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# Place of death of children and young adults with a life-limiting condition in England: a retrospective cohort study

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## ABSTRACT

**Objective** To assess trends in place of death for children with a life-limiting condition and the factors associated with death at home or hospice rather than hospital.

**Design** Observational cohort study using linked routinely collected data.

**Setting** England.

**Patients** Children aged 0–25 years who died between 2003 and 2017.

**Main outcome measures** Place of death: hospital, hospice, home. Multivariable multinomial logistic regression models.

**Results** 39 349 children died: 73% occurred in hospital, 6% in hospice and 16% at home. In the multivariable models compared with dying in a hospital: neonates were less likely, and those aged 1–10 years more likely, than those aged 28 days to <1 year to die in hospice. Children from all ethnic minority groups were significantly less likely to die in hospice, as were those in the most deprived group (RR 0.8, 95% CI 0.7 to 0.9). Those who died from 2008 were more likely than those who died earlier to die in a hospice. Children with cancer (RR 4.4, 95% CI 3.8 to 5.1), neurological (RR 2.0, 95% CI 1.7 to 2.3) or metabolic (RR 3.7, 95% CI 3.0 to 4.6) diagnoses were more likely than those with a congenital diagnosis to die in a hospice.

Similar patterns were seen for clinical/demographic factors associated with home versus hospital deaths.

**Conclusions** Most children with a life-limiting condition continue to die in the hospital setting. Further research on preferences for place of death is needed especially in children with conditions other than cancer. Paediatric palliative care services should be funded adequately to enable equal access across all settings, diagnostic groups and geographical regions.

## INTRODUCTION

Although deaths in childhood have been decreasing, there are still 4500 infants and children who die in England and Wales every year<sup>1</sup> and approximately 50% of deaths in children<sup>2</sup> are for children with a life-limiting or life-threatening condition. Access to palliative and end-of-life care are therefore important components of paediatric health services.<sup>3</sup>

Palliative care services for children and young people in the UK have developed locally with heavy reliance on individual clinicians and third sector organisations such as children's hospices.<sup>3</sup> That

## What is already known on this topic?

- Place of death is used as a quality measure of end-of-life care.
- More children die at home or in hospice setting if they have palliative care input.
- The current evidence states that most parents, children and providers prefer home death.

## What this study adds?

- The vast majority of children with a life-limiting condition continue to die in the hospital setting.
- Children with a cancer diagnosis are much more likely to die at home or in hospice than children with other life-limiting conditions.

ad hoc provision means delivery of palliative care is often 'inconsistent and incoherent'.<sup>4</sup> The recent NICE guidelines<sup>5</sup> and quality standards of providing care<sup>6</sup> include: 'Infants, children and young people approaching the end of life and being cared for at home have 24 hour access to both children's nursing care and advice from a consultant in paediatric palliative care'. Currently in England, while there are more than 50 children's hospices, there are even tertiary children's hospitals, including oncology centres, without a paediatric palliative care service.

Place of death has been used in policy documentation as a measure of quality of palliative or end-of-life care in developed countries such as the UK.<sup>7</sup> The assumption that everyone wants to die at home has been contested in both children's and adult palliative care in recent years.<sup>8 9</sup> A recent review has concluded that 'Most parents, children, and providers prefer home death and the long-term outcomes for parents (even 6–8 years after the death of their child) may be better when their child died at home' but the authors also acknowledge that not all parents prefer a home death and the evidence is often from small studies.<sup>10</sup> However, at a population level, if we are truly able to offer choice of place of care at the end of life then we should see a spread between the possible places of death. One of the aims of recent NHS England service specification for palliative care is that 'more children and young people will achieve their preferred place of care at the end of their lives'. A national study showed that children who had palliative care input were eight times as likely as those without palliative



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## Original research

care input to die in the community rather than in hospital.<sup>11</sup> Therefore, the distribution of deaths between hospital, home and hospice may provide an indication of the degree to which families are able to access palliative care.

### Aims and objectives

This study aims to assess the trends in place of death for children who died with a life-limiting condition in England from 2003 to 2017 and the clinical and demographic factors which are associated with death at home or hospice rather than hospital.

