

Pritchard-Jones
Appendix 1 – Round 1 Questionnaire

Rationale for collecting stage in pediatric cancer registries

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| <p><u>Statement 1</u></p> <p>Cancer registries should routinely collect disease stage data for cases of pediatric cancer.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 1</i> | | | | | |
| <p><u>Statement 2</u></p> <p>A primary reason for collecting disease stage in cancer registries is to allow stratified comparison of outcomes between groups or over time.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 2</i> | | | | | |

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| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
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| <p><u>Statement 3</u></p> <p>A primary reason for collecting disease stage in cancer registries is to identify trends in late presentation through the proxy of advanced stage at diagnosis.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <p><i>Comments on Statement 3</i></p> | | | | | |

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| <p><i>List any other reasons, if any, that you feel justify collecting disease stage in pediatric cancer registries.</i></p> |
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Guiding principles for the collection of cancer stage

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
|------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| <p><u>Statement 4</u></p> <p>Stage should reflect the extent of disease.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <p><i>Comments on Statement 4</i></p> | | | | | |
| <p><u>Statement 5</u></p> <p>Stage data in cancer registries do not need to be as detailed as stage data for the purposes of clinical decision making.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <p><i>Comments on Statement 5</i></p> | | | | | |

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
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| <u>Statement 6</u> Staging systems used in pediatric cancer registries should be as simple yet informative as possible. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 6</i> | | | | | |
| <u>Statement 7</u> TNM based staging systems used in adult patients are of limited use for pediatric cases. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 7</i> | | | | | |

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
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| <u>Statement 8</u> Cancer registries should routinely use pediatric specific staging systems for childhood cancer cases. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 8</i> | | | | | |
| <u>Statement 9</u> For malignancies common in both pediatric and adult populations (e.g. Hodgkin lymphoma, testicular cancer), staging systems should be the same across both populations. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 9</i> | | | | | |

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
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| <p><u>Statement 10</u></p> <p>Stage should be measured uniformly across all pediatric cancer registries globally to ensure comparability.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 10</i> | | | | | |
| <p><u>Statement 11</u></p> <p>Different pediatric staging systems for the same disease have been developed by different clinical trial organizations; any staging system that is adopted for pediatric cancer registration needs to reconcile these differences.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 11</i> | | | | | |

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
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| <p><u>Statement 12</u></p> <p>When staging pediatric malignancies, clinical staging (i.e. staging at the time of diagnosis) is important and should be collected.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 12</i> | | | | | |
| <p><u>Statement 13</u></p> <p>When staging pediatric malignancies, pathologic staging (i.e. staging at the time of surgery/resection) is important and should be collected.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 13</i> | | | | | |

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
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| <u>Statement 14</u> Clinical and pathologic staging classification systems should be identical, and differ only in the time point of collection. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 14</i> | | | | | |
| <u>Statement 15</u> Cancer registries should collect the methods of evaluation by which stage was determined (e.g. diagnostic modalities). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments on Statement 15</i> | | | | | |

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
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| <p><u>Statement 16</u></p> <p>Given significant differences in diagnostic capabilities, staging systems appropriate to settings with limited diagnostic and evaluation capabilities are needed.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <p><i>Comments on Statement 16</i></p> | | | | | |
| <p><u>Statement 17</u></p> <p>Staging systems designed for resource-limited settings with few diagnostic capabilities should be, when possible, based on collapsing traditional stages used in resource-rich settings, thus preserving a degree of comparability.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <p><i>Comments on Statement 17</i></p> | | | | | |

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
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| <p><u>Statement 18</u></p> <p>Online tools and/or algorithms which assign stage based on inputted data (e.g. involved sites of disease) are helpful when staging pediatric malignancies.</p> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <p><i>Comments on Statement 18</i></p> | | | | | |

Please list any additional principles you feel are important to guide the collection of disease stage by pediatric cancer registries.

Please list any barriers you foresee to the collection of pediatric stage by cancer registries

*We will be seeking endorsement of the results of this consensus process from stakeholders (international organizations, etc...)
Please list any stakeholders whose endorsement you feel would be important.*

What controversies do you anticipate when attempting to achieve consensus on how to collect stage for particular malignancies/tumor sites for pediatric cancer registries?