Epilepsy in England:
The local picture

• Just three out of 140 health and wellbeing boards are making plans for people with epilepsy

• Seventy-eight per cent of CCGs have not developed, and do not intend to develop, a written needs assessment for people with epilepsy

• Only 10 per cent of CCGs have a written needs assessment in place for people with epilepsy

A review of epilepsy service provision in England by Epilepsy Action
October 2014
What they told us:

Of the health and wellbeing boards we surveyed 91% (128/140) had a joint strategic needs assessment (JSNA) for 2013/2014.

Of these, nearly 3/4 (99/140) of the JSNAs included a section on long term conditions.

Just over 2/3 (96/140) of health and wellbeing boards told us that their JSNA did not include a section about neurology.

Only 21% of the JSNAs claimed to have a section on epilepsy. This represents just 30/140 health and wellbeing boards.

What we found:

Just 30 health and wellbeing boards reported that they have a section on epilepsy in their JSNA. We took a more in-depth look at the content of the JSNAs of the 30 boards:

Only 18 JSNAs stated how many people in their area have epilepsy.

Just 10% (3/30) provided us with evidence that they were making plans for people with epilepsy.

Despite telling us that their JSNA had a section on epilepsy, four of the 30 JSNAs did not mention the condition at all.

Recommendations

• Every health and wellbeing board must know how many people in their area have epilepsy

• Every health and wellbeing board must develop an epilepsy section for their JSNA by April 2016. This should include information about current local provision of services and future needs

• Every health and wellbeing board must work with their local CCG(s) to ensure that adults and children in their area experience a joined up approach to addressing their epilepsy healthcare needs

• Each local authority scrutiny board with responsibility for health must consider if their JSNA adequately meets the needs of adults and children with epilepsy in the local area

What we did

Following on from research carried out in 2012, Epilepsy Action surveyed CCGs and health and wellbeing boards in England to look at plans for epilepsy service provision. Each CCG and health and wellbeing board in England was sent a freedom of information request (FOI) with a series of questions. The FOIs were sent and the data collected between December 2013 and July 2014.
What is the local picture?

A follow-up to Epilepsy Action’s A Critical Time for epilepsy in England (2013), this review examines the work being carried out by those responsible for commissioning healthcare services for people with epilepsy in England. The 2013 report showed worryingly wide variations in healthcare service provision. It also highlighted that the majority of clinical commissioning groups (CCGs) and local authorities were not developing plans that included epilepsy.

Over a year into NHS reform, Epilepsy in England: The Local Picture asks the question – what are CCGs and health and wellbeing boards now doing to address the healthcare needs of people with epilepsy in their area?

The answer? Very little. It is clear that epilepsy is not important for most CCGs and local authorities despite the facts (see below).

Epilepsy, the facts

• Epilepsy on average affects 2,370 adults and children in each CCG area¹

• Around five people in every 100 will have an epileptic seizure at some time in their life². Out of these five people, around four will go on to develop epilepsy³

• The annual estimated cost of epilepsy in England is £2 billion⁴

• An estimated 114,080 people in England have been wrongly diagnosed as having epilepsy¹

• The cost of misdiagnosis of epilepsy in England is around £221 million a year¹

• As many as 48% of people with active epilepsy do not have their epilepsy controlled with anti-epileptic drugs⁵

• With optimal treatment 70% of the population with epilepsy could be seizure free⁶

• Adults and children with epilepsy have a risk of premature death that is 2–3 times higher than in the general population⁷

• The deaths of 973 adults and children were caused by epilepsy during 2013⁸. It is estimated that 42% of these could have been prevented⁹

• Of all the emergency admissions from ambulatory care-sensitive conditions in England, 10% were due to convulsions and epilepsy¹⁰

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Clinical commissioning groups

What we found:

Of the responding CCGs, 78% (157/204) stated that they had not produced, and had no plans to develop, a written needs assessment of the health and social care needs for people with epilepsy. This compares to 66% of CCGs surveyed in an earlier report, A Critical Time for epilepsy in England (2013). This indicates that a year on, epilepsy is even less of a priority for CCGs.

Just 10% (21/204) of CCGs told us they had produced a written needs assessment of the health and social care needs for people with epilepsy at the time of the survey.

Similarly, 70% (142/204) told us they had no plans to develop a written needs assessment for people with neurological conditions.

Of the CCGs we contacted, 48% (97/204) had neurology or epilepsy services identified in their Commissioning for Value Data pack from NHS England.

Of these, 48% (47/97) of CCGs told us that they had not developed a plan to address these issues.

Neurology had not been identified as a priority by their local health and wellbeing board according to 91% (175/192) of CCGs.

Eleven CCGs provided us with a copy of their assessments. We analysed the content of these eleven written needs assessments to see what factors are being considered to ensure that services meet the needs of people with epilepsy. We found that:

There was a wide variation in the level of detail about epilepsy included in the written needs assessments provided.

A small number of CCGs seem to be doing well and had very in-depth assessments that considered a range of factors and information and put forward good recommendations.

The majority of assessments included data on prevalence and admissions from epilepsy but did not seem to examine current service provision.

Good examples took into consideration the provision of epilepsy specialist nurses, patient concerns, routine care and gaps in knowledge and services.

These good examples are great to see, however we must remember that only 21 CCGs told us that they have a written needs assessment for people with epilepsy – this is not good enough. CCGs, like health and wellbeing boards were established to meet the health needs of a local population. If CCGs don’t recognise the needs of people with epilepsy, how will their needs be met?

Recommendations

- Each CCG must carry out an epilepsy needs assessment by April 2016, including assessing their services against the Quality Standards for the epilepsies and the NHS Outcomes Framework

- Each CCG must commission services based on their written needs assessment

- CCGs must work with their local health and wellbeing board to ensure that people in their area experience a joined up approach to addressing their healthcare needs

- Each CCG must identify priorities for people with epilepsy, including accurate initial diagnosis and a rapid review for those with difficult to treat epilepsy

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What next?

Pledge of Action

We want CCGs and health and wellbeing boards to make a commitment to people with epilepsy by agreeing to sign up to our Pledge of Action at epilepsy.org.uk/localpicture/pledge Signing up to the Pledge of Action is an agreement that they will implement the recommendations made in this report.

Resources

To help CCGs and health and wellbeing boards achieve this, we have developed and brought together a range of resources. These include links to the Neurological Intelligence Network to inform planning, a JSNA template, a guide to commissioning and case studies. These resources can be viewed and downloaded here epilepsy.org.uk/localpicture/resources

The findings

We have also produced interactive maps demonstrating the information given to us by CCGs and health and wellbeing boards. Please visit epilepsy.org.uk/localpicture/maps to see the findings from across England.
Epilepsy Action is the UK’s leading epilepsy organisation and exists to improve the lives of everyone affected by the condition.

Getting more information

Call our Epilepsy Helpline:
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Twitter @epilepsyadvice

epilepsy.org.uk

References

1 Joint Epilepsy Council of the UK and Ireland (2011) Epilepsy prevalence, incidence and other statistics


5 Moran et al, Epilepsy in the United Kingdom: seizure frequency and severity…….., Seizure, 6, 425-433, 2004


9 National Sentinel Clinical Audit of Epilepsy-Related Death, 2002.

10 The King’s Fund, Emergency hospital admissions for ambulatory care-sensitive conditions: identifying the potential for reductions, April 2012.

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