Chapter 6: Health conditions of childhood

6.1 Asthma

Emergency hospital admission rate for asthma for children and young people under 19 years of age in Great Britain

Key messages

- Asthma is the commonest long-term medical condition in the UK. One in 10 to 11 children and young people in the UK has asthma.

- The UK has one of the highest prevalence, emergency admission and death rates for childhood asthma in Europe.

- There is wide geographical variation in emergency asthma admission rates for children across the UK.

- Most emergency admissions are preventable, with high-quality management (including the use of asthma plans) and early intervention to address deterioration in control.

What is this indicator showing us?

This indicator shows the rate (per 100,000 children) of emergency admissions to hospital for asthma of children and young people under 19 years of age in Great Britain. Children and young people who are seen in the emergency department only (i.e. not admitted) are not included in this indicator.

Data availability and comparability

Data on emergency admissions are available for England from 2003/2004 to 2014/2015, for Scotland from 2010/2011 to 2014/2015 (historical data between 2005/2006 and 2009/2010 is only available for children aged 14 and under) and for Wales from 2003/2004 to 2015/2016. Data from Northern Ireland are not segregated by age and are therefore not available for these purposes.

Rate of emergency admissions to hospital for asthma among children and young people in England, Scotland and Wales

![Graph showing emergency hospital admissions for asthma per 100,000 children (<19 years) in England, Wales and Scotland, 2003/2004 to 2015/2016](image)

**Figure 6.1.1: Emergency hospital admissions for asthma per 100,000 children (<19 years) in England, Wales and Scotland, 2003/2004 to 2015/2016**

**Latest data:** The rate of emergency admissions to hospital of children under 19 with asthma in 2014/2015 was 206 in England, 199 in Scotland and 208 in Wales (all per 100,000 population).

**Trend:** Since 2003/2004 there has been a decrease in the asthma emergency admission rate in England and Wales, although the rate in both countries has fluctuated considerably within the period. Trends in Scotland are unclear.

**Source:** Health and Social Care Information Centre (HSCIC) for England, National Statistics Release for Scotland, and NHS Wales Informatics Service for Wales.
Spotlight on inequalities

As deprivation increases the number of emergency hospital admissions for asthma increases across all age-groups amongst children and young people. Further exploration is needed to understand if this variation is explained by variations in prevalence or if it is attributable to the aggravation of symptoms (for example, from air pollution or by active or passive smoking) or to differences in management.

![Figure 6.1.2: Emergency hospital admissions for asthma per 100,000 children by age and deprivation quintile (fifth of population), in England 2013/2014](image)

Why is this indicator important?

The prevalence of asthma in the UK is among the highest in the world\(^{308,309}\). It is estimated that 1.1 million children in the UK (36,000 children in Northern Ireland, 72,000 in Scotland, 59,000 in Wales and 932,000 in England) are currently receiving treatment for asthma\(^{309}\).

The number of reported asthma deaths in the UK is also amongst the highest in Europe\(^{310,311}\). The National Review of Asthma Deaths (NRAD) found that the overall standard of care for children was inadequate in 46% of the deaths reviewed and that there were potentially avoidable factors related to patients and their families in 65% deaths\(^{311}\).

The NHS spends around £1 billion a year treating people with asthma\(^{309}\), with around half of this expense being for unscheduled care. It is estimated that up to 70% of emergency admissions for asthma (adults and children) may be preventable\(^{312}\).

Where are we now in the UK?

Asthma is a leading cause of admission to hospital for children. A child is admitted to hospital every 20 minutes in the UK because of an asthma attack\(^{309}\).

In 2014/2015, there were 25,206 emergency admissions to hospital for children with asthma in England\(^{313}\), 2,188 in Scotland\(^{314}\) and 1,390 in Wales\(^{315}\).

The rates of emergency admissions for asthma (per 100,000) have shown an overall decrease in England and Wales over the last decade. The rate in Wales was consistently higher than in England and Scotland but has fallen to largely match the other countries.

What does good look like?

Asthma is a long-term condition that cannot be cured, but for the great majority of children it can be effectively managed. Children and young people with asthma should be able to lead a normal and active life, and one that does not include hospitalisations for asthma.

There is substantial geographical variation in the emergency admission rate; within England in 2012/2013 the emergency asthma admission rate for children (excluding outliers) ranged from 93 to 449 per 100,000 population (4.8-fold variation)\(^{316}\). The variation by deprivation shown
in Figure 6.1.2 suggests all UK children could have the same admission rate as the least deprived quintile.

Almost all emergency hospital admissions for asthma are preventable; therefore, with effective management we should see a decrease in the number of emergency admissions across the UK and a reduction in the geographical variation in admissions.

