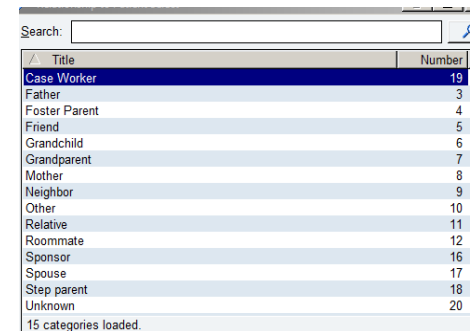
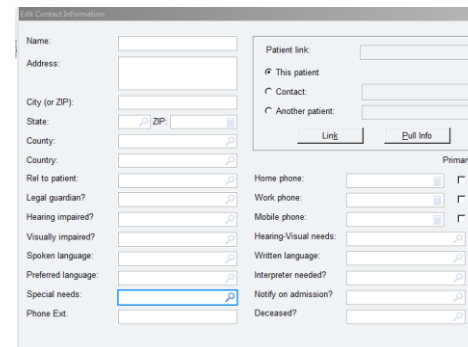


## Pediatric Data Collection Domains and Sample Practices

**Please note:** This is a working document and may be updated periodically as organizations adopt and modify their data collection processes.

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Caregiver	Unique Issues	Sample Practices	
	<ul style="list-style-type: none"> <li>In contrast to demographic data collection with adult patients, the pediatric context is more complex; caregiver demographics are important to collect because caregiver demographics impact child health status and health care experiences. Caregiver demographics thus reflect health disparities and healthcare inequities for children and youth.</li> <li>Aligned with a child and family-centered care approach, caregiver demographics, as well as child demographics are important to collect.</li> <li>Different family structures pose challenges to collecting accurate and meaningful data from caregivers; defining who the 'caregiver' is can aid in gathering accurate and consistent data.</li> <li>Different countries have different legislation regarding age of consent and this impacts how we perceive the role of the child in health care and when we would collect demographic data from children and youth.</li> <li>Demographic questions need to reflect the developmental stages of children and youth.</li> <li>Collecting demographic data from children and youth presents additional challenges in comparison to collecting this data from adult patients (e.g., workload, IT, privacy of child and youth data during data collection and storage, comfort level in collecting data from caregivers and youth, key messaging for caregivers why their data is being collected, etc.).</li> </ul> <p>Unique issues: Capturing non-traditional families (ex. same sex couples) (Cincinnati Children's)</p>	Cincinnati Children's Hospital	<p><b>Data Collection Method:</b></p> <ul style="list-style-type: none"> <li>Caregivers who are not legal guardians cannot sign consents</li> <li>Collect caregiver demographics as the Emergency Contact along with friends and family members</li> <li>Also collect guarantor information for billing purposes</li> <li>Family may choose a selected order to communicate with caregivers or guardians</li> </ul> <p><b>Data Collection Setting:</b> Data is collected on all patients, both inpatient and outpatient by admitting and registration staff (in-person and call-in) and recorded in EPIC.</p> <p><b>Data Collection Tool:</b></p> <ul style="list-style-type: none"> <li>Permanent Address</li> <li>Temporary Address</li> <li>Confidential Address</li> <li>Can choose multiple relationships in EPIC for a caregiver</li> </ul> 

	Unique Issues		Sample Practices	
Caregiver			<ul style="list-style-type: none"> <li>Detailed caregiver information can be recorded, but is not mandatory</li> </ul> 	
		Nationwide Children's	<ul style="list-style-type: none"> <li>Nationwide admits patients through age 21 years and selected adults.</li> <li>Caregiver <i>is not used</i> interchangeably with other terms such as Legal Guardian, Contact, Guarantor or Subscriber as all could be different.</li> </ul> <p>Patients 13 years and older may have access to their EHR (MyChart) without parent/guardian permission, and may remove parent/guardian access.</p> <p><b>Data Collection Method:</b> Caregiver information is collected by face-to-face registration and over the phone scheduling, and data entered into the EHR "contact Information"</p> <p><b>Data Collection Setting:</b> Registrars interview the caregivers of all patients (out-patient and in-patient)</p> <p>Within the <b>clinical</b> out-patient and in-patient workflow, nurses/MAs gather additional information on the caregivers</p>	

Caregiver	Unique Issues	Sample Practices	
			<p><b>Data Collection Tool:</b> The data collection is guided through the EHR template.</p> <p><b>Registrars</b> complete the following data fields: name; address; phone numbers; DOB; relationship to pt.; legal guardianship; hearing/visual needs; spoken language; preferred language; written language; interpreter needed; special needs; and notify on admission.</p> <p><b>Clinical staff:</b> complete the EHR section on “<i>barriers to learning</i>” which includes: hearing &amp; visual impairments, reading difficulties, language barriers, other barriers, and preferred language. An additional section includes data fields related to the caregivers’ “<i>learning method</i>” which includes visual, auditory, written, other and learning topics. The contact screen also has a separate box to link caregiver to a specific patient(s).</p> <ul style="list-style-type: none"> <li>Nationwide Children’s is moving to a “centralized registration” model for ambulatory patients. The implementation will occur in phases - 1<sup>st</sup> phase rolling out in fall 2014.</li> </ul>
		Nemours	<p><b>Data Collection Methods:</b></p> <ul style="list-style-type: none"> <li>Data are collected via questioning or <i>interview</i> at registration.</li> <li>Basic demographic &amp; access data are collected by <i>scheduling staff</i> (front desk).</li> <li>Similar data (basic and detailed) are collected throughout the process of care by <i>clinicians</i> (nurses/physicians).</li> </ul> <p>These data are entered into the <i>electronic medical records</i> (EMR)</p> <p><b>Data Collection Setting:</b></p> <ul style="list-style-type: none"> <li>Data are collected at the hospital, primary care locations and the satellite campuses/clinics throughout Delaware Valley.</li> </ul>

Caregiver	Unique Issues		Sample Practices	
			<ul style="list-style-type: none"> <li>Any caregiver provides data on the child/children.</li> <li>Scheduling staff, nurses, physicians, social workers, physical therapists, and other allied healthcare staff are responsible for data gathering.</li> </ul>	
			<p><b>Data Collection Tool</b></p> <ul style="list-style-type: none"> <li>The instrument used captures information from parents/guardians on: <ul style="list-style-type: none"> <li>✓ Relationship</li> <li>✓ Address</li> <li>✓ Insurance</li> <li>✓ Language – How well spoken and interpreter needed</li> <li>✓ Race/ethnicity</li> </ul> </li> <li>The <i>Office of Minority Health (OMH) standards</i> are used for the REaL data collection instrument.</li> </ul> <p><b>Next Directions:</b></p> <ul style="list-style-type: none"> <li>Scripts for scheduling staff are currently being revised to include <i>cultural competency</i> questions and the rationale for requesting such data.</li> <li>These data will be populated in special section in EMR as snapshot. This will facilitate access to these data for consideration in clinical decision-making regarding patient care.</li> </ul>	
		Seattle Children's	<p><b>Data Collection Tool:</b></p> <p>Have caregiver 1 and caregiver 2 fields in EPIC to document names of each caregiver (vs. "mother" and "father".)</p> <ul style="list-style-type: none"> <li>Legal Guardian documentation process has been difficult for our registration staff with single parent fathers, LGBT parents.</li> </ul>	

