

# Supplement

## MODEL

The model used was a random intercept logistic regression model with, in each year, stability (0) or instability (1) of an individual as the outcome of predictor variables for that year. Dependence in stability/instability outcomes across years for an individual, not explained by the predictors, is represented by a random intercept (model constant) for that individual across all years.

If  $p_{ij}$  is the probability of an individual  $i$  (level 2) experiencing instability in year  $j$  (level 1) then:

$$\log_e(p_{ij}/(1-p_{ij})) = \beta_1x_{1ij} + \beta_2x_{2ij} + \dots + \beta_nx_{nij} + C_i + \varepsilon_{ij}$$

where  $x_{nij}$  are predictors (values specific to individual and year),  $\beta$  the corresponding model coefficients (not specific to year nor individual),  $C_i$  the individual-specific random intercept and  $\varepsilon_{ij}$  the error term specific to individual and year, representing variance not explained by the model. For univariable models, there is only one predictor and so only one  $x_{ij}$ .

The variables had the following levels:

- Level 1 (possible variation each year for an individual):
  - Age group
  - Deprivation category
  - Primary diagnostic category
- Level 2 (constant for an individual across years):
  - Sex
  - Ethnic group

## TABLES

Table S1: Datasets used in the study

Name	Purpose	Type	Coding system	Population coverage	Data collection methods
<b>CHI Community Health Index</b>	The CHI number has been mandated as the primary patient identifier across Scotland.	Administrative	N/A	All persons who have been registered with a Scottish GP	Most health board patient administration and clinical systems have been seeded with CHI numbers for their patients.
<b>Scottish Birth Record</b>	Records all of a baby's neonatal care in Scotland, from antenatal through to post delivery, including readmissions and transfers in one electronic record.	Administrative	ICD10	All new births in Scotland	Continuous data collection
<b>Scottish Morbidity Record (SMR01) - General Acute Inpatient and Day Case</b>	Collects episode level data on hospital inpatient and day case discharges from acute specialities from hospitals in Scotland.	Administrative	ICD10	Covers all residents in Scotland that receive care in hospital and general acute specialities.	Continuous data collection
<b>Prescribing Information System</b>	The definitive data source for all prescribing relating to all medicines and their costs that are prescribed and dispensed in the community in Scotland.	Administrative	ICD10	Every prescription dispensed in the community in Scotland	Updated monthly

<b>Scottish Outpatient Dataset</b>	Collects episode level data from patients on new and follow up appointments at outpatient clinics in all specialities (except A&E and Genito-Urinary Medicine). Some variation over time and between providers on recording of follow-up appointments.	Administrative	ICD10	The Outpatient Attendance dataset covers all people offered a new or follow up outpatient appointment at a Scottish NHS hospital.	Continuous data collection
<b>Scottish Cancer Registry</b>	Responsible for the collection of information on Scottish residents when they are diagnosed with malignant (and some benign) tumours	Clinical register	ICD10	Covers all residents in Scotland that have had a diagnosis of cancer	Annual returns from clinicians
<b>GRO Death registration data</b>	Death records	Administrative	ICD10	All Deaths occurring in Scotland	Continuous data collection
<b>UK Paediatric Intensive Care Audit Network</b>	International audit of paediatric intensive care which collects data on all children admitted to paediatric intensive care units (PICUs) in the UK and Ireland.	National Clinical Audit	Read Codes	All admissions to PICU in the UK and Ireland	Continuous data collection

Table S2: Prevalence of life limiting conditions in children and young people in Scotland throughout the study