**How can we improve?**

The causes of asthma are not well understood and further research is needed. Good practice recommends that efforts begin with prevention, i.e. to reduce the risk of a child developing asthma. Actions should be focused on supporting pregnant women to stop smoking (see Indicator 2.1 on maternal smoking), encouraging breastfeeding (see Indicator 2.2 on breastfeeding) and reducing the impact of environmental smoke and air pollution\(^{317,318}\).

A whole pathway approach is required to reduce emergency admissions for asthma\(^{310}\), with a focus on high-quality management (through full implementation of applicable guidance, e.g. NICE\(^{319}\) and SIGN\(^{320}\), and early intervention to address any deterioration).

Treatment needs to be tailored to the individual and all children with asthma should be provided with a personal asthma action plan and have a structured review by a healthcare professional with specialist training in asthma, at least annually\(^{310,311,316}\).

The National Review of Asthma Deaths found that seven of 18 (39%) children were exposed to second-hand smoke\(^{311}\); exposure to allergens and second-hand smoke should be minimised wherever possible (see Indicator 2.1 on smoking). Poor recognition of risk factors which can trigger an asthma attack is an important avoidable factor for children. There needs to be better education to enable children and their families to understand what triggers their symptoms and support to help them avoid these triggers and self-manage their condition\(^{310,316,317}\).

As adolescents move towards adulthood and more independent self-management, there can be challenges in maintaining good asthma control. Ensuring all primary and secondary care professionals have training in working with adolescents is essential to help them continue good disease control.

There is also a substantial role for schools to play to deliver their responsibilities to support children with long-term conditions such as asthma. These responsibilities are statutory in some countries.

Health professionals must be aware of the factors that increase the risk of asthma attacks and death in order to better support children to understand and manage their known triggers.

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**Key actions**

- Strengthen research into the underlying causes of asthma and ways to prevent it.
- Ensure full implementation of NICE and SIGN asthma guidelines across the UK.
- Improve asthma education for children, families and healthcare professionals. Improve training for healthcare professionals in working with young people.
- Deliver school responsibilities in relation to children with asthma (e.g. implementation of statutory guidance in England compared with other nations etc.).
Chapter 6: Health conditions of childhood

6.2 Cancer

Proportion of children (0–14 years) surviving five years following a diagnosis of cancer

Key messages

- Despite continuing advances in treatment and consequent improvements in survival rates, cancer remains the most frequent medical cause of death for children in the UK \(^{321}\).

- The proportion of children surviving five years following a cancer diagnosis has doubled since the 1970s. This increase is likely to be due to improvements in treatment and supportive care.

- The increases in survival for many of the principal types of childhood cancer have occurred in parallel with clinical trials in the same period of time \(^{322}\).

- The UK has relatively low mortality rates compared with high-income countries worldwide, although there is some evidence that survival rates are poorer for some cancers than the best in Europe.

What is this indicator showing us?

This indicator shows the percentage of children aged 0–14 years who survive cancer (all types) by the five-year follow-up.

Data availability and comparability

Data for the proportion of children surviving five years following a diagnosis of cancer are not comparable across England, Northern Ireland, Scotland and Wales. We have therefore used data on survival collated across Great Britain \(^{323}\).

A range of other data are available within different countries of the UK, including incidence, mortality and proportions surviving for one, five or 10 years.

Cancer survival rates among children in Great Britain

![Cancer survival rates among children in Great Britain](image)

**Latest data:** For the period 2006–2010, 82% of children aged 0–14 years with cancer in Great Britain have survived at the five-year follow-up.

**Trend:** The percentage of children surviving cancer for five years after diagnosis has doubled between 1971 and 2010 in Great Britain.

**Source:** Children’s cancer survival statistics, Cancer Research UK

*Figure 6.2.1: Proportion of children aged 0–14 years surviving cancer (all types) after five years in Great Britain by five year epoch, 1971 to 2010*
Why is this indicator important?

Cancer is one of the leading causes of death during childhood\textsuperscript{11,16}.

Every day around five children in the UK are diagnosed with cancer\textsuperscript{324}, with around 1,700 children in Great Britain diagnosed each year\textsuperscript{325}.

There are many types of cancer that can affect children, which are often different from cancers in adults.

The most common type of cancer in childhood is leukaemia, with 480 cases diagnosed every year, followed by brain tumours (400 per year), lymphomas (160 per year) and soft tissue sarcoma (100 per year). Other cancers in childhood include germ cell, neuroblastoma, eye, kidney, liver and bone.

