

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

EQUALITY IMPACT ASSESSMENT

Epilepsies in Adults, Children and Young People

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

3.0 Guideline development: before consultation (to be completed by the Developer before consultation on the draft guideline)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

Management of epilepsy including the use of anti-seizure medication (ASM) in:

Women and girls who are of childbearing potential, are pregnant, or breastfeeding

Recommendations have been made on drug monitoring in women or girls planning pregnancy or who are pregnant, including to review anti-seizure medication, discuss treatment options and provide advice on the risks and benefits of adjusting medication, and identifying those who are at higher risk who may need more frequent monitoring. The MHRA guidance on the safety of ASMs in this population has been incorporated within the guideline.

Recommendations have also been made to discuss and provide information on sexual health and pregnancy, including contraception, changes to medication, preconception planning, planning delivery, postnatal care and breast feeding.

Due to the risk of major congenital malformations, neurodevelopmental disorders and delay, and other effects on the baby that may be associated if a pregnant woman takes some antiseizure medications (ASMs), the committee made explicit reference to the MHRA advice on the use of ASMs in women and girls who are able to have children in each section relating ASMs, and provided links to this information.

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The committee also made specific recommendations about the use of sodium valproate, which were repeated each time sodium valproate is recommended.

Older people with cognitive impairment

Recommendations have been made to arrange a regular review of the care needs of adults with cognitive difficulties which would include where appropriate, reviewing ASMs prescribed to older people.

The committee highlighted within the psychological therapies recommendations the increased prevalence of dementia within an epilepsy population and care should be co-ordinated using a multidisciplinary approach across service providers. Cross reference has been made to NICE Dementia guideline

Accessibility of services for people within black and Asian and minority ethnic groups

No evidence was found on inequalities relating to people within black, Asian and minority groups. However, the committee identified that phenytoin can have side effects for people of Han Chinese or Thai family background, and carbamazepine, oxcarbazepine and eslicarbazepine can have side effects for people of Japanese family background, and made a recommendation to highlight to healthcare professionals that these ASMs should be avoided if possible.

People with learning disabilities

Around 1 in 5 people with epilepsy also have a learning disability and therefore the committee made specific recommendations to improve the diagnosis, provision of information, accessibility of specialist services (including surgery), monitoring of ASMs, identification of comorbid mental health conditions and to improve the transition between services.

People with developmental disorders and/or learning disabilities are more likely to have a genetic cause of epilepsy, therefore the committee recommended that a whole genome sequencing genetic test should be conducted to identify the genetic cause to aid diagnosis and treatment.

Recommendations have been made on the information and support needs of people with learning disabilities including scheduling longer appointments, and providing information in different formats to meet the needs of individuals.

The committee highlighted that people with a learning disability may need additional specialist support to manage their epilepsy and therefore made a recommendation to improve access to tertiary services to ensure they received the extra support needed.

The committee highlighted that people with learning disabilities may not be referred for surgery because of the belief amongst health professionals that they

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are unsuitable for surgical intervention or would not cope with the surgical assessment. The committee agreed they should be treated in the same way as other people with epilepsy and recommended that they are referred if indicated .

The committee included adults with learning disabilities as a population that would require a regular review of their care, and acknowledged people with learning disabilities already have an annual general health review as standard practice, however this population may require specialist epilepsy input

The committee highlighted the higher prevalence of epilepsy in people with learning disabilities in their recommendations and this requires good communication and liaison using a multidisciplinary approach to ensure co-ordinated care across services is provided. Cross reference has been made to the NICE Learning disabilities and behaviour that challenges guideline.

The committee discussed the mental health needs of people with learning disabilities that may require referral to specialist mental health services and cross-referred to the NICE guideline on mental health problems in people with learning disabilities.

The evidence showed that young people with learning disabilities and their families found transition from children's to adult epilepsy services particularly challenging due to lack of information on how this would be organised and what care packages would be available. The committee recognised people with learning disabilities can have additional health care needs that require more co-ordination to organise and set up and recommended the planning for transition begins earlier.

People living in more deprived areas who may have difficulties accessing services

No evidence was found on inequalities relating to people living in more deprived areas who may have difficulties accessing services. However, a number of recommendations were made to support people to access to specialist services, and give people the opportunity to contact an Epilepsy Nurse Specialist about their care which should improve engagement and access.

People with mental health comorbidities

The evidence demonstrated the people with an underlying mental health problem such as depression and anxiety and who have had a seizure are at an increased risk of a second seizure. The committee recommended checking for these conditions as part of the initial assessment after a person has had a seizure. People with mental health problems have complex or additional care needs and will require a regular review of their care. The committee included this population in the recommendation identifying those who should have an annual follow-up review as a minimum.