	Financial Year				
	2009/10	2010/11	2011/12	2012/13	2013/14
<b>Prevalence per 10000 population (95% CI)</b>					
<b>Age 0-25</b>	75.0 (74.3-75.7)	80.2 (79.5-81.0)	85.0 (84.3-85.7)	90.3 (89.5-91.0)	95.7 (94.9-96.5)
<b>Age &lt; 1</b>	195.0 (189.3-200.6)	182.9 (177.4-188.4)	180.1 (174.7-185.5)	179.8 (174.3-185.2)	192.1 (186.3-197.8)
<b>Age 1-5</b>	122.9 (120.9-125.0)	123.8 (121.7-125.8)	125.9 (123.8-127.9)	125.2 (123.1-127.2)	124.3 (122.2-126.3)
<b>Age 6-10</b>	69.1 (67.5-70.7)	86.3 (84.5-88.1)	101.1 (99.2-103.1)	116.0 (114.0-118.1)	125.1 (122.9-127.2)
<b>Age 11-15</b>	54.5 (53.2-55.8)	58.0 (56.6-59.4)	62.1 (60.7-63.5)	68.5 (67.0-70.1)	74.0 (72.4-75.6)
<b>Age 16-20</b>	53.8 (52.6-55.1)	57.5 (56.3-58.8)	60.7 (59.4-62.0)	66.5 (65.1-67.9)	73.3 (71.8-74.8)
<b>Age 21-25</b>	58.7 (57.4-60.0)	63.9 (62.6-65.2)	66.2 (64.9-67.6)	67.7 (66.4-69.1)	72.5 (71.1-73.9)

Table S3: Clinical stage of children and young people in Scotland throughout the study

Clinical stage	Financial Year				
	2009/10	2010/11	2011/12	2012/13	2013/14
<b>Number of persons</b>					
Stable	9729	10678	11485	12310	13203
Not stable	2310	2252	2271	2263	2201
Unstable	1857	1816	1822	1834	1783
Deteriorating	262	253	258	236	254
Dying	191	183	191	193	164
<b>% of persons present in year</b>					
Stable	80.8	82.6	83.5	84.5	85.7
Not stable	19.2	17.4	16.5	15.5	14.3
Unstable	15.4	14.0	13.2	12.6	11.6
Deteriorating	2.2	2.0	1.9	1.6	1.6
Dying	1.6	1.4	1.4	1.3	1.1

Table S4: Odds-ratios for risk of instability in each year for children and young people with a life limiting condition in Scotland. Odds-ratios obtained from a random intercept logistic regression model on a binary outcome variable for the most severe clinical stage in each year: stable (0) or not stable (1). Sensitivity analysis excluding ethnic group from the model.

	Odds ratio	95% CI		P-value
<b>Age group</b>				
<1	7.20	6.47	8.01	< 0.01
1-5	Ref			
6-10	0.50	0.45	0.55	< 0.01
11-15	0.70	0.62	0.78	< 0.01
16-20	0.73	0.65	0.81	< 0.01
21-25	0.58	0.52	0.65	< 0.01
<b>Gender</b>				
Male	Ref			
Female	1.12	1.04	1.21	< 0.01
<b>Deprivation category</b>				
1 - most deprived	Ref			
2	1.05	0.95	1.17	0.31
3	0.97	0.87	1.09	0.64
4	0.90	0.81	1.01	0.08
5 - least deprived	0.88	0.79	0.99	0.04
<b>Primary diagnostic category</b>				
Neurological	2.61	2.29	2.96	< 0.01
Haematology	2.38	2.02	2.81	< 0.01
Oncology	3.77	3.34	4.25	< 0.01
Metabolic	2.15	1.73	2.66	< 0.01
Respiratory	3.86	3.38	4.41	< 0.01
Circulatory	0.57	0.48	0.69	< 0.01
Gastrointestinal	5.15	3.93	6.75	< 0.01
Genitourinary	4.40	3.77	5.14	< 0.01
Perinatal	0.19	0.15	0.22	< 0.01
Congenital	Ref			
Other	2.89	1.78	4.67	< 0.01
<b>Model characteristics</b>				
Log likelihood	-26486.66			
Degrees of freedom	22			
BIC	53218.29			
Data used	68554 observations from 20351 persons			