Caregiver	Unique Issues	Sample Practices	
		Toronto	<p><b>Data Collection Method:</b> A Pediatric Demographic Data Collection Instrument was developed for a city wide initiative to collect socio-demographic information from patients within hospitals, Community Health Centres, and Public Health to address health equity. A Caregiver Health Equity Survey and a Youth Health Equity Survey comprise the Pediatric Demographic Data Collection Instrument.</p> <p><b>Data Collection Setting</b> The Health Equity Surveys are administered at registration by clerical staff in inpatient units and outpatient clinics. Inpatient data collection may take place at point of care during admission process. In the fall, data collection will be implemented in the Emergency Department.</p> <p>The Health Equity Surveys have been administered with a variety of approaches: patient is interviewed, patient fills out a paper form, or patient provides information using a computer (note, data collection by a computer station has not been shown to be effective).</p> <p><b>Data collection tool</b> Socio-demographic questions are presented in the survey in order of a 'gradient of comfort'; questions that are less 'intrusive/personal' are asked first.</p> <p>Canada does not have a legal age of consent for health care. Based upon funding structures, age requirements for services that are provided for children and youth, and an interest in empowering youth to be active participants in their care earlier, rather than later in adolescence, we decided to collect socio-demographic information from caregivers of patients under the age of 14 and collect this information directly from patients who are 14 – 18 years of age.</p>

Caregiver	Unique Issues	Sample Practices	
			<p><b>Caregiver Health Equity Survey</b> – administered to caregivers of patients under 14 years of age and includes questions about the caregiver and the child. Completed by the caregiver. Caregiver demographics are:</p> <ul style="list-style-type: none"> <li>• Relationship to the child</li> <li>• Born in Canada, if not, date of arrival</li> <li>• Housing</li> <li>• Spoken language</li> <li>• Race/ethnicity</li> <li>• Religious affiliation</li> <li>• Education</li> <li>• Gender identity</li> <li>• Sexual orientation</li> <li>• Disability</li> <li>• Income, # of people supported by income</li> <li>• Child demographics are:</li> <li>• Born in Canada, if not, date of arrival</li> <li>• Spoken language</li> <li>• Race/ethnicity</li> <li>• Disability</li> </ul> <p><b>Youth Survey</b> – administered to patients from 14 to 18 years of age and includes questions about the patient and caregiver.</p> <p>Income questions completed by caregiver and youth questions completed by the youth on her/his own.</p> <ul style="list-style-type: none"> <li>• Youth demographics</li> <li>• Relationship to caregiver present at healthcare visit</li> <li>• Born in Canada, if not, date of arrival</li> <li>• Housing</li> </ul>

Caregiver	Unique Issues	Sample Practices	
			<ul style="list-style-type: none"> <li>• Spoken language</li> <li>• Race/ethnicity</li> <li>• Religious affiliation</li> <li>• Gender identity</li> <li>• Sexual identity</li> <li>• Disability</li> </ul> <p>Caregiver Income, # of people supported by income</p> <p><b>Next Directions:</b></p> <ul style="list-style-type: none"> <li>• Integrate pediatric socio-demographic data collection into “mixed” health care organizations (hospitals and Community Health Centers that serve both adult and pediatric patients).</li> <li>• Evaluate data collection processes at an organizational and system-level.</li> </ul> <p>Use caregiver socio-demographic data for care provision, quality improvement, and system planning</p>



Race and Ethnicity	Unique Issues	Sample Practices		
	<ul style="list-style-type: none"><li>Caregiver’s r/e may reflect disparities in care and affect health outcomes of child.</li><li>These are subjective and dynamic variables.</li><li>Adult standards as a guide but tailored to local institutional needs</li><li>Repeat collection of data (Asking more than once)</li><li>Equity/Diversity and IT Leader as a “shepherd” of the process</li><li>EHR/EMR lack consistency even within one system and they do not currently talk with one another.</li><li>Data in EHR needs to be entered once for many different areas in hospital system</li><li>Include Admissions and Registration staff in planning process</li><li>Making patients/family understand why we collect REaL data</li><li>Survey limits many demographics choices to only 1 selection</li></ul>	Cincinnati Children’s	<ul style="list-style-type: none"><li>In 2010, worked with the Greater Cincinnati Health Council to develop REL Data Collection Best Practices for participating hospitals by using OMB categories.</li><li>Data must be self-reported by patient.</li><li>Developed “We Ask Because We Care” marketing materials.</li><li>Distribution of registrar script and REL tip sheet to address family concerns.</li><li>Training includes role playing, “Guess My Race and Ethnicity” Game, Speaking Together video, overview of RWJF, and Aligning Forces for Quality</li><li>REL Refresher Training is completed annually by registers and managers.</li><li>Limitation in not capturing granular race and ethnicity. FYI field used to write details such as “family from Kuwait”</li></ul> <p><b>Data Collection Tool:</b></p> <ul style="list-style-type: none"><li>Patients can select more than one race. * indicates variation from OMB</li></ul> <div><p><u>R/E/L Categories at Cincinnati Children’s</u></p><table><tr><td><p><b>Race</b></p><ul style="list-style-type: none"><li>Black</li><li>Asian</li><li>American Indian/Alaska Native</li><li>Native Hawaiian /Pacific Islander</li><li>Patient Refused*</li><li>Other</li><li>Unknown*</li><li>White or Caucasian</li></ul></td><td><p><b>Ethnicity</b></p><ul style="list-style-type: none"><li>Hispanic</li><li>Non-Hispanic</li><li>Patient Refused*</li><li>Unknown*</li></ul></td></tr></table></div>	<p><b>Race</b></p> <ul style="list-style-type: none"><li>Black</li><li>Asian</li><li>American Indian/Alaska Native</li><li>Native Hawaiian /Pacific Islander</li><li>Patient Refused*</li><li>Other</li><li>Unknown*</li><li>White or Caucasian</li></ul>
<p><b>Race</b></p> <ul style="list-style-type: none"><li>Black</li><li>Asian</li><li>American Indian/Alaska Native</li><li>Native Hawaiian /Pacific Islander</li><li>Patient Refused*</li><li>Other</li><li>Unknown*</li><li>White or Caucasian</li></ul>	<p><b>Ethnicity</b></p> <ul style="list-style-type: none"><li>Hispanic</li><li>Non-Hispanic</li><li>Patient Refused*</li><li>Unknown*</li></ul>			

Race and Ethnicity	Unique Issues	Sample Practices	
			<b>Next Directions:</b> Putting a system in place to validate REL data is accurate
		Massachusetts General Hospital	<p><b>Data Collection Method:</b> In July 2014, MGH transitioned to Epic, resulting in minor changes to race and ethnicity data collection. When pediatric patients present for registration, registrars first ask the caregiver to identify the child's ethnicity, then race, and then answer the OMB standard question "Hispanic/Latino: Yes/No."</p> <p>Registrars use pre-defined category lists for both ethnicity and race, and the system contains two fields each for race and ethnicity, allowing a caregiver to provide up to two responses each for race and ethnicity. There is also a free-text field for ethnicity should a caregiver report an ethnicity that is not included on the pre-defined list.</p> <p>Verbal guidance is provided to registrars in training to communicate to the caregiver that the goal is to capture the child's race/ethnicity rather than the race/ethnicity of the caregiver(s). Registration staff are also trained to respond to questions about why we collect this data. Because self-identification is the gold standard for collecting data on race and ethnicity, registrars are trained never to enter their perception of the patient's race or ethnicity. If a caregiver does not wish to provide this information, registrars select the value of "Declined."</p> <p><b>Data Collection Setting:</b> Race and ethnicity data are collected by registrars for inpatient and outpatient visits. All data collected at the patient's initial registration are confirmed during subsequent registration updates.</p>

Race and Ethnicity	Unique Issues	Sample Practices	
			<p><b>Data Collection Tool:</b> Race categories include:</p> <ul style="list-style-type: none"> <li>• Asian</li> <li>• Black/African American</li> <li>• American Indian/ Native Alaskan</li> <li>• Native Hawaiian/Pacific Islander</li> <li>• White/Caucasian</li> <li>• Other</li> <li>• Declined</li> <li>• Unavailable</li> </ul> <p>Ethnicity categories include over 170 ethnicities, as well as the options of “Other,” “Declined,” and “Unavailable.” Registrars are provided with a job aid that lists the ethnicities and their associated codes.</p>
		Nationwide Children’s	<p><b>Data Collection Method:</b> Race and ethnicity data is collected by asking the parent/guardian to identify the patient’s race and ethnicity. A laminated list of categories is available to aid the parent/guardian in choosing. After the data has been collected and entered correctly into the EHR, the parent/guardian will not be asked for this information again.</p> <ul style="list-style-type: none"> <li>• Flyers were distributed hospital-wide in English, Spanish &amp; Somali to families explaining reason for collecting R/E data.</li> </ul> <p><b>Data Collection Setting:</b> The data is collected by registrars in the outpatient and in-patient settings, and by schedulers over the phone.</p> <p><b>The registrar/schedulers</b> are required to complete an annual e-learning module on the collection of race and ethnicity data.</p>