Cancer is also one of the leading causes of death in teenagers. Teenage cancer is not included in this indicator, because types of cancer differ from those in younger children.

Where are we now in the UK?

Data show that across Great Britain between 2006 and 2010, 82% of children (0–14 years) survived five years following a diagnosis. This proportion has doubled since the early 1970s.

In England, 81% of children diagnosed with cancer in 2009 survived for at least five years\textsuperscript{322}.

In Northern Ireland between 2000 and 2009, 79% of children aged 0–14 years survived five years after a cancer diagnosis (all types excluding non-melanoma skin cancer)\textsuperscript{326}.

In Scotland, the proportion of children surviving five years after a cancer diagnosis rose from 65% in 1983-1987 to 76% in 1998-2002\textsuperscript{327}.

Specific data for Wales are not available\textsuperscript{328}.

What does good look like?

Compared to countries across Europe the UK sits above the average for five year survival rates for children and young people diagnosed with cancer\textsuperscript{328}. However, there is some evidence that overall survival rates for some cancers are lower than the best in Europe\textsuperscript{329}.

It is important that we continue to make improvements in five year survival rates alongside other European countries.

However, there has been little recent progress in cancer mortality across Europe for a number of cancers, including Hodgkin’s lymphoma, Burkitt’s lymphoma, CNS tumours, neuroblastoma, Wilms’ tumour, Ewing’s sarcoma, osteosarcoma, and rhabdomyosarcoma. Further work is needed to understand how we can make improvements in diagnosis, treatment and care for children and young people diagnosed with these types of cancer\textsuperscript{328}.

How can we improve?

Improvements thus far have been based on science – on better understanding of the biology of cancer and on high-quality clinical trials of treatment regimens.

Research must continue to understand the basic biology of cancer, identifying the genes and molecules that are the cause of most childhood cancers. The UK and international system of research trials in childhood cancer has been one of the most impressive achievements of paediatric medicine over the last 30 years, and investment must continue to develop and test more effective, kinder treatments.

Survivors of childhood cancer need support throughout adulthood, and clinicians should be aware of risks to physical and mental health\textsuperscript{329,330}, many of which are life long and require regular, active surveillance; as survival rates increase for children and young people, so do the number of adult survivors.

Primary care professionals in the UK need better access to support and training, both initial training and ongoing development opportunities, to help them to engage effectively with children and young people, and to confidently identify potential cancer diagnoses early in this age group\textsuperscript{329,331}.

It is essential to ensure that cancer services put children and young people at the centre of care provided to them and that they receive support, information and advice as part of a holistic approach to help them cope with adversity\textsuperscript{329-333}. 
Key actions

- Collect comparable data across the UK to give a UK-wide and country-level overview of cancer incidence, mortality and survival.

- Re-establish the ability to analyse UK-wide data on childhood cancer routinely.

- Ensure children and young people are fully involved in decisions about their cancer treatment and care.

- Strengthen research into childhood cancers, including ensuring wide access to clinical trials.

Additional data note

Comparable data were not available for the four nations across the UK, hence aggregated Great Britain data have been used here.
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6.3 Diabetes

Proportion of children and young people with Type 1 diabetes meeting recommended targets for blood glucose control

Key messages

- Type 1 diabetes is an increasingly common childhood condition affecting rising numbers of children and young people in the UK.
- Poor management of the condition in childhood can have severe long-term health implications.
- There has been an increase in the proportion of children and young people in England and Wales with HbA1c levels below the target of 58mmol/mol since 2010/2011.
- Those from deprived or black and minority ethnicity backgrounds have poorer diabetes control.

What is this indicator showing us?

This indicator shows the proportion of children and young people with diabetes meeting the pre-August 2015 NICE recommended HbA1c target of less than 58mmol/mol, indicative of good control. The guidance has subsequently been updated and the threshold reduced to 48mmol/mol\(^3\). HbA1c refers to glycated haemoglobin and is used to estimate average blood glucose exposure over the previous two months.

Data availability and comparability

Data are available for England and Wales from 2010 to 2015\(^3\) through the National Paediatric Diabetes Audit for children and young people aged 0 to 24 years.

Proportion of children with Diabetes in England and Wales

England

![Graph showing proportion of children with diabetes by HbA1c level in England, 2010/2011 to 2014/2015](image)

**Latest data:** In 2014/2015, 24% of children and young people in England had HbA1c levels less than the NICE recommended threshold of 58 mmol/mol.

**Trend:** There has been an increase in the proportion of children and young people with HbA1c levels below the 58 mmol/mol threshold and a corresponding fall in proportions with poor control (>80mmol/mol) since 2010/2011.