## METHODS

### Data sources

Linked individual-level inpatient Hospital Episode Statistics (HES) and Office for National Statistics (ONS) death records were obtained from NHS Digital. These two data sets were linked by NHS Digital based on National Health Service number, gender date of birth and postcode.<sup>12 13</sup> Children and young people with a life-limiting condition were identified by

matching recorded diagnostic codes in inpatient records against the previously developed ICD-10 coding framework<sup>14</sup> (online supplemental table 1), for individuals aged 0–25 years (1 January 2000 to 31 December 2017).

### Data management

Place of death was categorised as hospital, hospice, home, other and missing based on the recorded *address of death* in the ONS death certificate data. The ‘other’ category included deaths at respite care centres, nursing homes, deaths outside the home (eg, in a park or school). Deaths where the street address was not present were recorded as missing.

The year of death was assigned from the ONS death certificate date of death and the sex was assigned as the most commonly recorded sex from the HES data.

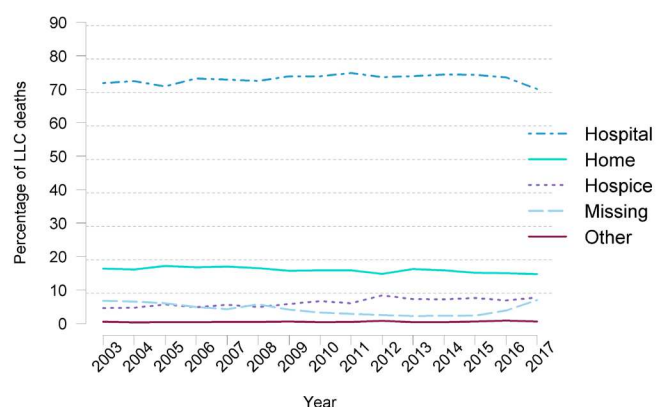
Age of death at last birthday was calculated by subtracting date of birth (HES record) from date of death (ONS record). Those who had died in the neonatal period (<28 days) were flagged on the death record. Seven age groups were created: neonate <28

**Table 1** Demographic characteristics of children and young people with a life-limiting condition who died\*

	Hospital		Hospice		Home		Other or missing†		Total
	n	%	n	%	n	%	n	%	n
Total	28753	73	2453	6	6269	16	1874	5	39349
Sex									
Male	15846	73	1332	6	3579	16	1066	5	21823
Female	12885	74	1121	6	2689	15	750	4	17445
Age group at death									
Neonate (<28 days)	9511	97	163	2	171	2			9846
28 days to 1 year	5586	71	380	5	614	8	1301	17	7881
1–5 years	3498	68	488	10	1063	21	79	2	5128
6–10 years	1554	57	295	11	819	30	48	2	2716
11–15 years	1772	59	302	10	856	29	68	2	2998
16–20 years	3010	63	347	7	1266	27	138	3	4761
21–25 years	3822	63	478	8	1480	25	239	4	6019
Ethnic group									
White	18017	69	1973	8	5030	19	949	4	25969
Black	1937	83	73	3	187	8	136	6	2333
Pakistani	2521	84	99	3	301	10	93	3	3014
Indian	888	81	39	4	117	11	47	4	1091
Bangladeshi	544	85	16	2	61	9	22	3	643
Mixed/Chinese/other	2393	78	167	5	340	11	175	6	3075
Region									
North-East	1227	71	60	4	392	23	58	3	1737
North-West	4100	75	292	5	889	16	211	4	5492
Yorkshire and Humber	2745	71	361	9	663	17	122	3	3891
East Midlands	2212	75	153	5	512	17	87	3	2964
West Midlands	3270	75	291	7	661	15	164	4	4386
East of England	2435	68	295	8	710	20	120	3	3560
London	4874	77	267	4	775	12	423	7	6339
South-East	3631	69	457	9	985	19	219	4	5292
South-West	2136	68	250	8	626	20	119	4	3131
Deprivation category									
Category 1 (least deprived)	3179	66	431	9	1071	22	156	3	4837
Category 2	3866	68	454	8	1186	21	220	4	5726
Category 3	4851	70	495	7	1287	19	294	4	6927
Category 4	6096	74	507	6	1302	16	325	4	8230
Category 5 (most deprived)	7851	78	533	5	1339	13	409	4	10132

\*Those with missing demographics are not presented due to small numbers.

†Combined to prevent small numbers.