Race and Ethnicity	Unique Issues	Sample Practices	
			<p><b>Data Collection Tool:</b> After much research, discussion and feedback from our Data Enhancement Team of professionals, physicians and other leaders, we decided on the following <b>race categories</b>:</p> <ul style="list-style-type: none"> <li>♦ African</li> <li>♦ American Indian/Alaska Native</li> <li>♦ Asian</li> <li>♦ Bi-racial/Multi-racial</li> <li>♦ Black/African American</li> <li>♦ Latino/Hispanic/Black</li> <li>♦ Latino/Hispanic/Unspecified</li> <li>♦ Latino/Hispanic/White</li> <li>♦ Native Hawaiian &amp; Other Pacific Islander</li> <li>♦ White</li> <li>♦ Patient/Family Declined</li> <li>♦ Guardian Unavailable to Ask</li> </ul> <p>Ethnicity categories include 107 ethnicities as a result of our pilot projects and patient population analyses. (see attachment for a complete list)</p>
		Nemours	<p><b>Data Collection Methods:</b></p> <ul style="list-style-type: none"> <li>• Race and ethnicity data are collected via patient/caregiver questioning or <i>interview</i> at registration.</li> <li>• Similar data are collected throughout the process of care as applicable by <i>clinicians</i>.</li> <li>• These data are entered into the <i>electronic medical records</i> (EMR).</li> </ul> <p><b>Data Collection Setting:</b></p> <ul style="list-style-type: none"> <li>• Race and ethnicity data are collected at the hospital, primary care locations and the satellite campuses/clinics throughout Delaware Valley.</li> <li>• Any parents/guardians provide data on the child/children.</li> <li>• Older children as patients also provide race and ethnicity data</li> </ul>

Race and Ethnicity	Unique Issues	Sample Practices	
			<ul style="list-style-type: none"> <li>Scheduling staff, nurses, physicians, social workers, physical therapists, and other allied healthcare staff are responsible for data gathering.</li> </ul> <p><b>Data Collection Tool</b> The race and ethnicity instrument used captures information from parents/guardians as well as older children on <b>race</b>:</p> <ul style="list-style-type: none"> <li>✓ White/Caucasian</li> <li>✓ African American/Black</li> <li>✓ Asian</li> <li>✓ American Indian/Alaskan Native</li> <li>✓ Hawaiian/Pacific Islander</li> <li>✓ Some other Race (SOR)</li> </ul> <p>The returned responses include:</p> <ul style="list-style-type: none"> <li>✓ Information not available</li> <li>✓ Refused to answer</li> </ul> <p><b>Ethnicity</b> data captured are:</p> <ul style="list-style-type: none"> <li>✓ Hispanic/Latino</li> <li>✓ Non-Hispanic/Latino</li> </ul> <p>The returned responses include:</p> <ul style="list-style-type: none"> <li>✓ Information not available</li> <li>✓ Refused to answer</li> </ul> <p>By 2013, ethnicity data included:</p> <ul style="list-style-type: none"> <li>✓ Puerto Rican</li> <li>✓ Mexican</li> <li>✓ Cuban</li> <li>✓ Another Hispanic/Latino</li> </ul> <ul style="list-style-type: none"> <li>The <i>Office of Minority Health (OMH) standards</i> are applied for the race and ethnicity data collection instrument.</li> </ul> <p><b>Next Directions:</b> Further granulation of the ethnicity data is considered, given the current direction and recommendation of OMH.</p>

Race and Ethnicity	Unique Issues	Sample Practices	
		Seattle Children's	<p><b>Data Collection Method:</b> Use OMB standards and caregiver may select as many races as they identify for their child. Dichotomized Hispanic / Non-Hispanic ethnicity.</p> <p>1.) "Is your child Latino or Hispanic?"  <input type="radio"/> Yes or no            "What is your child's race?" If family is stuck or confused list out the options.            Race options:</p> <ul style="list-style-type: none"> <li>• American Indian / Alaskan Native</li> <li>• Asian</li> <li>• Black or African American</li> <li>• Native Hawaiian / Other Pacific Islander</li> <li>• Other</li> <li>• Patient refused/did not wish to indicate</li> <li>• White</li> </ul> <p><b>Data Collection Setting:</b> Data is collected by registration staff in the following settings: scheduling call center; in person ambulatory check in; Emergency Dept. check in.</p> <ul style="list-style-type: none"> <li>• Has found that more information staff is given about why the information is collected the more confident they are asking and responding to families who ask why we're collecting the information</li> <li>• Many staff at Seattle Children's report that if they just ask (avoid too much explanation or hesitation) it just flows into normal conversation.</li> <li>• The difference between race and ethnicity for families who answer yes to being Hispanic or Latino</li> </ul> <p><b>Data Collection Tools:</b> EPIC registration system captures dichotomized Hispanic / non-Hispanic ethnicity and as many races as parent identifies for their child.</p>

Race and Ethnicity	Unique Issues	Sample Practices	
		Toronto	<p><b>Data Collection Method:</b> Race/ethnicity<sup>1</sup> is asked of caregivers and patients as part of a city wide initiative to collect socio-demographic from patients to address health equity.</p> <p>For patients from birth to 14 years of age, the race/ethnicity of the primary caregiver present at the hospital visit and the patient is collected from the primary caregiver.</p> <p>For patients 14 to 18 years of age, race/ethnicity is collected from the patient.</p> <p><b>Data Collection Setting:</b> Race/ethnicity is collected at registration by clerical staff in inpatient units and outpatient clinics. Inpatient data collection may take place at point of care during admission process. In the fall, data collection will be implemented in the Emergency Department.</p> <p>Data has been collected in a variety of approaches: patient is interviewed, patient fills out a paper form, or patient provides information using a computer (note, data collection by a computer station has not been shown to be effective).</p> <p><b>Data collection tool:</b> Response options presented are based on the prevalence in which these identities occur within the city, thus they are subject to change over time as the diversity in the city changes.</p>

Race and Ethnicity	Unique Issues	Sample Practices	
			<p><b>Caregiver &amp; Youth Question:</b></p> <p><b>Which of the following BEST describes your racial or ethnic group? Check <i>ONE</i> only.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Asian - East (e.g., Chinese, Japanese, Korean)</li> <li><input type="checkbox"/> Asian - South (e.g., Indian, Pakistani, Sri Lankan)</li> <li><input type="checkbox"/> Asian - South East (e.g., Malaysian, Filipino, Vietnamese)</li> <li><input type="checkbox"/> Black - African (e.g., Ghanaian, Kenyan, Somali)</li> <li><input type="checkbox"/> Black - Caribbean (e.g., Barbadian, Jamaican)</li> <li><input type="checkbox"/> Black - North American (e.g., Canadian, American)</li> <li><input type="checkbox"/> First Nations</li> <li><input type="checkbox"/> Indian - Caribbean (e.g., Guyanese with origins in India)</li> <li><input type="checkbox"/> Indigenous/Aboriginal, <i>not included elsewhere on this list</i></li> <li><input type="checkbox"/> Inuit</li> <li><input type="checkbox"/> Latin American (e.g., Argentinean, Chilean, Salvadorian)</li> <li><input type="checkbox"/> Métis</li> <li><input type="checkbox"/> Middle Eastern (e.g., Egyptian, Iranian, Lebanese)</li> <li><input type="checkbox"/> White - European (e.g., English, Italian, Portuguese, Russian)</li> <li><input type="checkbox"/> White - North American (e.g., Canadian, American)</li> <li><input type="checkbox"/> Mixed heritage (e.g., Black-African and White-North American)</li> </ul> <p><i>(please specify):</i> _____</p> <p><input type="checkbox"/> Other <i>(please specify):</i> _____</p> <p><input type="checkbox"/> Do not know</p> <p><input type="checkbox"/> Prefer not to answer</p> <p>Child Question:</p> <p><b>Which of the following BEST describes the child's racial or ethnic group? Check <i>ONE</i> only.</b> Same response options.</p>



