Appendix 2 – Round 2 Questionnaire

PART A (no action necessary)

The following statements achieved consensus:

Statement 1: Cancer registries should routinely collect disease stage data for cases of pediatric cancer.

Statement 2: A primary reason for collecting disease stage in cancer registries is to allow stratified comparison of outcomes between groups or over time.

Statement 3: 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.

Statement 4: Stage should reflect the extent of disease.

Statement 6: Staging systems used in pediatric cancer registries should be as simple yet informative as possible.

Statement 8: Cancer registries should routinely use pediatric specific staging systems for childhood cancer cases.

Statement 9: For malignancies common in both pediatric and adult populations (e.g. Hodgkin lymphoma, testicular cancer), staging systems should be the same across both populations.

Statement 10: Stage should be measured uniformly across all pediatric cancer registries globally to ensure comparability.

Statement 12: When staging pediatric malignancies, clinical staging (i.e. staging at the time of diagnosis) is important and should be collected.

Statement 16: Given significant differences in diagnostic capabilities, staging systems appropriate to settings with limited diagnostic and evaluation capabilities are needed.

Statement 17: 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.

Statement 18: Online tools and/or algorithms which assign stage based on inputted data (e.g. involved sites of disease) are helpful when staging pediatric malignancies.

The following statement was eliminated based on ratings and comments:

Statement 5: Stage data in cancer registries do not need to be as detailed as stage data for the purposes of clinical decision making

PART B. (ACTION NECESSARY)

The following ***two*** statements either did not achieve consensus, were modified based on comments, or both. Next to each statement you will see, the median group score, interquartile range, range, your personal score, and a representative sampling of participant comments. Based on the modifications and the above information, please re-rate the statement. You may either change your rating or leave it the same.

	Round 1 Median (IQR)	Round 1 Range	Your Round 1 Score	Representative Comments	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Statement 7 *Old statement:* TNM based staging systems used in adult patients are of limited use for pediatric cases. *Modified statement:* TNM based staging systems used in adult patients are of limited use for *many, but not all* pediatric *malignancies*.	**2 (1.75-3)**	**1-3**		*It does not work for all, but it still works for some solid tumors and is better than nothing. When applicable, TNM can be very informative.* *Depends entirely on the cancer type, so may be perfectly useful for some cancers and perfectly useless for others. Maybe clarify "useful for a limited number of pediatric cases" to specify the meaning of "limited" here?* *Depends on the tumour type* *For solid tumours, TNM can be used* *Not applicable for brain tumors*	**1☐**	**2☐**	**3☐**	**4☐**	**5☐**

	Round 1 Median (IQR)	Round 1 Range	Your Round 1 Score	Representative Comments	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
<u>Statement 15</u> *Old statement:* Cancer registries should collect the methods of evaluation by which stage was determined (e.g. diagnostic modalities). *Modified statement:* *Ideally*, cancer registries should collect the methods of evaluation by which stage was determined *in order to assess the adequacy of staging (e.g. Chest X-ray vs. CT scan for lung metastases).*	**2 (1-3)**	**1-4**		*The value of the data is extreme, since US diagnosis of abdominal lymph nodes in Hodgkin is probably much less sensitive than PET-CT scan, so very important to know if it is a stage II Hodgkin with US of abdomen versus with PET-CT of abdomen.* *In an ideal world yes, but this will be resource intensive unless we have standardized radiology reporting and more automatic data feeds.* *If it could be done well, it may be useful, but this has not been my experience.* *In hospital registries, this is possible. But in population-based registries, this is difficult but certainly can be attempted.* *In the ideal world yes, but depends what you are using the data for, I don't think its necessary as it would be rarely used and sometimes difficult to find* *It sounds like a laudable goal but one might have to collect the evaluation for each component rather than just one for stage because the information for overall stage may be based on multiple methods.*	**1☐**	**2☐**	**3☐**	**4☐**	**5☐**

PART C. (ACTION NECESSARY)

Based on comments, the following ***one*** statement was added. As in the first round, please rate the statement and add any comments you feel are important:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Statement 19 A primary reason for collecting disease stage in cancer registries is because stage may be used as a proxy for treatment.	☐	**FORMCHECKBOX**	**FORMCHECKBOX**	**FORMCHECKBOX**	**FORMCHECKBOX**

Comments on Statement 19

PART D. (ACTION NECESSARY)

Based on the comments to statements 13 and 14, two new statements have been added. Below you will find the information for each of the original statements, followed by the new statements. Please rank the new statements:

	Round 1 Median (IQR)	Round 1 Range	Your Round 1 Score	Representative Comments
Statement 13 When staging pediatric malignancies, pathologic staging (i.e. staging at the time of surgery/resection) is important and should be collected.	**2 (1-3)**	**1-3**		*I am on clear of the value of this in the setting of neoadjuvant chemotherapy. It seems it would work and be key for staging the primary tumor and the region when surgery is the first step. However, it would not be as useful to evaluate metastatic disease or if treatment has been provided. We also need to consider the "staging of the patient" vs. "staging of the tumor" as it occurs in retinoblastoma.* *The logistics should be taken into account: at which stage is it most feasible for cancer registries to collect stage information? Is pathological (or clinical) stage always available in the records?* *This could applied just for some specific pediatric tumors like Wilm's tumor, RMS.* *For Australian whole-of-population cancer registries, the rule that is applied is that stage "at diagnosis" refers to all information available from diagnosis up to 4 months post-diagnosis. Could a similar rule be used for paediatric registries?* *With neoadjuvant therapy this may not be applicable to some cases like neuroblastoma or germ cell tumor but is very important for response evaluation and prognostication in ewings or wilms or rhabdomyosarcoma.*

	Round 1 Median (IQR)	Round 1 Range	Your Round 1 Score	Representative Comments
<u>Statement 14</u> Clinical and pathologic staging classification systems should be identical, and differ only in the time point of collection	**3 (2-4)**	**1-5**		*Once again, I am not sure this would be correct because pathologic staging alone would not necessarily address distant disease. I believe the correct extent of disease is obtained with the information available at diagnosis. If a patient needs to be restaged after surgery, then the stage is updated. If surgery occurs upfront, pathologic stage + clinical findings will determine local, regional, and metastatic disease extent* *Not sure that the time point is the most relevant factor – many possible variations on this issue for many cancer types.* *They are fundamentally different, apart from timing.* *Though the need to keep the staging classification simple, clinical and pathological classification need to be different based on the time point and treatment parameters.*

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Statement 20 The importance of pathologic staging (i.e. staging at the time of surgery/resection), and the staging system by which it should be collected, will vary between pediatric malignancies.	☐	**FORMCHECKBOX**	**FORMCHECKBOX**	**FORMCHECKBOX**	**FORMCHECKBOX**
Comments on Statement 20					
Statement 21 Stage at diagnosis, when	☐	**FORMCHECKBOX**	**FORMCHECKBOX**	**FORMCHECKBOX**	**FORMCHECKBOX**

collected, should incorporate all information available from diagnosis to 4 months post diagnosis.					
Comments on Statement 21					