**Figure 1** Trends in place of death of children and young people with a life-limiting condition in England from 2003 to 2017. LLC, life-limiting or life-threatening condition.

days, 28 days–1 year, 1–5 years, 6–10 years, 11–15 years, 16–20 years and 21–25 years.

Self-reported ethnicity for each hospital episode was coded according to the 16 census groups;<sup>15</sup> to prevent small numbers, these groups were collapsed into six ethnic groups as follows with the most commonly recorded ethnicity (from the six collapsed groups) assigned to each individual:

- ▶ White (white: British, white: Irish, other white)
- ▶ Black (black or black British: black Caribbean, black or black British: black African, black or black British: other black)
- ▶ Indian (Asian or Asian British: Indian)
- ▶ Pakistani (Asian or Asian British: Pakistani)
- ▶ Bangladeshi (Asian or Asian British: Bangladeshi)
- ▶ Other (Chinese, mixed or other)

The last known government office region of residence was assigned using the HES and ONS data for each individual.

An Index of Multiple Deprivation (IMD2010) Score<sup>16</sup> was assigned to each individual based on last known lower super output area (LSOA) of residence. LSOAs are small geographical areas with a population from 1000 to 3000 individuals. Five population-weighted categories were created (category 1—least deprived) based on the IMD Scores with approximately 20% of the population living in each category.

The life-limiting condition diagnoses were grouped according to 11 diagnostic groups (neurology, haematology, oncology, metabolic, respiratory, circulatory, gastrointestinal, genitourinary,

perinatal, congenital and other).<sup>14</sup> The most common diagnostic group across all inpatient records for each individual was calculated with ties resolved by giving preference to later diagnoses.

## Analysis

To avoid missing data issue at the start of the study time period, children were included in the analyses 2003 onwards.

Temporal trends in place of death were plotted as a visual assessment of change over time. Place of death was described by sex, age group, ethnicity, government office region, deprivation category and main diagnostic group.

The association between the place of death and key clinical (diagnostic group) and demographic (age, sex, ethnic group, deprivation status and region) variables was assessed using multi-variable multinomial logistic regression modelling comparing hospital death to both home and hospice deaths. Year of death was included in three equal epochs: 2003–2007, 2008–2012 and 2013–2017.<sup>17</sup>

All data manipulation was undertaken using Microsoft SQL server and statistical analysis using STATA V.15 (StataCorp, Collage Station, Texas, USA). Statistical significance was assumed at  $p \leq 0.05$  (two-sided).

## RESULTS

### Cohort

The total cohort of children with a life-limiting condition who had died from 2000 to 2017 was 53 518. After removal of those not resident in England ( $n=1512$ ) and those who died before 2003 or after 2017 ( $n=7853$ ) and those who died  $>25$  years ( $n=4804$ ), the final cohort for analyses was 39 349.

### Place of death

Overall 73% of deaths occurred in hospital, 6% in hospice and 16% at home. Five per cent died elsewhere or were missing place of death (table 1).

The percentage of deaths in hospital remained relatively static at just over 70% of deaths (figure 1). The percentage of children who died at home remained relatively static at around 15%–16%. This was in contrast to deaths in hospices which rose from 5% to 8% during the period of this study.

Place of death varied considerably by age with 97% of neonates and 71% of those aged 28 days to 1 year dying in hospital and only 2% and 8%, respectively, dying at home (table 1). The percentage of children dying at home peaks at 30% in those aged 6–10 years. Deaths in hospices were also most common, at 11%, in the 6–10 years age group.

**Table 2** Clinical characteristics of children and young people with a life-limiting condition who died

	Hospital			Hospice		Home		Other or missing*		Total
Cancer	3515	44	1075	14		3224	41	100	1	7914
Metabolic conditions	830	61	179	13		306	23	36	3	1351
Neurological conditions	3387	68	458	9		965	19	184	4	4994
Other conditions	530	71	73	10		92	12	51	7	746
Circulatory conditions	8276	81	425	4		917	9	621	6	10239
Genitourinary conditions	1775	82	44	2		196	9	160	7	2175
Respiratory conditions	1766	82	69	3		243	11	86	4	2164
Haematological conditions	559	85	13	2		63	10	20	3	655
Congenital conditions	1074	86	20	2		105	8	46	4	1245
Gastrointestinal conditions	475	88	11	2		25	5	30	6	541
Perinatal conditions	6566	90	86	1		133	2	540	7	7325

\*Combined due to small numbers.