## FIGURES

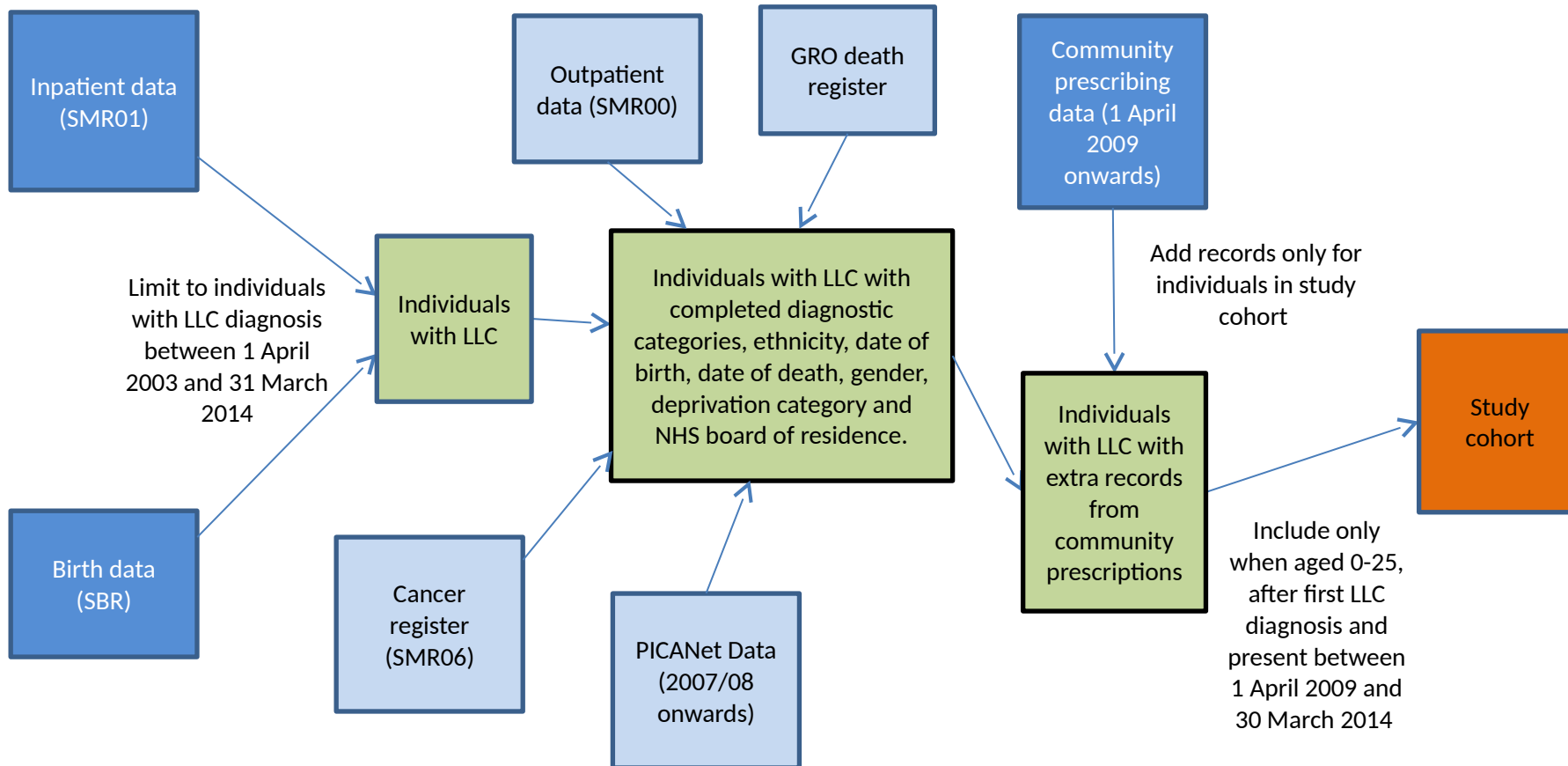


Figure S1: Datasets used to form the study cohort and complete patient demographics for prevalence analyses and the process of identifying children and young people in Scotland with a life limiting condition.