**Source:** NPDA Annual reports 2010/2011 to 2014/2015.

Figure 6.3.1: Proportion of children and young people* with diabetes by HbA1c level in England, 2010/2011 to 2014/2015
Why is this indicator important?

Type 1 diabetes is a common condition of childhood, with an estimated 31,500 children in the UK under the age of 19 living with the illness. The UK is currently sixth highest in the world for number of new cases of Type 1 diabetes, with 28.2 per 100,000 being diagnosed each year.

Early diagnosis is essential. In 2011/2012, 16% of Type 1 diabetes diagnoses occurred following the development of diabetic ketoacidosis (DKA), a potentially life-threatening condition where there is a lack of insulin preventing the body from using glucose for fuel.

The twin goals of managing Type 1 diabetes are maintaining good control of blood glucose (assess by HbA1c below target) and maintaining a good quality of life for children and young people. Diabetes can lead to high or low blood glucose issues and psychological problems during childhood. There are also serious long-term complications related to poor diabetes control during childhood and adolescence, including retinopathy, renal dysfunction, and other microvascular complications, as well as later macrovascular complications including heart disease and stroke and higher risk of death.

The direct and indirect costs of treating diabetes (of all types) in the UK were £23.7 million in 2010/2011, a figure estimated to increase to £39.8 million by 2035/2036 although much of this is driven by increases in Type 2 diabetes.

What does good look like?

Children and young people with good diabetes control, i.e. an HbA1c below target, are less likely to develop complications related to diabetes. All children with Type 1 diabetes in the UK should have a HbA1c level of less than 48mmol/L as per current NICE guidance.

There are marked variations in diabetes clinic performance in terms of patient and parent satisfaction with their care and in average HbA1c. This may relate to differing use of or access to more intensive diabetes regimens, such as insulin pumps and continuous glucose monitoring. Both of these can improve diabetes control and patient satisfaction; however, access to such technologies varies across and within each country.

Work is needed to minimise variation between clinics so that all children and young people with diabetes receive high-quality care.

All children and young people with Type 1 diabetes should be offered an ongoing integrated package of care by a multidisciplinary paediatric diabetes care team. Monitoring progress in each young person is essential. All children and young people should receive four HbA1c tests each year, again following the NICE guidance. In addition, those over the age of 12 years should have annual complication screening and other health checks completed and recorded, as per NPDA recommendations.

Latest data: In 2014/2015, 18% of children and young people in Wales had HbA1c levels less than the NICE recommended threshold from 2004 of 58mmol/mol.

Trend: There has been no overall change in the proportion of children and young people with HbA1c levels equal to or below the 58mmol/mol threshold since 2010/2011.

Source: NPDA Annual reports 2010/2011 to 2014/2015
Spotlight on inequalities

There is a strong social gradient in diabetes control, with more deprived groups having poorer control (higher HbA1c). However, it is also important to note that the strong social gradient seen in obesity is also visible in children and young people with chronic conditions such as diabetes. There are also significant inequalities by ethnicity, with black children and young people having poorer diabetes control; it is likely that the poor outcomes seen in minority ethnicity groups are not only due to deprivation.

Where are we now in the UK?

In 2014/2015, 24% of children and young people in England had HbA1c levels lower than the NICE recommended threshold of 58mmol/mol; this is an overall increase since 2010/2011. Correspondingly, overall levels of HbA1c above 80mmol/mol (poor diabetes control) have decreased since 2010/2011 by 8%.

In 2014/2015, 18% of children and young people in Wales had HbA1c levels lower than the NICE recommended threshold of 58mmol/mol, with no overall change since 2010/2011. However, levels of HbA1c above 80mmol/mol have decreased since 2010/2011 by 2%.

In Scotland, directly comparable data are not available; however, 13.8% of children and young people less than 15 years old had an HbA1c level below 58 mmol/mol in July 2016.

How can we improve?

All four nations should collect data comparable with the NPDA data collected for England and Wales to give a UK-wide overview of diabetes care and management.

Further research is needed into ways to improve diabetes control at both the individual level and within diabetes clinics and networks.

At the individual level, all children and young people should have access to the full range of intensive insulin therapies as recommended by NICE and SIGN. All patients should receive appropriately tailored education concerning the management of diabetes from specialist multidisciplinary paediatric diabetes teams.

Schools have a major and statutory role to play in providing support for all children and young people with Type 1 diabetes, ensuring they can achieve the same educational and social outcomes as all other children.
Clinics must work within geographic networks in each country to ensure spread of best practice, support training and facilitate access to intensive regimens and specialist opinion\textsuperscript{350}.