**Table 3** Multivariable multinomial logistic models (n=34 425)

	Hospice versus hospital				Home versus hospital			
	RR	95% CI		P value	RR	95% CI		P value
Age at death								
Neonate	0.4	0.3	0.5		0.2	0.2	0.3	
28 days to 1 year	REF				REF			
1–5 years	1.1	0.9	1.3	<0.001	1.6	1.4	1.8	<0.001
6–10 years	1.1	0.9	1.3	<0.001	2.2	1.9	2.5	<0.001
11–15 years	1.0	0.8	1.2	0.002	2.0	1.7	2.3	<0.001
16–20 years	0.7	0.6	0.8	0.242	1.7	1.5	1.9	<0.001
21–25 years	0.8	0.6	0.9	0.956	1.6	1.4	1.8	<0.001
Sex								
Male	REF				REF			
Female	1.0	0.9	1.1	0.286	0.9	0.9	1.0	0.104
Ethnic group								
White	REF				REF			
Black	0.5	0.4	0.6	<0.001	0.5	0.4	0.6	<0.001
Pakistani	0.3	0.3	0.4	<0.001	0.5	0.5	0.6	<0.001
Indian	0.5	0.3	0.6	<0.001	0.6	0.5	0.7	<0.001
Bangladeshi	0.3	0.2	0.6	<0.001	0.6	0.4	0.8	<0.001
Mixed/Chinese/other	0.7	0.6	0.8	<0.001	0.6	0.5	0.7	<0.001
Missing	0.6	0.5	0.8	<0.001	0.7	0.6	0.9	<0.001
Deprivation category								
Category 1—least deprived	REF				REF			
Category 2	1.0	0.8	1.1	0.529	1.0	0.9	1.1	0.952
Category 3	0.9	0.8	1.0	0.145	0.9	0.8	1.0	0.147
Category 4	0.9	0.8	1.0	0.054	0.9	0.8	0.9	0.01
Category 5—most deprived	0.8	0.7	0.9	0.003	0.8	0.7	0.8	<0.001
Government office region								
London	REF				REF			
North-East	0.7	0.6	1.0	0.047	1.7	1.4	1.9	<0.001
North-West	1.2	01.0	1.4	0.062	1.2	1.1	1.4	0.002
Yorkshire and Humber	2.3	1.9	2.7	<0.001	1.4	1.2	1.6	<0.001
East Midlands	1.0	0.8	1.3	0.933	1.1	1.0	1.3	0.118
West Midlands	1.6	1.4	12.0	<0.001	1.2	1.1	1.4	0.003
East of England	1.8	1.5	2.1	<0.001	1.4	1.2	1.6	<0.001
South-East	1.8	1.5	2.2	<0.001	1.3	1.2	1.5	<0.001
South-West	1.7	1.4	2.1	<0.001	1.4	1.3	1.6	<0.001
Year of death								
2003–2007	REF				REF			
2008–2012	1.5	1.3	1.6	<0.001	1.1	1.04	1.2	0.003
2013–2017	1.7	1.5	1.9	<0.001	1.2	1.07	1.3	0.003
Main diagnostic group								
Congenital conditions	REF				REF			
Circulatory conditions	0.3	0.2	0.5	<0.001	0.6	0.5	0.7	<0.001
Gastrointestinal conditions	0.4	0.2	0.7	0.005	0.3	0.2	0.5	<0.001
Genitourinary conditions	0.4	0.3	0.6	<0.001	0.6	0.5	0.7	<0.001
Haematological conditions	0.4	0.2	0.7	0.003	0.6	0.5	0.8	0.004
Metabolic conditions	3.7	3.0	4.6	<0.001	2.1	1.8	2.5	<0.001
Neurological conditions	2.0	1.7	2.3	<0.001	1.3	1.2	1.5	<0.001
Cancer	4.4	43.8	5.1	<0.001	4.0	3.6	4.4	<0.001
Other conditions	2.4	1.8	3.1	<0.001	1.2	0.9	1.5	0.134
Perinatal conditions	0.3	0.3	0.4	<0.001	0.4	0.3	0.5	<0.001
Respiratory conditions	0.6	0.4	0.8	0.002	0.7	0.6	0.8	<0.001

NICE, National Institute for Health and Care Excellence; REF, reference group; RR, relative risk.