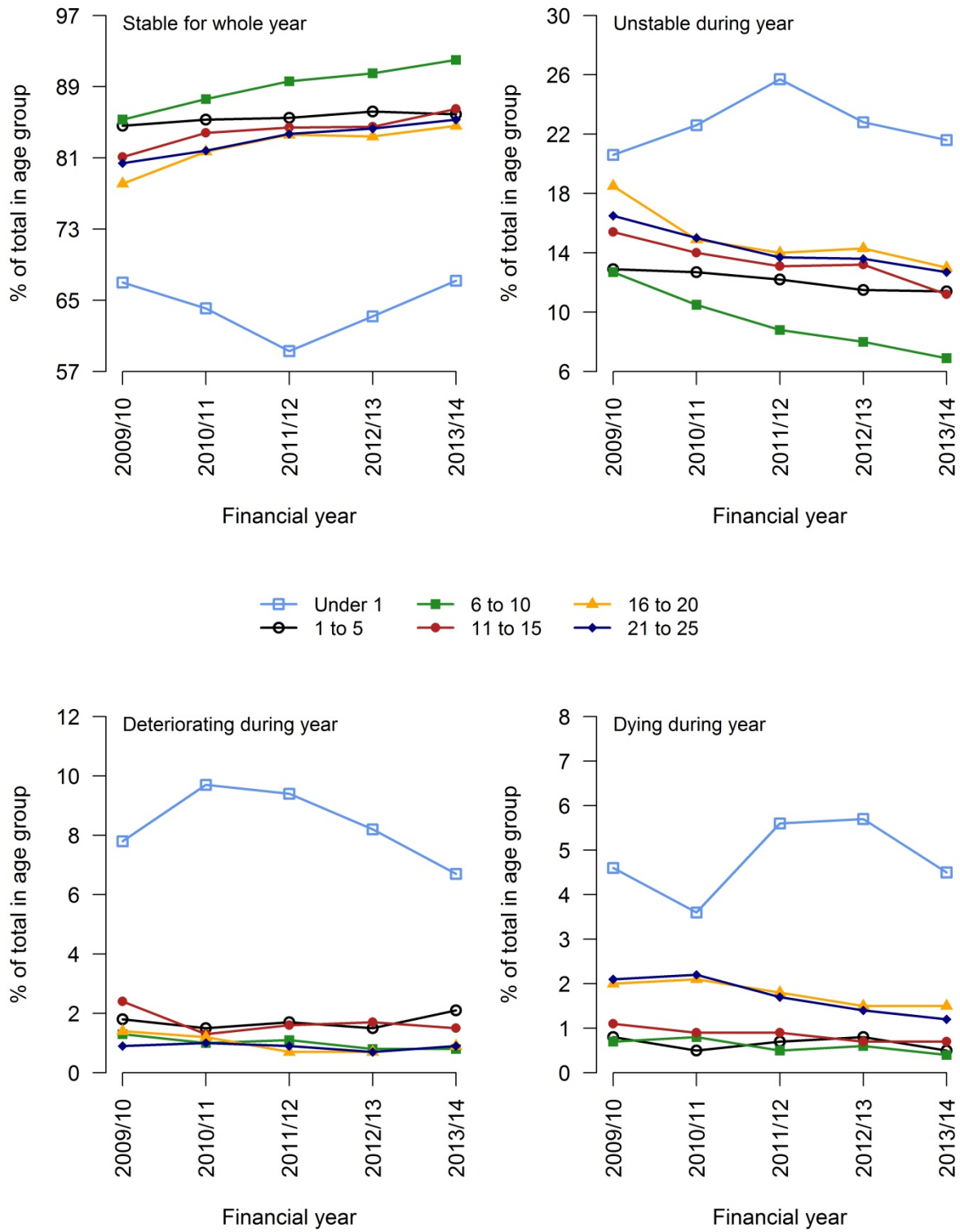


Figure S2: Clinical stage by age group among children and young people in Scotland with a life limiting condition. Recorded status is the most severe clinical stage in the year.