Transition from paediatric to adult care should be a priority for all clinics, given evidence of poor diabetes outcomes if transition is managed poorly\textsuperscript{357}. Research has shown the benefits of patient education and the institution of specific transition clinics\textsuperscript{357}, along with transition co-ordinators\textsuperscript{358} to manage this process more effectively.

The routine collection of diabetes outcome data at a national level through ongoing national audits in each country is essential for supporting quality improvement both locally and nationally and improving outcomes for children and young people with diabetes.

**Key actions**

- Strengthen research into the underlying causes of diabetes and ways to manage it effectively.
- Collect comparable data across the UK to give a UK-wide overview of diabetes care and management.
- Ensure joined-up care which meets the wider needs of children with diabetes, including appropriate transition to adult diabetes services.
- Ensure full implementation of updated NICE guidance for HbA1c levels across the UK, along with the recommendations from the NPDA regarding care management.
- Improve diabetes education for children, young people, families and healthcare and educational professionals to decrease stigma and discrimination.

**Additional data note**

The National Paediatric Diabetes Audit reports include a small proportion of data from young people aged 19 to 24 years who have not yet transferred to adult diabetes services. It has not been possible to separate these from the reported data; however, they only represent a small proportion ($\leq 1.7\%$) of the total.

England: data from adults (19 to 24 years) who have not yet transitioned to adult services in Wales contribute a very small proportion ($\leq 1.5\$%) to the overall dataset.

Wales: data from adults (19 to 24 years) who have not yet transitioned to adult services in Wales contribute a very small proportion ($\leq 1.2\%$) to the overall dataset.
Chapter 6: Health conditions of childhood

6.4 Disability and additional learning needs

Percentage of pupils with Special Educational Needs and Disabilities (SEND) / Additional Support Needs (ASN)

Key messages

- Each country in the UK has its own statutory provisions and systems to identify and support children and young people with disabilities and learning difficulties.

- In the UK there are currently between 14% and 23% of children and young people identified as having a special or additional educational need.

- There is a clear link between low income and prevalence of a special/additional educational need being identified.

- Children and young people with a special or additional educational need must be supported through appropriate statutory provisions and consistent data capture.

What is this indicator showing us?

This indicator shows the percentage of pupils identified with Special Educational Needs and Disabilities (SEND) in England, Northern Ireland and Wales or Additional Support Needs (ASN) in Scotland. This reflects the different thresholds set for SEND or ASN in each country.

Data availability and comparability

Data are available for all four nations in the UK. Data presented for England have been taken from the Department for Education School Census Results 2007 to 2016. Data for Northern Ireland have been taken from the Annual Enrolments in Schools and in State Funded Pre-school Education in Northern Ireland. Data presented for Scotland have been taken from the Summary Statistics for Schools in Scotland 2010 to 2015. Data presented for Wales have been taken from the Welsh Government School Census Results 2003 to 2016 (see additional data note).

Pupils identified with Special Educational Needs and Disabilities (SEND) in England, Northern Ireland and Wales or Additional Support Needs (ASN) in Scotland

**England**

![Graph showing percentage of children identified with SEND in England from 2007 to 2016](image)

*Figure 6.4.1: Proportion of children in England enrolled in education identified with SEND, January 2007 to January 2016*
Wales

Figure 6.4.2: Proportion of children in Wales enrolled in education identified with SEND, January 2004 to January 2016

Northern Ireland

Figure 6.4.3: Proportion of children in Northern Ireland enrolled in education identified with SEND, March 2006 to March 2016

Scotland

Figure 6.4.4: Proportion of children in Scotland enrolled in education identified with ASN, January 2010 to January 2015

Latest data: The percentage of children and young people enrolled in education with an identified SEND is 23% as of January 2016.

Trends: There has been a slow increase in the overall number of children and young people identified as having SEND since 2003 – a 5% rise over 12 years.


Latest data: The percentage of children and young people enrolled in education with an identified SEND is 23% as of March 2016.

Trends: There has been a slow increase in the overall percentage of children and young people identified as having SEND – a 6% rise over 10 years.

Source: Enrolments in Schools and in funded pre-school education in Northern Ireland 2006 to 2016.

Latest data: The percentage of children and young people enrolled in education with an identified ASN is 23% as of 2015.

Trends: There has been a notable increase in the overall number of children and young people identified as having ASN since 2010 – a 13% rise over five years.

Source: Summary Statistics for Schools in Scotland 2010 to 2015
Why is this indicator important?