Race and Ethnicity	Unique Issues	Sample Practices	
			<p><sup>1</sup>Wray, R., Agic, B., Bennett-AbuAyyash, C., Kanee, M., Lam, R., &amp; Tuck, A. (2013, September). <i>We ask because we care: The tri-hospital+ TPH health equity data collection project</i>. Toronto, ON: Health Equity Data Collection Project Committee. Retrieved from <a href="http://www.mountsinai.on.ca/about_us/human-rights/measuring-health-equity/we-ask-because-we-care-complendum-september-2013/index.html">http://www.mountsinai.on.ca/about_us/human-rights/measuring-health-equity/we-ask-because-we-care-complendum-september-2013/index.html</a></p> <p><b>Next Directions:</b> Use race/ethnicity data for care provision, quality improvement, and system planning.</p>

Language	Unique Issues	Sample Practices	
	<ul style="list-style-type: none"><li>Language preferences can be different between caregivers and between caregiver and child.</li><li>Limitation of data collection<ul style="list-style-type: none"><li>to capture medical interpreter need based on multiple guardians/caregivers</li><li>to capture refusal of a medical interpreter by guardians/caregivers</li><li>To capture dialects within languages. EPIC does capture 7 dialects of Chinese. However, Arabic has 26 dialects and only Arabic is available to select from.</li><li>To capture medical interpreter gender preference as child enters puberty based on religion.</li></ul></li></ul> <div><div>Language:Arabic</div><div>Marital status:Single</div><div>Ethnicity:Non-Hispanic</div><div>Race:1Asian</div><div>Permanent comments:ONLY Female Interpreters noted on 6/7/2013</div></div> <ul style="list-style-type: none"><li>To capture parent/caregiver ability to read or write the preferred written language. For example, Spanish is chosen as the preferred written language. Documents are given in Spanish, but caregiver is unable to read in the language they speak.</li></ul>	Cincinnati Children’s	<p><b>Data Collection Method :</b> Language collection is collected for both patient and guardian. This is part of a regional initiative to standardize REL data collection.</p> <p><b>Data Collection Setting :</b> Data is collected on all patients, both inpatient and outpatient by admitting and registration staff (in-person and call-in) and recorded in EPIC.</p> <p><b>Data Collection Tools:</b> EPIC is integrated and used to schedule medical interpreters by Linguistic Services. EPIC fields</p> <ul style="list-style-type: none"><li>Preferred spoken language for Patient (child)</li><li>Preferred spoken language for Guardian</li><li>Preferred written language for Patient (child)</li><li>Preferred written language for Guardian</li><li>Preferred Language</li><li>Need Interpreter?<div><input type="checkbox"/> No</div><div><input type="checkbox"/> Yes</div></li></ul> <p><b>Next Directions:</b> Although EPIC currently has over 160 languages to choose from, Linguistic Services would like to expand the options to include dialects within languages.</p>
		Nationwide Children’s	<p><b>Data Collection Method:</b> “Preferred language” and “Interpreter Needed” is captured upon every patient registration and scheduling interaction. (This data essentially reflects the caregiver’s language needs.)</p> <p><b>Data Collection Setting:</b> At registration the data on language is recorded in 2 different places in the EMR. It is located in registration for the patient and in the “contact information” which is specifically designated for the caregiver.</p>

Language	Unique Issues	Sample Practices	
			<p><b>Data Collection Tools:</b> The information collected on the caregiver includes: spoken language; preferred language; written language; interpreter needed.</p> <ul style="list-style-type: none"> <li>• EPIC houses 108 different languages.</li> </ul> <p>Current challenges include:</p> <ul style="list-style-type: none"> <li>• Limited “signage” in multiple or universal languages.</li> <li>• No uniform process for referring families to Interpreter Services.</li> </ul> <p>Our current language services data system is not tied to the EHR.</p>
		Nemours	<p><b>Data Collection Methods:</b></p> <ul style="list-style-type: none"> <li>• Data are collected via questioning or <i>interview</i> at registration.</li> <li>• Language data are collected by scheduling staff</li> <li>• These data will be entered into the <i>electronic medical records</i> (EMR).</li> </ul> <p><b>Data Collection Setting:</b></p> <ul style="list-style-type: none"> <li>• Data are collected at the hospital, primary care locations and the satellite campuses/clinics throughout Delaware Valley.</li> <li>• Any caregiver or patients (older children) provide data on preferred language and language required for interpreter service.</li> <li>• Social workers, and other allied healthcare staff are responsible language for data gathering.</li> </ul> <p><b>Data Collection Tool</b></p> <ul style="list-style-type: none"> <li>• Data on language include: <ul style="list-style-type: none"> <li>✓ English</li> <li>✓ Spanish</li> <li>✓ European languages such as Polish</li> </ul> </li> </ul> <p>Returned response include:</p> <ul style="list-style-type: none"> <li>✓ None</li> <li>✓ Other/unknown</li> </ul>

Language	Unique Issues	Sample Practices	
			<p><b>Next Directions:</b> Other languages (European, Caribbean, African) are expected to be included in the choices as preferred language and language required for interpreter service.</p>
		Seattle	<p><b>Data Collection Method:</b> <i>We ask two questions:</i></p> <p><i>“What is your family’s preferred language for your child’s health care?”</i></p> <p><i>“Will anyone in the family need an interpreter? We provide them free of charge.”</i></p> <p>We document preferred language for care in EPIC language field and have a Y / N interpreter field, in addition to an interpreter field that can change per the unique caregiver need at upcoming encounter.</p> <p><b>Data Collection Setting:</b> Data is collected by registration staff in: call center, in person ambulatory check-in, emergency department check-in, as well as by emergency department nurses.</p> <p><b>Data Collection Tools:</b> EPIC registration system captures preferred language for care (name of language) and interpreter need (Y/N). See attachment for screen shot.</p> <p>We also free text note language preference differences between multiple caregivers and between caregiver and child.</p>

Language	Unique Issues	Sample Practices	
		Toronto	<p><b>Data Collection Method:</b> Preferred spoken language<sup>1</sup> is asked of caregivers and patients as part of a city wide initiative to collect socio-demographic from patients to address health equity.</p> <p>For patients from birth to 14 years of age, preferred spoken language is collected from the patient's primary caregiver and the patient from the primary caregiver that is present at the hospital visit.</p> <p>For patients 14 to 18 years of age preferred spoken language is collected from the patient.</p> <p><b>Data Collection Setting:</b> Preferred spoken language is collected at registration by clerical staff in inpatient units and outpatient clinics. Inpatient data collection may take place at point of care during admission process. In the fall, data collection will be implemented in the Emergency Department.</p> <p>Data has been collected in a variety of approaches: patient is interviewed, patient fills out a paper form, or patient provides information using a computer (note, data collection by a computer station has not been shown to be effective).</p> <p><b>Data collection tool:</b> Response options presented are based on the prevalence in which these languages are spoken within the city, thus they are subject to change over time as the diversity in the city changes.</p>