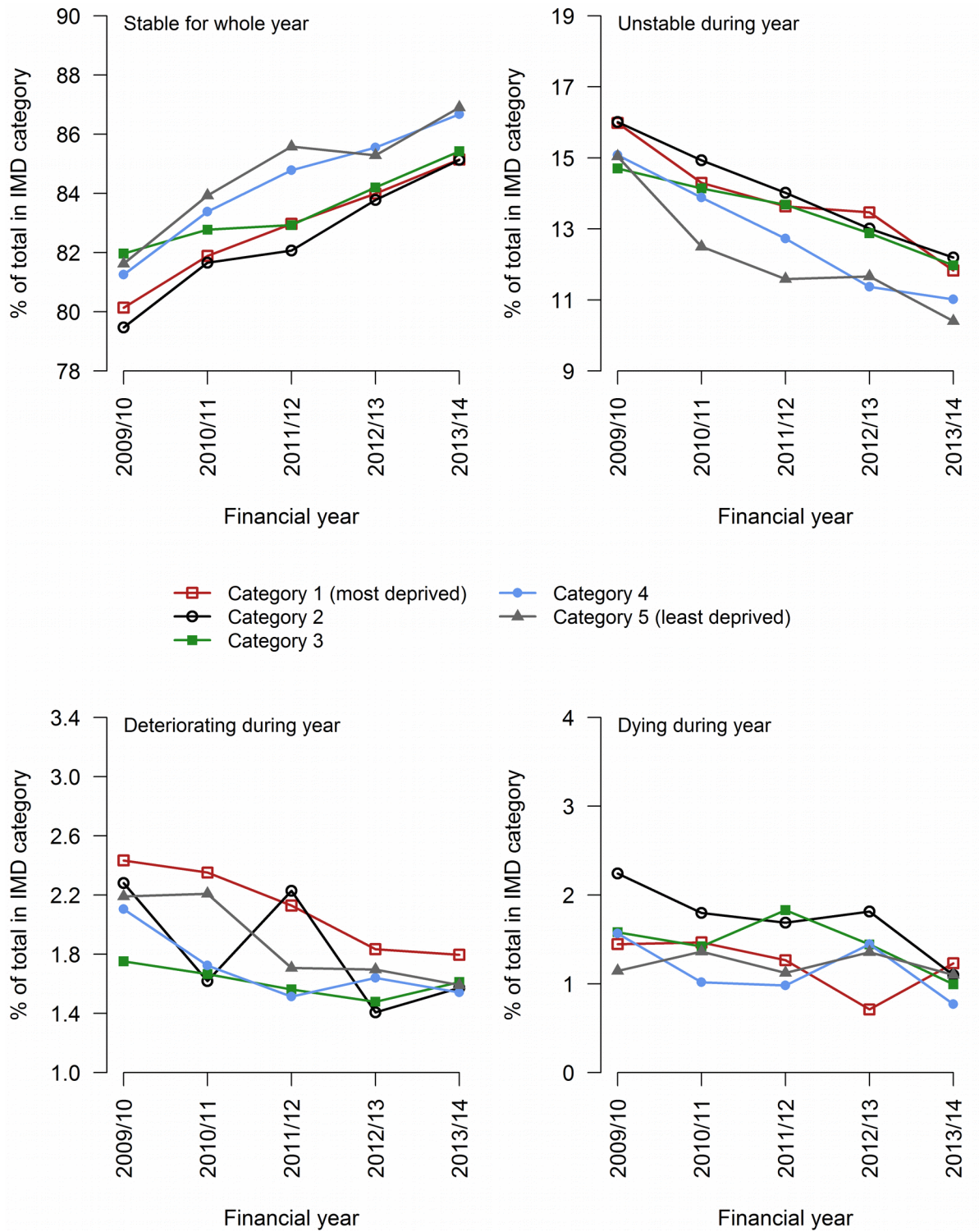


Figure S3: Clinical stage by deprivation (SIMD 2009) category among children and young people in Scotland with a life limiting condition. Recorded status is the most severe clinical stage in the year.