This indicator provides a measure of the number of children in the UK identified as having a disability and/or other learning impairment. These are a population group who require specialist support to maximise their developmental, social, educational, and health outcomes as they develop and transition into young adulthood. This measure will only capture those children and young people who are considered to be above the threshold for having a special or additional need or disability; where this threshold is set will vary by locality. Some children who are not enrolled in formal education (many of whom may have very complex needs) will not be captured in the data.

Children with SEND or ASN tend to be less engaged in an educational setting\textsuperscript{359}, and those with incorrect, unidentified or insufficiently supported needs are more likely to experience poorer outcomes in a range of areas\textsuperscript{360}, including:

- increased risk of mental health difficulties\textsuperscript{361}
- lack of academic progress\textsuperscript{362}
- poor behaviour
- difficulty in forming healthy relationships with others, impacting on their wellbeing\textsuperscript{359}

A recent survey found that 83% of teachers and support staff in England did not feel that children with SEND were getting the support required for them to maximise their potential\textsuperscript{363}.

Where are we now in the UK?

The proportion of children in England identified with SEND in January 2016 was 14.4%. Included within this category are those with complex needs who require a Statement of Special Educational Need (Statement) or an Educational Health & Care (EHC) Plan; this proportion has remained constant at 2.8% since 2007\textsuperscript{364}. Similar proportions of children with SEND can be found in both local authority and academy primary and secondary schools in England\textsuperscript{364}.

In Wales in 2016, 23% of pupils were identified to have SEND, although this varied markedly by school type. In maintained schools, 22.5% were identified to have SEND, with 11.8% of those having a Statement. This is compared with 13.8% of children at independent schools who have some form of SEND, with 33.6% of those having a Statement. Across Wales, similarly to England, the percentage of pupils with a Statement at maintained schools in Wales has remained at 2.7% since 2013.

In Northern Ireland, the number of children with an identified SEND has been rising steadily, with 1,300 more children identified in 2016 compared with 2015; this includes almost 600 additional children with Statements\textsuperscript{365}.

In Scotland in 2015, the percentage of children and young people in education with an identified ASN was 23%. This has risen markedly since 2010 when only 10% were identified.

Spotlight on inequalities

There is a strong link between low income and higher rates of SEND prevalence (especially those with a Statement)\textsuperscript{366}. In England, 27.2% of children with an identified SEND are eligible for free school meals, compared with 12.1% of children without SEND\textsuperscript{364,367}. Children identified as having a SEND are more likely to both experience poverty and have lower educational outcomes, each of which increases the risk of experiencing poverty as an adult\textsuperscript{368}.

It should also be noted that families raising a disabled child experience higher costs than those raising a non-disabled child, with some estimates suggesting it can be up to three times more expensive\textsuperscript{369,370}.

What does good look like?

Proportions with SEND/ASN tell us more about numbers of children in the system than about the true prevalence of SEND/ASN, as it is dependent on definitions and thresholds for provision of additional support.

A good system is one with appropriate diagnostic thresholds, with mechanisms in place to allow proper identification of needs, and one that provides appropriate support for students once a need has been identified.

Services should:

- be staffed with well-trained professionals
- identify needs at the earliest possible stage
- place the needs of children, young people and their families at centre-stage at all times
- utilise all specialist and clinical resources available
- make long-term plans for the child or young person and their family, including transition to adult services
- create clinical and care networks between education, health, and social care services.
**How can we improve?**

There is a statutory duty imposed on local authorities in England that appropriate education provision is provided for all children and young people with an identified SEND, and that appropriate measures must be put in place to support children and young people with medical conditions\(^3\). This is not currently the case in Northern Ireland\(^4\), Wales\(^5\) or Scotland\(^6\), and similar guidance and implementation is required to ensure consistency and equality across the whole of the UK.

Having a consistent and unified method of data collection is vital for better understanding the needs of this group of children and young people, forward planning, allocation of resources and increasing the profile of children and young people with special or additional educational needs. One way in which this could be done is through the universal use of a recognised vocabulary throughout the UK, such as the Disabilities Terminology Set (DTS), so that data are comparable\(^7,8\).

Provision in maintained and independent schools must be adequately funded, and all staff must be trained to identify, assess and fully support all children and young people, whatever their learning needs are. Often SEND or ASN are not identified until a child reaches the school environment – thus health visitors and early years' staff along with teachers and educational professionals have a vital role to play in helping to identify and assess the needs of the child at an early stage.

Finally, government, educational and local authorities should follow the guidance and learning resources available for free through Disability Matters\(^9\).

**Key actions**

- Ensure statutory provisions are in place for children and young people with SEND and ASN, in particular those with additional medical needs.
- Strengthen comparable data capture for SEND and ASN across all nations, and use a universal measure of recognised vocabulary.
- Implement Disability Matters across all educational, healthcare and social care settings\(^9\).