Language	Unique Issues	Sample Practices	
			<p><b>Caregiver and youth question:</b></p> <p><b>What language would you feel MOST comfortable speaking in with your healthcare provider? Check <i>ONE</i> only.</b></p> <p> <input type="checkbox"/> Amharic  <input type="checkbox"/> Arabic  <input type="checkbox"/> American Sign Language (ASL)  <input type="checkbox"/> Bengali  <input type="checkbox"/> Chinese (Cantonese)  <input type="checkbox"/> Chinese (Mandarin)  <input type="checkbox"/> Czech  <input type="checkbox"/> Dari  <input type="checkbox"/> English  <input type="checkbox"/> Farsi  <input type="checkbox"/> French  <input type="checkbox"/> Greek  <input type="checkbox"/> Hindi  <input type="checkbox"/> Hungarian  <input type="checkbox"/> Italian  <input type="checkbox"/> Karen  <input type="checkbox"/> Korean  <input type="checkbox"/> Nepali  <input type="checkbox"/> Polish  <input type="checkbox"/> Portuguese  <input type="checkbox"/> Punjabi  <input type="checkbox"/> Russian  <input type="checkbox"/> Serbian  <input type="checkbox"/> Slovak  <input type="checkbox"/> Somali  <input type="checkbox"/> Spanish  <input type="checkbox"/> Tagalog  <input type="checkbox"/> Tamil  <input type="checkbox"/> Tigrinya  <input type="checkbox"/> Turkish  <input type="checkbox"/> Twi  <input type="checkbox"/> Ukrainian  <input type="checkbox"/> Urdu  <input type="checkbox"/> Vietnamese </p>

Language	Unique Issues	Sample Practices	
			<input type="checkbox"/> Other ( <i>please specify</i> ): _____ <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer  <b>Child question:</b>  <b>What language would the child feel MOST comfortable speaking in with her/his healthcare provider? Check <i>ONE</i> only.</b>  <b>Same response categories with 2 additional response options:</b> <input type="checkbox"/> The child does not yet speak <input type="checkbox"/> The child is non-verbal  <b>Next Directions:</b> Use language data for care provision, quality improvement, and system planning.  <sup>1</sup> Wray, R., Agic, B., Bennett-AbuAyyash, C., Kanee, M., Lam, R., & Tuck, A. (2013, September). <i>We ask because we care: The tri-hospital+ TPH health equity data collection project</i> . Toronto, ON: Health Equity Data Collection Project Committee. Retrieved from <a href="http://www.mountsinai.on.ca/about_us/human-rights/measuring-health-equity/we-ask-because-we-care-complendium-september-2013/index.html">http://www.mountsinai.on.ca/about_us/human-rights/measuring-health-equity/we-ask-because-we-care-complendium-september-2013/index.html</a>

Gender Identity Sexual Orientation	Unique Issues	Sample Practices
	<ul style="list-style-type: none"> <li>• Asking sexual attractions opens the conversation vs. immediately identifying patient as straight, gay, lesbian or bisexual.</li> <li>• Allow for greater flexibility in having data change during adolescence into adulthood. Sexual experimentation with same-sex partners occurs among youth who later identify as both straight and gay<sup>1</sup></li> <li>• There may be discordance between sexual orientation and sexual behavior.</li> <li>• Further limited collection and standardization of data for transgender patients <ul style="list-style-type: none"> <li>○ Collection of birth sex and current anatomy</li> <li>○ In the case of transgender, preferred name is added to the patient registration sheet and highlighted on the title page of the EPIC computer screen.</li> </ul> </li> <li>• Discrimination: Patients may experience discrimination as a result of sharing this information</li> <li>• Privacy: Questions around who can view or access this information need to be addressed early on. Data collection procedures and storage of information need to ensure that youth's reporting of gender and sexual identity is not disclosed to primary caregivers without permission from the youth.</li> <li>• Comfort level: Hospital should invest in increasing staff comfort around collecting LGBT data and answering patient questions</li> </ul>	<p>Cincinnati Children's</p> <p><b>Data Collection Method:</b> Sex data is collected on patients, both inpatient and outpatient by admitting and registration staff (in-person and call-in) and recorded in EPIC</p> <p><b>Data Collection Setting:</b> Detailed questions about sexuality are asked in the social history in some units of the hospital by clinicians.</p> <p><b>Data Collection Tool:</b> EPIC fields</p> <p><b>Sex:</b></p> <p><input type="checkbox"/> Female</p> <p><input type="checkbox"/> Male</p> <p><input type="checkbox"/> Unknown</p> <p>○ An Example of unknown – information on a patient is gathered by the Transport Team prior to the patient's actual birth, or a Group/Entity is listed as a patient's guarantor (Ward of the County).</p> <div data-bbox="1352 865 1873 1120"> <p>Sex and Sexuality  Sexual attractions:: Same sex only  Currently dating?: Yes  Relationship safety?: Feels safe  Ever sexually active?: Yes  Age of sexual debut (in years):: 17  Date of most recent sex:: 03/05/14  Number of lifetime partners:: 1  Number of partners in the last 6 months:: 1  Number of current (within last 1 month) partners:: 1  Condoms/barrier methods:: Never/0%  Other contraceptive method(s):: No</p> </div> <p><b>Next Directions:</b> Transgender Health Program was launched to provide evidence-based comprehensive services to this vulnerable group of adolescent and their families in the Division of Adolescent and Transition Medicine. There a committee working to address the registration process of this patient population to include gender identity as a field.</p>

<sup>1</sup> Steever, John B, MD Cooper-Serber, Emma, LMSW, MPH. A Review of Gay, Lesbian, Bisexual, and Transgender Youth Issues for the Pediatrician. **Pediatric Annals** 42.2 (Feb 2013): 34-9.



Gender Identity/ Sexual Orientation	Unique Issues	Sample Practices	
			Starting to work on a training video to address different family structures in conjunction with providing better customer service. Sensitivity training to be addressed also.
		Nationwide Children's	<p><b>Data Collection Method:</b> This data is collected by interview and recorded in the EHR. The only data options the registration staff collects are male or female. More detailed data is collected in specific areas throughout the hospital using paper forms which are completed by the patients (with assistance if necessary) and then scanned into the patient chart.</p> <p>Physicians in primary care and adolescent medicine collect this data from patients age 12 years and above during their annual physical exam after asking the parent/guardian to step out of the room. This data is entered into the EHR at the patient visit level.</p> <p><b>Data Collection Setting:</b> There are areas throughout the hospital that collect more gender specific and self-identified categories and/or research projects that collect this data. <b>For example:</b> The Family AIDS and Educational Services (FACES) Program requires the social workers to complete a "testing demographic form".</p> <p><b>Data Collection Tool:</b> Data collection in the FACES program includes: female, male, unknown, transgender, male to female, female to male and other. There is also a <i>sexual orientation</i> section: homosexual/gay; heterosexual/straight; lesbian/gay; and heterosexual/straight.</p> <p><b>Next Directions:</b> Future discussions with the Data Enhancement Team and Diversity Senior Leadership regarding adding gender and sexual orientation categories to either the registration workflow or clinical workflow.</p>
		Nemours	<p><b>Data Collection Methods:</b></p> <ul style="list-style-type: none"> <li>Data are collected via questioning or <i>interview</i> at registration.</li> </ul>