A lower percentage of white children died in hospital (69%) when compared with the other ethnic groups where between 78% (Chinese/mixed/other) to 85% (Bangladeshi) died in hospital.

The highest percentage of deaths in hospital were in London (77%) with the lowest in the South-West (69%). Yorkshire and the Humber and the South-East had the highest percentage of hospice deaths (9%) and the North-East the lowest (4%).

Conversely the highest percentage of home deaths was also in the North-East (23%) and the lowest in London (12%).

There is a linear trend with deprivation, the more deprived being more likely to die in hospital.

Table 2 shows the distribution of place of death by diagnostic category. The percentage of children with cancer who died in hospital was 44% with the next lowest metabolic at 61%. Home deaths were also highest among children who had cancer (41%) and were lowest among those who had perinatal conditions (2%). Children with cancer (14%), metabolic conditions (13%), other conditions (10%) or neurological conditions (9%) had the highest percentage of hospice deaths.

The results of the multivariable multinomial logistic regression model comparing dying at home or in a hospice compared with dying in hospital are shown in table 3. The reference group for comparison throughout this section is hospital.

Hospice versus hospital: Neonates were less likely than those aged 28 days to <1 year to die in hospice and those aged 1–10 years were more likely to die in a hospice than those aged 28 days to 1 year. However, those aged 11–25 years were no more likely than the those aged 28 days to <1 year to die in a hospice.

Children from all the ethnic minority groups were significantly less likely to die in hospice with children of Bangladeshi origin being the least likely to die in a hospice (RR 0.3, 95% CI 0.2 to 0.6) compared with white children. Those in the most deprived group were also less likely to die in a hospice compared with the least deprived (RR 0.8, 95% CI 0.7 to 0.9). There were some geographical differences, with those who died in Yorkshire and Humber more likely than those in London to die in a hospice (RR 2.3, 95% CI 1.9 to 2.7). Those in the North-East were less likely than those in London to die in a hospice (RR 0.7, 95% CI 0.6 to 1.00).

Those who died after 2008 were more likely than those who died before 2008 to die in a hospice.

Children with a cancer (RR 4.4, 95% CI 3.8 to 5.1), neurological (RR 2.0, 95% CI 1.7 to 2.3) or metabolic (RR 3.7, 95% CI 3.0 to 4.6) diagnosis were more likely than those with a congenital diagnosis to die in a hospice.

There are some similarities in the home versus hospice component of the model for sex, ethnic group, deprivation and trends over time. The key differences in this comparison were that all age groups over 1 year were more likely than the 28 days to <1 year old group to die at home. Children from all other regions were more likely than those living in London to die at home compared (including the North-East, RR 1.7, 95% CI 1.4 to 1.9, in contrast to the results for hospice compared with hospital).

## DISCUSSION

The majority of children with a life-limiting condition in England continue to die in a hospital setting. There is some evidence of an increase in hospice deaths since the government report 'Better Care, Better Lives' in 2008<sup>18</sup> but there is still a relatively small number of deaths (<200) in hospices each year. The most recent national children's hospice data collection showed that only 21% of their caseload who died, died in the hospice.<sup>19</sup>

A higher proportion died in hospital in the present study than in studies from other countries<sup>20 21</sup> which may not be surprising given the different models of provision of palliative care and funding of healthcare systems across the world. The proportion of deaths at home are similar to figures from the USA (10.1% in 1989 rising to 18.2% in 2003)<sup>22</sup> and Portugal (19.4%).<sup>23</sup>

Palliative care input has been associated with more children dying outside the hospital; a national study from England and

Wales of 7709 children who died after being discharged from paediatric intensive care units showed that children who had palliative care recorded at the time of discharge were eight times more likely to die in the community than children who were not referred to palliative care.<sup>11</sup> Likewise the study by Chang *et al*, showed that those who had palliative care were less likely to die in hospital.<sup>20</sup> A study from Germany showed that of children who received specialist paediatric palliative care, 84% died at home with 96% in their preferred place.<sup>24</sup> The general consensus among studies to date is that home is the preferred place of death, although not all families prefer home deaths; preferences vary over time and the research base consists of small studies which were prone to selection bias.<sup>10</sup>