**Additional data note**

Data for England, Northern Ireland, Scotland and Wales are presented separately because each country sets its own education agenda and produces relevant legislation.

**England**

According to the Department for Education, in England a child has SEND if he or she:

- has a significantly greater difficulty in learning than the majority of others of the same age, or
- has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools\(^10\).

This encompasses a huge range of needs, from those requiring minimal support (e.g. more time to complete specific tasks) to those with a range of physical and medical needs necessitating specialist equipment and additional one-to-one support. English as an Additional Language (EAL), gifted and talented or higher ability are not included.

The English educational system has been reformed in recent years, and we are currently in a transitional period (September 2014 to April 2018) where schools are using both the old and new systems. Those with complex needs will slowly be transitioned from Statements to EHC plans during this period.

**Wales**

According to s.312(2) of the Education Act 1996 a child has an SEN if they:

- have a significantly greater difficulty in learning than the majority of children of the same age; or
- have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority\(^11\).

This legal provision is identical to the old English system, and children are assessed and identified based on the complexity of their needs; those with the most complex needs will receive a Statement of SEN.

The Welsh educational system is currently undergoing reforms. The Welsh Government draft Additional Learning Needs Bill\(^12\) was published in July 2015, with accompanying Additional Learning Needs (ALN) Code of Practice published in September 2015\(^13\); the consultation closed in December 2015. The Bill is expected to be
introduced before Christmas 2016, with an updated ALN Code of Practice published thereafter. Some proposed changes include:

- change in terminology from ‘Special Educational Needs’ to ‘Additional Learning Needs’, although ALN will incorporate all needs previously identified as being ‘School Action’, ‘School Action Plus’, and ‘Statements of SEN’
- increased provision to cater for all children and young people from birth to 25 (in line with England)
- ‘Statements of SEN’ will be replaced with Individual Development Plans (IDPs)

Scotland

In Scotland, a child or young person has an Additional Support Need if, ‘for whatever reason, the child or young person is, or is likely to be, unable without the provision of additional support to benefit from school education provided or to be provided for the child or young person’. The focus of the Scottish system is circumstantial, focusing on a variety of factors that may affect a child’s ability to learn, from having English as an Additional Language (this is expressly not included in England), to being a young carer or having a physical disability. As of 2010 the term ‘additional support’ includes any extra resources or support required by the child inside or outside of the school environment.

Northern Ireland

A child is entitled to special educational provision in Northern Ireland if they have ‘a learning difficulty which calls for special educational provision to be made for him’. If this is believed to be the case then the Education Authority is required to complete an assessment on the child, leading to a Statement of Educational Needs setting out the needs and additional resources required.

Northern Ireland is also in the process of educational reform in relation to SEND. The Special Educational Needs and Disability (Northern Ireland) Act received Royal Assent on 23 March 2016 and started to become operational on 30 September 2016, although most provisions are not expected to become operational until the Special Educational Needs (SEN) Framework is published around September 2017.

Some notable changes include additional duties on schools to meet the needs of children and young people with SEND, new duties on the Educational Authority, and a requirement that every child with an SEND have a personal learning plan.
6.5 Epilepsy

Emergency hospital admission rate for epilepsy in children and young people under 19 years of age

Key messages

- Epilepsies are a complex spectrum of conditions. Delivering high-quality diagnosis, treatment, and support can all be challenging. The Epilepsy 12 audit shows areas of progress across the UK, but also the need for continued improvement.

- There is wide geographical variation in emergency epilepsy admission rates for children across the UK.

- High-quality epilepsy care requires a holistic approach that includes psychological and practical support in addition to medical expertise, plus early recognition and support of additional needs (including mental health and special educational needs).

What is this indicator showing us?

This indicator shows the rate of emergency admissions to hospital for epilepsy per 100,000 children and young people under 19 years of age. Children and young people who are seen in the emergency department only (i.e. not admitted) are not included in this indicator. Admissions for febrile convulsions are not included.

Data availability and comparability

Data on emergency admissions are available for England from 2003/2004 to 2014/2015, for Scotland from 2010/2011 to 2014/2015 (although the exclusion criteria are slightly different in the Scottish data as they include all afebrile seizures, not just seizures secondary to epilepsy), and for Wales from 2003/2004 to 2015/2016. Data from Northern Ireland are not segregated by age and are therefore not available for these purposes.

Rate of emergency admissions to hospital for epilepsy among children and young people in England, Scotland and Wales

Latest data: The rate of emergency admissions to hospital of children under 19 with epilepsy in 2014/2015 was 70 in England and 68 in Scotland; in 2015/2016 the rate was 109 in Wales (all per 100,000 population).

