

Data recording flow chart

Data source	Process	Registry	Tasks	Responsible
Delivery Room Log	Record Perinatal Data	MNDS B34	Check log and record details on all live-births	MNDS, B34 Representative
Patient History	Child died in Delivery Room? Yes No Record / Update Primary Hospitalization Child transferred to other hospital?	MNDS B34 ASP	Upon discharge planning, dataset can be recorded in SwissNeoNet	MNDS, B34, ASP Representative
Patient History Patient History	Record Data at 1st Discharge Record Data at Final Discharge or Death 1) eCRF 2) csv-Import	MNDS B34 ASP MNDS B34	If child discharged to another hospital before discharge home, both discharge to other hospital and discharge home need to be filled in (MNDS). Be sure to notify discharge hospital of own data requirement. Data Transfer Options: 1) case report form in web app 2) bulk export to *.csv file and import to web app 3) Bi-directional Simple Object Access Protocol from clinical information system case report to web app and back	MNDS, B34, ASP Representative Consult local IT departmet

Data source	Process	Registry	Tasks	Responsible
Lost to FU	Child eligible for 2 year FU?	MNDS (<28w) ASP	Check FU2 Missing List regularly to see if child: - is on list - needs to be recruited - assistance by MD is needed for recruitment	Secretary FU center
Routine 2-year Follow-up Report	Record FU2		Fill in report (eCRF)	MD, Psychologist FU center
Lost to FU	Child eligible for 5-6-year FU?	MNDS (<28w) ASP	Check FU5 Missing List regularly to see if child: - is on list - needs to be recruited - assistance by MD is needed for recruitment	Secretary FU center
Routine 5-6-year Follow-up Report	Record FU5		Fill in report (eCRF)	MD, Psychologist FU center
	Parents refuse FU5?	MNDS (<28w) ASP	If parents refuse FU5, consider asking them if they would answer a few simple questions and go through parent questionnaire (FUP) with them.	Secretary FU center
Phone conver- sation with parents (if consent given)	Record FUP		Fill in report (eCRF)	MD, Psychologist FU center