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The evidence showed the prevalence of mental health problems is higher in people with epilepsy and the committee recommended the provision of co-ordinated care across services using a multidisciplinary approach. The committee acknowledged the variability in the evidence for psychological treatments and that making recommendations for specific sub-groups of people for specific interventions would not be possible. However, the committee agreed recommendations highlighting that health professionals should be alert to psychological comorbidities and check for them in people with epilepsy as part of regular review should be made. The committee also agreed if psychological treatment was needed or referral to mental health services existing NICE mental health guidelines were relevant to people with epilepsy and decided to cross refer to guidance on depression, anxiety, mental health problems, psychosis and schizophrenia.

The committee agreed it is important to provide opportunities to discuss any mental health issues during consultations with patients and recommended that emotional health and psychological wellbeing, such as experiences of depression or anxiety be raised.

Children and young people who are looked after or in care

No evidence was found for this particular group, however the recommendations made in relation to planning and organisation of transferring care from children's to adult epilepsy services would also include children and young people looked after or in care.

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

- Age

Children with an early age of epilepsy onset, particularly those with associated developmental disorders, are more likely to have a genetic cause of epilepsy, and therefore a recommendation was made to conduct a whole genome sequencing genetic test to identify the genetic cause to aid diagnosis and treatment.

A recommendation was made for children under 3 to be referred to tertiary services without delay, because of the risk of developmental problems with some paediatric syndromes with onset before this age. Also, because myoclonic seizures may start after 3 years and could indicate an underlying neurodegenerative disorder that may be treatable, it was recommended that

children with myoclonic seizures presenting aged up to 4 years should also be referred.

Babies who have infantile spasms are at risk of serious poor neurodevelopmental outcomes if the spasms are not treated urgently. The committee made recommendations to ensure that these babies are given the most appropriate treatment as soon as possible, and are referred to a tertiary paediatric neurologist.

Children and young people with self-limited epilepsy with centrotemporal spikes may not always need treatment due to the nature of this type of epilepsy. To ensure they (and their families and carers) are able to make informed decisions about their care the committee recommended that balance of risks and benefits relating to treatment should be discussed with them.

Successful treatment of myoclonic atonic epilepsy, a rare condition in young children, depends on accurate diagnosis. Therefore, the committee recommended that these children are referred to a tertiary paediatric neurologist to advise on their care.

- Disability

The committee highlighted that people with a learning disability, a physical disability or mental health problem may need additional specialist support to manage their epilepsy and therefore made a recommendation to improve access to tertiary services to ensure they received the extra support needed.

The committee agreed that in usual circumstances, treatment with ASMs should only be started once a diagnosis of epilepsy has been confirmed. However, for people with a neurological deficit or structural abnormality in the brain clinicians should consider treating with ASMs before the diagnosis is made because the risk of a reoccurring seizure is high.

- Gender reassignment

No potential equality issues were identified in the evidence.

- Religion or belief

No potential equality issues were identified in the evidence.

- Sex

No potential equality issues were identified in the evidence.

- Sexual orientation

No potential equality issues were identified in the evidence.

- Other definable characteristics (these are examples):

- refugees
- asylum seekers
- migrant workers
- looked-after children

- people who are homeless
- prisoners and young offenders
- any others identified

No potential equality issues were identified in the evidence.

3.3 Have the Committee's considerations of equality issues been described in the guideline for consultation, and, if so, where?

Consideration of equality issues are discussed in the committee discussion sections of the following evidence reviews:

- C Effectiveness of genetic testing evidence report
- E Monotherapy for generalised tonic-clonic & focal onset seizures evidence report
- F Add-on for generalised tonic-clonic & focal onset seizures evidence report
- G Antiseizure therapies for absence seizures evidence report
- H Antiseizure therapies for myoclonic seizures evidence report
- I Antiseizure therapies for tonic or atonic seizures evidence report
- J Antiseizure therapies for idiopathic generalised epilepsy evidence report
- K Antiseizure therapies for Dravet syndrome evidence report
- L Antiseizure therapies for Lennox-Gastaut syndrome evidence report
- M Discontinuation of antiseizure medications evidence report
- N Referral to specialist services evidence report
- P Antiseizure therapies for infantile spasms evidence report
- Q Antiseizure medications for centrotemporal spikes evidence report
- R Antiseizure therapies for myoclonic atonic epilepsy evidence report
- 02 Second seizure risk factors evidence report
- 04 Information and support evidence report
- 07 Monitoring evidence report
- 08 Therapeutic drug monitoring in women and girls evidence report
- 13 Surgery evidence report
- 15 Prevalence of psychological, developmental and cognitive difficulties evidence report
- 16 Psychological treatments evidence report

3.3 Have the Committee's considerations of equality issues been described in the guideline for consultation, and, if so, where?

20 Transition from children to adult epilepsy services evidence report

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No, the recommendations are not expected to make it more difficult for specific groups to access services

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No, the recommendations are not expected to have an adverse impact on people with disabilities.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in box 3.4, or otherwise fulfil NICE's obligation to advance equality?

N/A

Completed by Developer: Katherine Andrea & Gill Ritchie

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