Trend: The overall admission rates in England and Wales since 2003/2004 have remained fairly stable.

Source: Health and Social Care Information Centre (HSCIC) for England, National Statistics Release for Scotland, and NHS Wales Informatics Service for Wales.

Figure 6.5.1: Emergency hospital admissions for epilepsy per 100,000 children and young people < 19 years in England, Scotland and Wales, 2003/2004 to 2015/2016
Spotlight on inequalities

There is widespread variation in epilepsy admission rates, with admission rates in deprived areas being higher than those in less deprived areas. While some of this variation is likely to reflect population factors, the quality and co-ordination of care is also important. There may also be issues related to diagnostic accuracy and coding, as a diagnosis of epilepsy was not confirmed in up to 40% of children and young people referred to specialist clinics.

![Figure 6.4.2: Emergency hospital admissions for epilepsy per 1,000 children and young people aged > 19 by age and deprivation quintile, in England 2013/2014](image)

**Why is this indicator important?**

Epilepsy is the most common significant neurological disorder in children under the age of 19: more than one in 220 have epilepsy (approximately 63,400). Although some types of epilepsy last for a limited period of time, for most children it will be a life-long condition. Whilst deaths from epilepsy are rare, there were 44 registered deaths of children aged zero to 17 where epilepsy was the underlying cause in England and Wales in 2014.

It is recognised that a comprehensive measure of epilepsy outcomes would include a range of indicators, including deaths (especially potentially avoidable deaths and SUDEP deaths), school attendance, educational and mental health outcomes, and wider quality of life measures. However, unplanned admission rates act as a proxy for seizure control and quality of local acute pathways impact on quality of life, and are available at the local level. They therefore offer the best current available single indicator of epilepsy clinical outcomes for this purpose.

**Where are we now in the UK?**

In 2014/2015 the rate of emergency admissions to hospital of children under 19 with epilepsy was 70 in England, 68 in Scotland and 111 in Wales (all per 100,000 population).

Within each nation, the rates of emergency admissions for epilepsy have remained fairly stable over time.

Many children and young people and their families report poor experiences of care and management, and their epilepsy has a major impact on school attendance, educational attainment, mental health and life chances.

**What does good look like?**

Epilepsy is a long-term condition that cannot be cured but, for the majority of children and young people, it can be effectively managed to enable the child or young person to be able to lead a normal and active life.

Many hospital admissions for epilepsy are unnecessary and expensive. Therefore, with effective management we should see a decrease
in the number of emergency admissions across the UK and a reduction in the geographical variation in admissions. Similarly, a national review by the RCPCH in 2013 showed that a significant proportion of epilepsy deaths were potentially avoidable.

How can we improve?

The causes of different types of epilepsy are complex, and sometimes a root cause cannot be found. Further research is required to more fully understand the causes of different types of epilepsy and how they can be better treated.

Nearly four in five children and young people with epilepsy have some form of comorbidity, including mental health problems, neurological disorders, or other medical concerns. A fully-integrated, multi-agency approach is required to reflect the multifaceted impact of epilepsy and any related concerns on a child’s life and reduce fragmented management which, ultimately, does not efficiently utilise increasingly limited resources.

Since 2011, the national Epilepsy12 programme has shown significant improvements in the standard of epilepsy care provided, as well as ongoing challenges. For example, the proportion of paediatric services with input from an epilepsy specialist nurse has increased from 46% to 59%. Some argue that this is welcome progress, but it remains the case that over one-third of paediatric services across the country do not contain a vital component of an adequate service.

The epilepsy passport was introduced by the RCPCH in 2015 in the hope of improving emergency care for children and young people with epilepsy as vital information about a child’s condition can be carried with them at all times.

It is essential to include children, young people, parents and carers in designing appropriate care and management strategies.

As well as improving management and care of epilepsy for children, it should be noted that children with epilepsy often struggle with academic progress in educational settings.

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**Key actions**

- Strengthen research into the underlying causes of epilepsy and ways to prevent it.
- Develop new methods of collecting and sharing data to facilitate delivery of more integrated, person-centred care.
- Ensure joined-up care which meets the wider needs of children with epilepsy, including timely access to mental health services.
- Ensure full implementation of NICE and SIGN guidelines across the UK and the recommendations from the Epilepsy12 programme.
- Increase use of the epilepsy passport or similar patient-held care plans.
- Improve epilepsy education for children, young people, families and healthcare and educational professionals to decrease stigma and discrimination.
## Indicator list

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