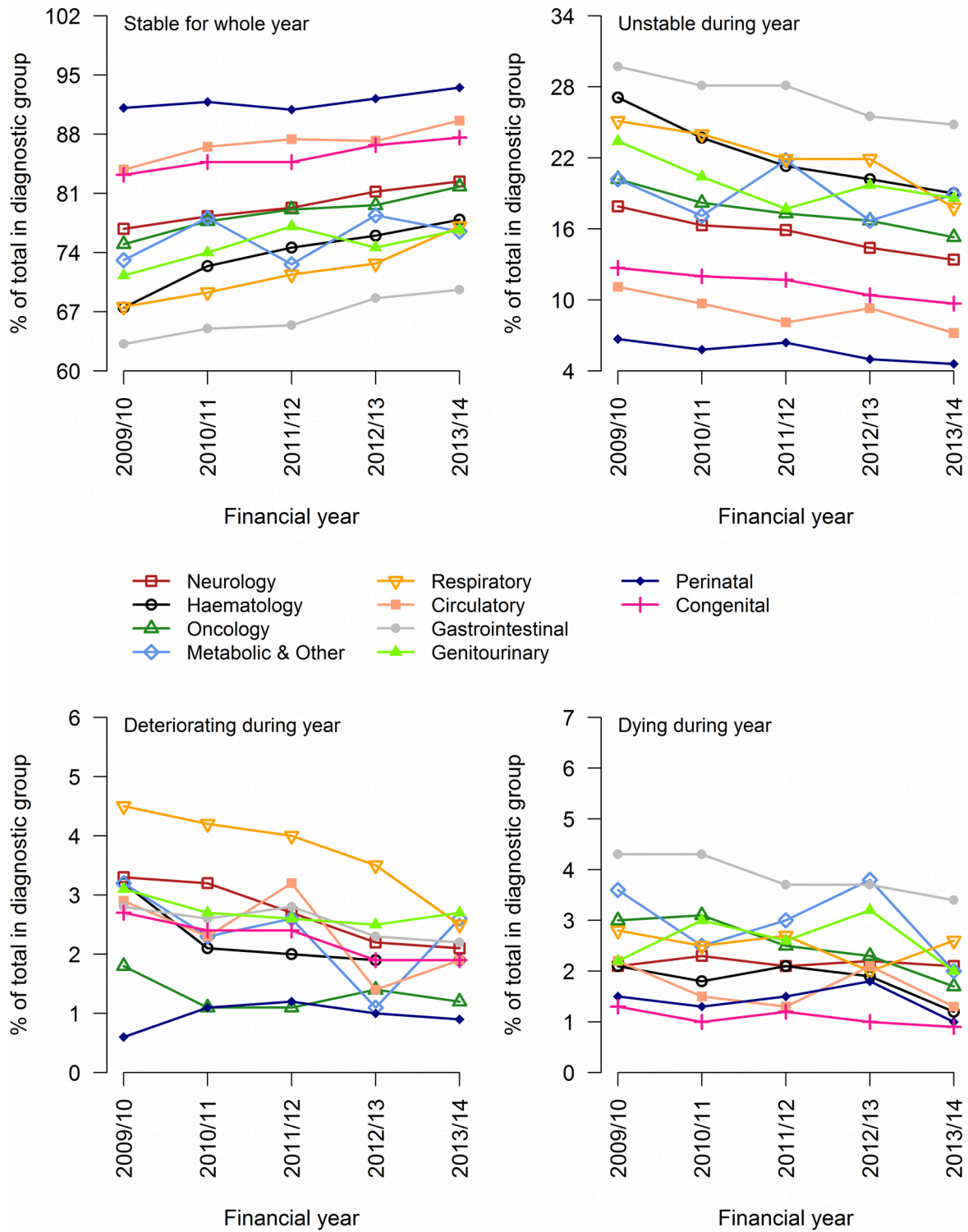


Figure S4: Clinical stage by diagnostic category among children and young people in Scotland with a life limiting condition. Recorded status is the most severe clinical stage in the year.