Gender Identity/ Sexual Orientation	Unique Issues		Sample Practices	
			<ul style="list-style-type: none"> <li>Basic demographic including gender (male/female) data are collected by <i>scheduling staff</i> (front desk).</li> <li>These data are entered into the <i>electronic medical records</i> (EMR).</li> </ul> <p><b>Data Collection Setting:</b></p> <ul style="list-style-type: none"> <li>Data are collected at the hospital, primary care locations and the satellite campuses/clinics throughout Delaware Valley.</li> <li>Any caregiver provides data on the child/children.</li> <li>Scheduling staff, nurses, physicians, social workers, physical therapists, and other allied healthcare staff are responsibility for data gathering.</li> </ul> <p><b>Data Collection Tool</b></p> <ul style="list-style-type: none"> <li>Data are collected on patients gender as: <ul style="list-style-type: none"> <li>✓ Male</li> <li>✓ Female</li> </ul> </li> </ul> <p><b>Next Directions:</b> Nemours Healthcare System is an LGBT sensitive institution. There are currently no self-identified granular data on sexual orientation, gender identity or expression. Effort is in place to collect such data in the near future.</p>	
		Toronto	<p><b>Data Collection Method:</b> Gender and sexual orientation questions<sup>1</sup> are asked of caregivers and patients as part of a city wide initiative to collect socio-demographic from patients to address health equity.</p> <p>For patients from birth to 14 years of age, gender and sexual orientation are collected from the patient's primary caregiver that is present at the hospital visit.</p> <p>For patients 14 to 18 years of age, gender and sexual identity is collected from the patient.</p>	

Gender Identity/ Sexual Orientation	Unique Issues	Sample Practices	
			<p><b>Data Collection Setting:</b></p> <p>Gender and sexual orientation questions are collected at registration by clerical staff in inpatient units and outpatient clinics. Inpatient data collection may take place at point of care during admission process.</p> <p>In the fall, data collection will be implemented in the Emergency Department.</p> <p>Data has been collected in a variety of approaches: patient is interviewed, patient fills out a paper form, or patient provides information using a computer (note, data collection by a computer station has not been shown to be effective).</p> <p><b>Data collection tool:</b></p> <p><b>Caregiver Questions:</b></p> <p><b>What is your gender? Check <i>ONE</i> only.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Female</li> <li><input type="checkbox"/> Intersex</li> <li><input type="checkbox"/> Male</li> <li><input type="checkbox"/> Trans - female to male</li> </ul> <p><b>What is your sexual orientation? Check <i>ONE</i> only.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Bisexual</li> <li><input type="checkbox"/> Gay</li> <li><input type="checkbox"/> Heterosexual (“straight”)</li> <li><input type="checkbox"/> Lesbian</li> <li><input type="checkbox"/> Queer</li> </ul>

Gender Identity/ Sexual Orientation & Behavior	Unique Issues	Sample Practices
		<p><b>Youth Questions:</b></p> <p><b>What is your gender? Check <i>ONE</i> only.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Female</li> <li><input type="checkbox"/> Intersex - female</li> <li><input type="checkbox"/> Intersex - male</li> <li><input type="checkbox"/> Intersex, do not identify as either female or male</li> <li><input type="checkbox"/> Male</li> <li><input type="checkbox"/> Trans - female to male</li> </ul> <p><b>How do you identify? Check <i>ONE</i> only.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Asexual</li> <li><input type="checkbox"/> Bisexual</li> <li><input type="checkbox"/> Gay</li> <li><input type="checkbox"/> Heterosexual (“straight”)</li> <li><input type="checkbox"/> Lesbian</li> <li><input type="checkbox"/> Queer</li> </ul> <p><b>Next Directions:</b>  Incorporation of demographic questions into hospital-wide patient registration system.  Evaluate currently data collection practices</p> <p><sup>1</sup>Adapted by SickKids Hospital and Holland Bloorview Children’s Rehab Hospital from Wray, R., Agic, B., Bennett-AbuAyyash, C., Kanee, M., Lam, R., &amp; Tuck, A. (2013, September). <i>We ask because we care: The tri-hospital+ TPH health equity data collection project</i>. Toronto, ON: Health Equity Data Collection Project Committee. Retrieved from <a href="http://www.mountsinai.on.ca/about_us/human-rights/measuring-health-equity/we-ask-because-we-care-complendium-september-2013/index.html">http://www.mountsinai.on.ca/about_us/human-rights/measuring-health-equity/we-ask-because-we-care-complendium-september-2013/index.html</a> Transgender youth response options modified from Conron, Scout, &amp; Austin (2008). Everyone Has a Right to, Like, Check Their Box.” Findings on a Measure of Gender Identity from a Cognitive Testing Study with Adolescents. <i>Journal of LGBT Health Research</i>, 4, 1-9.</p>

Disability	Unique Issues	Sample Practices	
	<ul style="list-style-type: none"> <li>Diversity of approaches to conceptualizing disability:               <ol style="list-style-type: none"> <li>Medical terminology</li> <li>Human rights terminology</li> </ol> </li> <li>Lack of consensus on disability categories and terms</li> <li>Disability currently captured in a variety of ways:               <ul style="list-style-type: none"> <li>Patient identifies services or accommodation needs (e.g. 'require wheelchair access')</li> <li>Patient selects a disability category (e.g. 'physical disability')</li> </ul> </li> <li>Need for culturally competent definition of a disability</li> <li>Wording different for disabilities among children (may not have had official diagnosis)</li> </ul>	Nationwide Children's	<p><b>Data Collection Method:</b> Currently, Nationwide has a screening/learning section within the EHR labeled "Barriers to Learning" and includes questions pertaining to hearing impairment, visual impairment, reading difficulties, language barriers, and other barriers for both the patient and the caregiver.</p> <p><b>Data Collection Setting:</b> Our data enhancement team is struggling with where this section should fall in the workflow and the EHR. Currently the "barriers to learning" is in the clinical flow, but the registration staff also asks, "Does your child have any problems with his/her vision, hearing and/or mobility?"</p> <p><b>Data Collection Tool:</b> Registration asks: "Does your child have any problems with his/her vision, hearing and/or mobility?" Clinical Staff ask: hearing impairment, visual impairment, reading difficulties, language barriers, and other barriers for both the patient and the caregiver.</p> <p><b>Next Directions:</b> We would like to pilot the following in the clinical workflow and remove these medical questions from registration: "Does your child have a disability? (check as many as apply to your child) Y/N</p> <ul style="list-style-type: none"> <li>Chronic illness</li> <li>Developmental illness</li> <li>Drug or alcohol dependence</li> <li>Learning Disability</li> <li>Mental Illness</li> <li>Physical Disability</li> <li>Sensory Disability</li> <li>Other Disability</li> </ul> <p>Patient/family declined</p>

Disability	Unique Issues	Sample Practices	
		Nemours	<p><b>Data Collection Methods:</b></p> <ul style="list-style-type: none"> <li>• Data will be collected via questioning or <i>interview</i> at registration.</li> <li>• Disability data will be collected by clinical staff and social workers</li> <li>• These data will be entered into the <i>electronic medical records</i> (EMR).</li> </ul> <p><b>Data Collection Setting:</b></p> <ul style="list-style-type: none"> <li>• Data will be collected at the hospital, primary care locations and the satellite campuses/clinics throughout Delaware Valley.</li> <li>• Any caregiver or patient (older children) will provide data on physical or mental inabilities</li> <li>• Nurses, physicians, social workers, physical therapists, and other allied healthcare staff are responsibility for data gathering.</li> </ul> <p><b>Data Collection Tool</b></p> <ul style="list-style-type: none"> <li>✓ Data on disability are expected to include:</li> <li>✓ Physical disability</li> <li>✓ Mental disability</li> </ul> <p><b>Next Directions:</b></p> <ul style="list-style-type: none"> <li>• Data collection instrument is ready to be administered on disability</li> <li>• Administration of the disability instrument is expected before long.</li> </ul>

Disability	Unique Issues	Sample Practices	
		Toronto	<p><b>Data Collection Method:</b> A disability question<sup>1</sup> is asked of caregivers and patients as part of a city wide initiative to collect socio-demographic from patients to address health equity.</p> <p>For patients from birth to 14 years of age, disability is collected on the patient's primary caregiver and the patient from the primary caregiver that is present at the hospital visit.</p> <p>For patients 14 to 18 years of age, disability is collected from the patient.</p> <p><b>Data Collection Setting:</b> Disability is collected at registration by clerical staff in inpatient units and outpatient clinics. Inpatient data collection may take place at point of care during admission process. In the fall, data collection will be implemented in the Emergency Department.</p> <p>Data has been collected in a variety of approaches: patient is interviewed, patient fills out a paper form, or patient provides information using a computer (note, data collection by a computer station has not been shown to be effective).</p> <p><b>Data collection tool:</b></p> <p><b>Caregiver question:</b></p> <p><b>Do you have any of the following? Check <i>ALL</i> that apply.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Chronic illness (e.g., diabetes, cancer, heart disease, arthritis)</li> <li><input type="checkbox"/> Developmental disability</li> <li><input type="checkbox"/> Drug or alcohol dependence</li> <li><input type="checkbox"/> Learning disability</li> </ul>