Children with cancer were much more likely than other children to die at home or in a hospice. In England, children with cancer are treated and managed under a different model of care with palliative care being provided by specialists, including the paediatric oncology outreach nurses in most principal treatment centres.<sup>25</sup> A recent national study showed that from 1993 to 2014, among children who died from cancer in England, those dying at home remained static at approximately 40%; hospital deaths decreased slightly from >50% to 45% and hospice deaths increased from 6% to 13%.<sup>26</sup> An international study<sup>21</sup> highlighted large variations in place of death between countries and that children with conditions other than cancer were less likely to die at home.

Age has been shown in several studies to be associated with dying at home with infants less likely than older children to die outside hospital.<sup>22 27</sup> The predominance of hospital death in the neonatal group may highlight the unpredictability of their prognosis and the additional challenges of offering choice of place of death in neonatal care.<sup>28</sup>

This study highlighted the differences in place of death for children from a minority ethnic group. This has been shown in other studies.<sup>20 26</sup> There is little evidence on preferences of place of care in these populations and differences could possibly be due to access to healthcare services, divergent cultural attitudes or differing levels of financial or social support within a patient's family or social network.<sup>22</sup> Importantly, services must be flexible enough to meet the needs of all children and their families.<sup>17 29</sup>

## Strengths and limitations

This study used a whole population data set to identify children with a life-limiting condition and national death registration records. There can be delays in the registration of deaths for children if the coroner is involved so the recent years of data may be incomplete.

It was not possible to identify those children who had and had not received palliative care prior to death. There were no data on preferred place of death available for this cohort of children.

## CONCLUSIONS

Despite small increases in hospice deaths over the last 15 years the vast majority of children with a life-limiting condition die in the hospital setting. Further research is needed on preferences for place of death especially in children with conditions other than cancer. Paediatric palliative care services should be funded adequately to enable equal access across all settings, diagnostic groups and geographical regions.

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**Contributors** DG-S, SWJ, LKF have all made a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data; drafted the article or revised it critically for important intellectual content; approved

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**Competing interests** None declared.

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**Data availability statement** Data may be obtained from a third party and are not publicly available. Data are available from NHS Digital.

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Supplementary Table 1

: ICD-10 diagnostic coding framework used to identify and categorise children with life-limiting conditions.	
Diagnostic Group	ICD-10 Numbers
Neurology	A17 A810 A811 F803 F842 G10 G111 G113 G12 G20 G230 G238 G318 G319 G35 G404 G405 G600 G601 G702 G709 G710 G711 G712 G713 G800 G808 G823 G824 G825 G934 G936 G937
Haematology	B20 B21 B22 B23 B24 D561 D610 D619 D70 D761 D81 D821 D83 D891
Oncology	C D444 D48 (Central Nervous System: C70,C71,C72, D33, D43)
Metabolic	E310 E348 E702 E71 E72 E74 E75 E76 E77 E791 E830 E880 E881
Respiratory	E84 J841 J96 J984
Circulatory	I21 I270 I42 I613 I81
Gastrointestinal	K550 K559 K72 K74 K765 K868
Genitourinary	N17 N18 N19 N258 (Early stage (1-3) renal:N181, N182, N183)
Perinatal	P101 P112 P210 P285 P290 P293 P350 P351 P358 P371 P524 P525 P529 P832 P912 P916 P960
Congenital	Q000 Q01 Q031 Q039 Q040 Q042 Q043 Q044 Q046 Q049 Q070 Q200 Q203 Q204 Q206 Q208 Q213 Q232 Q218 Q220 Q221 Q224 Q225 Q226 Q230 Q234 Q239 Q254 Q256 Q262 Q264 Q268 Q282 Q321 Q336 Q396 Q410 Q419 Q437 Q442 Q445 Q447 Q601 Q606 Q614 Q619 Q642 Q743 Q748 Q750 Q772 Q773 Q774 Q780 Q785 Q792 Q793 Q804 Q81 Q821 Q824 Q858 Q860 Q870 Q871 Q872 Q878 Q91 Q920 Q921 Q924 Q927 Q928 Q932 Q933 Q934 Q935 Q938 Q952
Other	H111 H498 H355 M313 M321 M895 T860 T862 Z515

