Supplementary

Appendix Table A: Criteria for assessing the coverage and accuracy of clinical databases (Adapted from Black and Payne Framework)

	Level 1	Level 2	Level 3	Level 4
A. Extent to which the eligible population is representative of the country	No evidence or unlikely to be representative	Some evidence eligible population is representative.	Good evidence eligible population is representative.	Total population of the country included.
B. Completeness of recruitment of eligible population	Few (<80%) or unknown	Some (80%-90%)	Most (90%-97%)	All or almost all (>97%)
C. Variables included in the database	• Identifier • Admin info • Condition or Intervention	• Identifier • Admin info • Condition or intervention • Short-term or long-term outcome	• Identifier • Admin info • Condition • Intervention • Short-term or long-term outcome • Major known Confounders	• Identifier • Admin info • Condition • Intervention • Short term outcome • Major known confounders • Long term outcome
D. Completeness of data (percentage variables at least 95% complete)	Few (<50%) or Unknown	Some (50–79%)	Most (90–97%)	All or almost all (>97%) or No continuous data collected
E. Form in which continuous data (excluding dates) are collected (percentage collected as raw data)	Few (<70%) or Unknown	Some (70–89%)	Most (90–97%)	All or almost all (>97%) or no Continuous data collected
F. Use of explicit definitions for variables	None	Some (<50%)	Most (50–97%)	All or almost all (>97%)
G. Use of explicit rules for deciding how variables are recorded	None	Some (<50%)	Most (50–97%)	All or almost all (>97%)
H. Reliability of coding of conditions and interventions	Not tested	Poor	Fair	Good
I. Independence of observations of the primary outcome	Outcome not included or independence unknown	Observers neither independent nor blinded to intervention	Independent observer not blinded to the intervention	Independent observer blinded to intervention or not necessary as the objective outcome (e.g., death or lab test)
J. Extent to which data are validated	No validation	Range or consistency checks	Range and consistency checks	Range and consistency check plus external validation using an alternative source

Appendix Table B: Quality assessment of registry procedures using the Arts et al., framework

Central coordinating center	Local sites
Prevention during set up and organization of registry	
At the onset of the registry	**At the onset of participating in the registry**
Compose minimum set of necessary data items☒	Assign a contact person☒
Define data and data characteristics in data dictionary☒	Check developed software for data entry and for extraction☒
Draft a data collection protocol☒	Check reliability and completion of extraction sources. No
Define pitfalls in data collection☒	Standardize correction of data items No
Compose data checks☒	**Continuously**
Create user-friendly case record forms☒	Train (new) data collectors☒
Create quality assurance plan☒	Motivate data collectors: to some extend
In case of new participating sites	Make data definitions available☒
Perform site visit☒	Place data and initials on completed forms☒
Train new participants☒	Keep completed case record forms☒
Continuously	Data collection close to the source and as soon as possible☒
Motivate participants☒	Use the registry data for local purposes No
Communicate with local sites☒	**In case of changes**
In case of changes (e.g., in data set)	Adjust forms, software, data dictionary, protocol, etc☒
Adjust forms, software, data dictionary, protocol, training material, etc. ☒	Communicate with data collectors☒
Communicate with local sites ☒	

Detection during data collection	
During import of data into central database	**Continuously**
Perform automatic data checks. No	Visually inspect completed forms. No
Periodically and in case of new participants	Perform automatic data checks No
Perform site visits for data quality audit (registry data–source data) and review local data collection procedures ☒	Check completeness of registration No
Periodically	
Check inter-observer and intra-observer variability No	
Perform analyses of the data: No	
Actions for quality improvement	
After data import and data checks	**After receiving quality reports**
Provide local sites with data quality reports: No	Check detected errors No
Control local correction of data errors: No	Correct inaccurate data and fill in incomplete data No
After data audit or variability test	Resolve causes of data errors No
Give feedback of results and recommendations: No	**After receiving feedback**
Resolve causes of data error: No	Implement recommended changes No
	Communicate with personnel No

Appendix Table C: Classification of neurological and respiratory diseases recorded in the IICUR
Other neurologic diseases
Abscess/Infection-cranial, surgery for
Anastomosis, vascular
Biopsy, brain
Burr hole placement
Cerebrospinal fluid leak, surgery for
Cranioplasty and complications from previous craniotomies
Neurologic surgery, other
Seizures-intractable, surgery for
Shunts and revisions
Stereotactic procedure
Ventriculostomy
Cranial nerve, decompression/ligation
Coiling of aneurysm
Endovascular clot retrieval
Other respiratory diseases
Apnea-sleep; surgery for (e.g., UPPP-uvulopalatopharyngoplasty)
Biopsy, open lung
Bullectomy
Facial surgery (if related to trauma)
Respiratory surgery, other
Thoracotomy for bronchopleural fistula
Thoracotomy for lung reduction
Thoracotomy for other reasons
Thoracotomy for pleural disease
Tracheostomy
Lung transplant (including heart/lung)
ENT, maxillofacial and dental surgery (e.g., parotidectomy, mandibulectomy, mastoidectomy, tonsillectomy, non-cancer airway surgery)