ASCENT Common Data Elements (CDEs) – Pediatric Patient

Part A: REQUIRED Pediatric Participant Demographics – <u>required</u> reporting in all ASCENT protocols for prospectively collected data on pediatric study participants	
*Required data capture from survey / interview when these variables are planned to be collected via primary data collection. *ASCENT recognizes that for specific scientific questions more detailed race and/or ethnicity categorization will be critical, and we encourage investigators to use detailed categorization when relevant to their study question.*	
A1a. Who is completing the survey?	(1) Patient (2) Caregiver → A1b. (3) Health Care Provider (4) Clinical research coordinator (997) Other, please specify: _____
A1b. Caregiver relationship to the patient	(1) Parent (2) Grandparent (3) Legal Guardian (4) Other relative (5) Other non-relative (997) If other, please specify: _____ (998) Prefer not to answer
A2. Age	_____ (years) _____(months)_____(days)
A3. Sex at Birth	(1) Male (2) Female (999) Unknown
A4. Ethnicity	(1) Hispanic or Latino (2) Not Hispanic or Latino (998) Prefer not to answer (999) Unknown

A5. Race	(1) American Indian or Alaska Native (2) Asian (3) Black or African American (4) Native Hawaiian or Other Pacific Islander (5) White (6) More than one race (997) Other race: _____ (998) Prefer not to answer (999) Unknown
A6. Patient Insurance Status	(1) Insurance through a current or former employer or union (of yours or another family member's). This would include COBRA coverage. (2) Insurance purchased directly from an insurance company (by you or another family member). This would include coverage purchased through an exchange or marketplace (3) Original Medicare (4) Medicare Fee for Service (5) Medicaid, Medical Assistance (MA), the Children's Health Insurance Program (CHIP), or any kind of state or government-sponsored assistance plan based on income or a disability. (6) TRICARE or other military health care, including VA health care. (7) Indian Health Service (8) Any other type of health insurance. coverage or health coverage plan (9) Uninsured (998) Prefer not to answer (999) Unknown
A7. Primary Language Spoken at Home	(1) English

	(2) Spanish (3) …Create response options based on languages appropriate for your patient/caregiver population (997) Other: _____ (998) Prefer not to answer (999) Unknown
A9. Residence area type	(1) A big city (population >= 250,000) including suburbs/outskirts (2) A small town/ small city (population 500-10,000) (3) Rural area (population =< 500) (999) Unknown
A10. Household's financial situation. **Without giving exact dollars, how would you describe the household's financial situation right now?** **Would you say:**	(1) After paying the bills, you still have enough money for special things that you want. (2) You have enough money to pay the bills, but little spare money to buy extra or special things. (3) You have money to pay the bills, but only because you have cut back on things. (4) You are having difficulty paying the bills, no matter what you do. (998) Prefer not to answer (999) Unknown
Part B: Primary Diagnosis (Dx) – RECOMMENDED for all ASCENT protocols with patient participants	
Recommended data capture from diagnosis lists or text in health and medical records, or ICD diagnosis codes from administrative data	
B1. Complex chronic conditions (check all that apply)	(1) Cardiovascular (2) Neurologic or neuromuscular (3) Malignancy → B2 (4) Congenital or genetic (5) Respiratory

	(6) Neonatal (7) Hematologic or immunologic (8) Renal (9) Metabolic (10) Gastrointestinal (11) Transplant
B2. Primary Cancer site	(1) Hematologic malignancy (e.g. leukemia, lymphoma) (2) Solid Tumor (3) Brain Tumor (997) Other: _____
Part C: Use of Palliative and/or Hospice Services – RECOMMENDED for all ASCENT protocols with patient participants	
Recommended data capture from health and medical records, or from billing codes specific to Hospice; data capture may also be from survey / interview	
C1a. Enrolled in Hospice? *(collect at each data collection time point)*	(0) No (1) Yes (999) Unknown
C2a. Receiving Palliative Care? (defined as currently under the care of an inpatient or home palliative care service or seen in an outpatient palliative care clinic within the past 3 months; collect at each data collection time point)	(0) No (1) Yes (999) Unknown
Part D: Information at Time of Death - RECOMMENDED for all ASCENT protocols with patient participants	
Recommended data capture from death records, health and medical records; data capture may also be from survey / interview	
D1. Did the patient die?	(0) No → end Part D (1) Yes (998) Prefer not to answer → end Part D (999) Unknown → end Part D

D2. Source of death information	(1) Family (2) Non-Family legally authorized representative (LAR) (3) Physician report (4) Health record (5) Social Security Death Index (SSDI) (6) National Death Index (NDI) (7) Obituary (8) Internet (997) Other source _____
D3. Location of death	(1) Inpatient acute care facility: general floor (2) Inpatient acute care facility: ICU (3) Inpatient acute care facility: palliative care unit (4) Home (5) Long-term care facility (7) Inpatient hospice (997) Other (specify): _____ (999) Unknown
D4. Enrolled in Hospice at time of death?	(0) No (1) Yes (999) Unknown
D5. Enrolled in palliative care at time of death? (defined as currently under the care of an inpatient or home palliative care service or seen in an outpatient palliative care clinic within the past 3 months)	(0) No (1) Yes (999) Unknown

A full list of Common Data Elements recommended by the National Institutes of Health can be found here: https://cde.nlm.nih.gov/home.