Disability	Unique Issues	Sample Practices
		<div> <input type="checkbox"/> Mental illness (e.g., anxiety, depression)           <input type="checkbox"/> Physical disability           <input type="checkbox"/> Sensory disability (e.g., hearing or vision)           <input type="checkbox"/> Other (<i>please specify</i>): _____           <input type="checkbox"/> None           <input type="checkbox"/> Do not know           <input type="checkbox"/> Prefer not to answer         </div> <p><b>Child and youth question:</b></p> <p><b>Do you (Does the child) have any of the following? Check <i>ALL</i> that apply.</b></p> <div> <input type="checkbox"/> Chronic (long-term) illness (e.g., asthma, diabetes, cancer, arthritis)           <input type="checkbox"/> Developmental disability (e.g., intellectual disability, autism)           <input type="checkbox"/> Drug or alcohol dependence           <input type="checkbox"/> Learning disability           <input type="checkbox"/> Emotional health disorder (e.g., anxiety, depression)           <input type="checkbox"/> Behavioral disorder (e.g., attention deficit hyperactivity disorder)           <input type="checkbox"/> Physical disability           <input type="checkbox"/> Sensory disability (e.g., hearing or vision)           <input type="checkbox"/> Other (<i>please specify</i>): _____           <input type="checkbox"/> None           <input type="checkbox"/> Do not know           <input type="checkbox"/> Prefer not to answer         </div> <p><b>Next Directions:</b> Use disability data for care provision, quality improvement, and system planning.</p>



Social Determinants	Unique Issues	Sample Practices	
	<ul style="list-style-type: none"> <li>• New approach to looking at socio-cultural factors influencing care</li> <li>• Children may reside in more than one family structure (multiple caretakers with different social determinants)</li> <li>• Need for <u>relevant</u> data collection. Collect only value added demographics</li> <li>• Data that can speak to what drives disparities</li> <li>• More precise fields related to needs of patient/family</li> <li>• If these questions are asked- may need more social workers available</li> <li>• Staff angst about asking questions, extra burden on staff to fill in data for family</li> <li>• Training Needs</li> <li>• Imperative that Cultural Competency Training of Clinical Staff give background and premise for the data points being collected and their integration into clinical care.</li> <li>• Requires “buy-in” and collaboration with both in-house I.T. and with EMR company</li> </ul>	Nationwide Children’s	<ul style="list-style-type: none"> <li>• Nationwide’s <b>Patient’s Rights and Responsibilities</b> include the following expectation: <i>“the patient, parent or guardian will receive care from hospital staff who respect your personal values, beliefs, and customs regardless of your race, ethnicity, gender, religion, sexual orientation, gender identity or expression, cultural background, income level (socioeconomic status), physical or mental disability, education or illness”.</i></li> </ul> <p><b>Data Collection Method:</b> During registration of an in-patient stay, families are asked if they would like to list a religious preference and it is recorded in their EHR.</p> <p><b>Data Collection Setting:</b> During in-patient care, urgent care, emergency department and other outpatient settings, social workers are consulted to assess the patient and family for social, emotional, economic high risk and bio psychosocial complexity including protection, safety, crisis, conflict and environmental impediments. This documentation is listed in the EHR <i>“Social Work Case Tracking Flow sheet”</i></p> <p>The hospital chaplains are also consulted to assess the patient’s/family’s desire or need for spiritual and/or emotional support.</p> <p>Also in the outpatient EMR clinicians have a page under “History” for social concerns but it is under-utilized. In the in-patient setting clinicians’ have a Family/Patient interview section.</p> <p><b>Data Collection Tool:</b> The clinicians’ Family/Patient interview section includes the following questions: <i>“Any concerns about the patient’s eating habits, the patient’s development or activities, the patient’s behavior, meeting spiritual or cultural needs while here, and feeling safe at home?”</i> Religion: the current EHR registration question is “would you like us to list a religious preference”? The EHR has 46 choices.</p>

Social Determinants	Unique Issues	Sample Practices	
		Nemours	<p><b>Data Collection Methods:</b></p> <ul style="list-style-type: none"> <li>• Data will be collected via questioning or <i>interview</i> at clinical encounter.</li> <li>• Data on patients/families' culture, SES, healthcare beliefs, and religiosity/spirituality will be collected during clinical encounter.</li> <li>• These data will be entered into the <i>electronic medical records</i> (EMR) as <b>CULTURAL SNAPSHOT</b>.</li> </ul> <p><b>Data Collection Setting:</b></p> <ul style="list-style-type: none"> <li>• Data will be collected at the hospital, primary care locations and the satellite campuses/clinics throughout Delaware Valley.</li> <li>• Any parent/guardian, families, will provide data on the patient.</li> <li>• Older children will provide data.</li> <li>• Scheduling staff, nurses, physicians, social workers, physical therapists, and other allied healthcare staff such as dieticians are responsibility for data gathering.</li> </ul> <p><b>Data Collection Tool</b> Data are expected to be collected throughout all practices on:</p> <ul style="list-style-type: none"> <li>✓ Religious/spiritual beliefs</li> <li>✓ Health beliefs</li> <li>✓ Education (child/parents/guardian)</li> <li>✓ SES (income, employment, occupation)</li> <li>✓ Health insurance status</li> <li>✓ Food-diet preference</li> <li>✓ Medical decision-making preference</li> <li>✓ Housing</li> <li>✓ Transportation to healthcare/clinic appointment</li> <li>✓ Family structure</li> <li>✓ Home utilizes including internet access</li> <li>✓ Recent immigration-acculturation</li> <li>✓ Social support system/network</li> <li>✓ Objection to blood transfusion</li> </ul>

Social Determinants	Unique Issues	Sample Practices	
			<ul style="list-style-type: none"> <li>Disability status as per OMH standards</li> </ul> <p><b>Next Directions:</b> We expect to implement the Cultural Snapshot (CSS) data gathering before long. Initial piloting cultural data collection to gain feedback from clinicians, and patients/families within each organization to understand relevance within each population and organization.</p> <p>Provider alerts of potential barriers identified with resource links/triggers for social worker/care coordination , and patient navigator support dependent on patient/family responses, e.g.: 1)low literacy level would trigger appropriate patient education, 2) transportation barriers to trigger social worker support/transportation voucher, etc.</p>
		Toronto	<p><b>Data Collection Method:</b> Income (household income that supports the child and number of people support by the income), immigration, housing, religious/spiritual affiliation, and education questions<sup>1</sup> are asked of caregivers and patients as part of a city wide initiative to collect socio-demographic from patients to address health equity.</p> <p>For patients from birth to 14 years of age, household income, number of people supported by income, education, housing, and religious/spiritual affiliation are collected from the patient's primary caregiver that is present at the hospital visit. Immigration is collected on the primary caregiver and the patient from the primary caregiver. Note, income questions, immigration, and education are mandatory questions for hospitals to collect as part of a city wide initiative. Housing and religious/spiritual affiliation questions are optional for hospitals to collect.</p>

