnaire, it needs to be in language the patient/parent will understand, with minimal interpretation needed for whoever enters the data into the registry. Linda – it might be good to look at some of the questionnaires that have been done to see how the questions should be asked and what should be asked, e.g. the Ann Haynes Questionnaire. How do you ask people to get information about these types of disorders? Nancy and Kiki will look at wording and ask the MN genetics people to look at as well. <b>Consensus –</b> <ul style="list-style-type: none"> <li>• <b>Add another option “other”</b></li> <li>• <b>Revisit as discussed above.</b></li> </ul>
31	If infant/sibling death(s): enter sibling #, date(s) of death, cause(s) of death if known, and sex of sibling male/female if known (enter 99999 if NA or 88888 if unknown)			Sex if known was added for very virilized female where testing wasn't done. Nancy – would this happen? Linda – I think parents would say a gender, even if they were incorrect. Kiki – we need to break this question down – too loaded. Kupper – what is the reasoning behind identifying birth order, vs. just naming them all? I am trying to figure out some way to simplify this. If yes – number of deceased siblings and then get the information about the deceased. <b>Consensus –</b> <ul style="list-style-type: none"> <li>• <b>Add an explanation that sibling # refers to birth order.</b></li> <li>• <b>Revisit as discussed above.</b></li> </ul>