PREVALENCE OF LIFE LIMITING ILLNESS IN CHILDREN AND YOUNG PEOPLE IN THE UK

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Background Life-limiting illness describes conditions with no reasonable hope of cure that will ultimately be fatal. There is little national or local data are available to estimate the burden of these conditions.

Methods An extract of inpatient Hospital Episodes Statistics (HES, England), Scottish Morbidity Records Inpatient activity database (Scotland, SMR 01), inpatient Patient Episode Database (PEDW, Wales) and Hospital Inpatient Statistics (HIS, Northern Ireland) were obtained (2000/01–2009/10). Children (0–19 years) with life-limiting conditions were identified within these datasets by applying a customised coding framework of ICD-10 disease codes. Prevalence per 10 000 population (0–19 years) was calculated by age, diagnostic group, ethnicity, deprivation and region for each year.

Results Overall prevalence in England in 2010 was double previous estimates at 33 per 10 000 population (0–19 years). Prevalence was highest in the under 1 age group and decreased through the age bands. Male prevalence was significantly higher than in the female prevalence in all years. The highest prevalence was of congenital anomalies with the lowest prevalence in circulatory and gastrointestinal diagnoses. The overall prevalence rates differed between the countries within the UK but the patterns seen for age, sex and diagnostic group were similar. The ethnicity data was only available for England: prevalence (per 10 000) in the South Asian (50), Black (43) and Chinese and other (34) populations were significantly higher compared to the White population (28). The effect of ethnicity is not completely accounted for by deprivation as ethnicity exerts a strong influence in the most affluent category, especially in the South Asian population.

Conclusions In 2010 the prevalence of life-limiting conditions in children and young people in England was double the

previously reported estimates and had increased annually in all areas over the last decade. This clearly identifies an escalating need for specialist paediatric palliative care services.