Social Determinants	Unique Issues	Sample Practices
		<p>For patients 14 to 18 years of age, household income, number of people is collected from the primary caregiver present at the hospital visit. Housing and religious/spiritual affiliation is collected from the patient. Note, immigration is mandatory for hospitals to collect as part of a city wide initiative. Housing and religious/spiritual affiliation questions are optional for hospitals to collect.</p> <p><b>Data Collection Setting:</b> Socio-demographic questions are collected at registration by clerical staff in inpatient units and outpatient clinics. Inpatient data collection may take place at point of care during admission process. In the fall, data collection will be implemented in the Emergency Department.</p> <p>Data has been collected in a variety of approaches: patient is interviewed, patient fills out a paper form, or patient provides information using a computer (note, data collection by a computer station has not been shown to be effective).</p> <p><b>Data collection tool:</b></p> <p><b>Caregiver, child, and youth immigration question:</b></p> <p><b>Were you (the child) born in Canada?</b></p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Do not know</p> <p><input type="checkbox"/> Prefer not to answer</p> <p>If <b>NO</b>, what year did you arrive in Canada?</p> <p><b>Caregiver Housing Question:</b></p> <p><b>What type of housing do you live in? Check <i>ONE</i> only.</b></p> <p><input type="checkbox"/> Purchased home/condo</p>

Social Determinants	Unique Issues	Sample Practices
		<p>Rental home/apartment/condo</p> <p><input type="checkbox"/> Geared-to-income rental</p> <p><input type="checkbox"/> Relative's home</p> <p><input type="checkbox"/> Friend's home</p> <p><input type="checkbox"/> Boarding home</p> <p><input type="checkbox"/> Group home</p> <p><input type="checkbox"/> Supportive/assisted housing</p> <p><input type="checkbox"/> Shelter/hostel</p> <p><input type="checkbox"/> Homeless/on the street</p> <p><input type="checkbox"/> Correctional facility</p> <p><input type="checkbox"/> Other (<i>please specify</i>): _____</p> <p><input type="checkbox"/> Do not know</p> <p><input type="checkbox"/> Prefer not to answer</p> <p><b>Youth Housing Question:</b></p> <p><b>Where do you live most of the time? Check <i>ONE</i> only.</b></p> <p><input type="checkbox"/> My own place (with roommate(s)/a partner)</p> <p><input type="checkbox"/> Parent/guardian's home</p> <p><input type="checkbox"/> Relative's home</p> <p><input type="checkbox"/> Foster home</p> <p><input type="checkbox"/> Friend's home</p> <p><input type="checkbox"/> School residence</p> <p><input type="checkbox"/> Supportive/assisted housing</p> <p><input type="checkbox"/> Group home</p> <p><input type="checkbox"/> Boarding home</p> <p><input type="checkbox"/> Shelter/hostel</p> <p><input type="checkbox"/> Homeless/on the street</p> <p><input type="checkbox"/> Correctional facility</p> <p><input type="checkbox"/> Other (<i>please specify</i>): _____</p> <p><input type="checkbox"/> Do not know</p> <p><input type="checkbox"/> Prefer not to answer</p>

Social Determinants	Unique Issues	Sample Practices
		<p><b>Caregiver and youth religious/spiritual affiliation question:</b></p> <p><b>What is your religious or spiritual affiliation? Check <i>ONE</i> only.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> I do not have a religious or spiritual affiliation</li> <li><input type="checkbox"/> Animism or Shamanism</li> <li><input type="checkbox"/> Atheism</li> <li><input type="checkbox"/> Baha'i Faith</li> <li><input type="checkbox"/> Buddhism</li> <li><input type="checkbox"/> Christian, <i>not included elsewhere on this list</i></li> <li><input type="checkbox"/> Christian Orthodox</li> <li><input type="checkbox"/> Confucianism</li> <li><input type="checkbox"/> Hinduism</li> <li><input type="checkbox"/> Islam</li> <li><input type="checkbox"/> Jainism</li> <li><input type="checkbox"/> Jehovah's Witnesses</li> <li><input type="checkbox"/> Judaism</li> <li><input type="checkbox"/> Native Spirituality</li> <li><input type="checkbox"/> Pagan</li> <li><input type="checkbox"/> Protestant</li> <li><input type="checkbox"/> Rastafarianism</li> <li><input type="checkbox"/> Roman Catholic</li> <li><input type="checkbox"/> Sikhism</li> <li><input type="checkbox"/> Spiritual</li> <li><input type="checkbox"/> Unitarianism</li> <li><input type="checkbox"/> Zoroastrianism</li> <li><input type="checkbox"/> Other (<i>please specify</i>): _____</li> <li><input type="checkbox"/> Do not know</li> <li><input type="checkbox"/> Prefer not to answer</li> </ul> <p><b>Caregiver education question:</b></p> <p><b>What is your highest level of education? Check <i>ONE</i> only.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> No education</li> <li><input type="checkbox"/> Some elementary school</li> <li><input type="checkbox"/> Completed elementary school</li> </ul>

Social Determinants	Unique Issues	Sample Practices
		<input type="checkbox"/> Some high school <input type="checkbox"/> Completed high school <input type="checkbox"/> Trade school/Apprenticeship (e.g., carpentry, plumbing) <input type="checkbox"/> Some college or university <input type="checkbox"/> College degree or diploma <input type="checkbox"/> University undergraduate degree (e.g., BA, BSc, BEd) <input type="checkbox"/> University graduate degree (e.g., MA, PhD) <input type="checkbox"/> Professional degree (e.g., JD, MD, PEng) <input type="checkbox"/> Other ( <i>please specify</i> ): _____ <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer  <b>Caregiver income questions:</b>  <b>Last year, what was the total household income before taxes that supported the child? Check <i>ONE</i> only.</b> <input type="checkbox"/> \$0 - \$29,999 <input type="checkbox"/> \$30,000 - \$59,999 <input type="checkbox"/> \$60,000 - \$89,999 <input type="checkbox"/> \$90,000 - \$119,999 <input type="checkbox"/> \$120,000 - \$149,999 <input type="checkbox"/> \$150,000 or more <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer  <b>How many people does this income support (include yourself, you partner, and all dependents)? ____ person(s)</b> <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer  <b>Youth income question (to be completed by the caregiver):</b> Before filling out this survey, please have your caregiver answer questions #1 and #2. If you do not have a caregiver with you today, please select 'Not Applicable'.

Social Determinants	Unique Issues	Sample Practices
		<p><b>Last year, what was the total household income before taxes that supported your child? Check <i>ONE</i> only.</b></p> <p> <input type="checkbox"/> \$0 - \$29,999  <input type="checkbox"/> \$30,000 - \$59,999  <input type="checkbox"/> \$60,000 - \$89,999  <input type="checkbox"/> \$90,000 - \$119,999  <input type="checkbox"/> \$120,000 - \$149,999  <input type="checkbox"/> \$150,000 or more  <input type="checkbox"/> Do not know  <input type="checkbox"/> Prefer not to answer  <input type="checkbox"/> Not Applicable         </p> <p><b>How many people does this income support (include yourself, you partner, and all dependents)? ____ person(s)</b></p> <p> <input type="checkbox"/> Do not know  <input type="checkbox"/> Prefer not to answer  <input type="checkbox"/> Not Applicable         </p> <p><b>Next Directions:</b>          Use income, immigration, housing, religious/spiritual affiliation, and education data for care provision, quality improvement, and system planning</p> <ul style="list-style-type: none"> <li><sup>1</sup> Income, immigration, religious/spiritual affiliation, and housing questions adapted by SickKids Hospital and Holland Bloorview Children's Rehab Hospital from Wray, R., Agic, B., Bennett-AbuAyyash, C., Kanee, M., Lam, R., &amp; Tuck, A. (2013, September). <i>We ask because we care: The tri-hospital+ TPH health equity data collection project</i>. Toronto, ON: Health Equity Data Collection Project Committee. Retrieved from <a href="http://www.mountsinai.on.ca/about_us/human-rights/measuring-health-equity/we-ask-because-we-care-complendium-september-2013/index.html">http://www.mountsinai.on.ca/about_us/human-rights/measuring-health-equity/we-ask-because-we-care-complendium-september-2013/index.html</a></li> </ul>