EQG Commission: Report on concerning themes arising from National Clinical Audit and Patient Outcomes Programme (NCAPOP) in the care of patients with epilepsy

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About HQIP

The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies. www.hqip.org.uk/national-programmes

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1. Background

Findings from two recently published National Clinical Audit and Patient Outcomes Programme (NCAPOP) reports demonstrated areas that require improvement relating to the care of patients with Epilepsy, particularly with regards to delays in access to diagnostic tests for children and young people, and access to specialist advice for women with epilepsy during antenatal care.

The Epilepsy-12 audits on CYP published in 2020 and 2021 made recommendations on diagnostic pathways, diagnostic capacity, screening for mental health issues, expert specialist nurses, paediatricians and paediatric neurologists. Of note in the pre-pandemic cohort NHS services did not meet the NICE Quality Standard of having an EEG within 4 weeks of request for 40% of CYP with new onset seizures. Less than 70% of CYP diagnosed with epilepsy that met the defined indications for an MRI received this within the first year of care.

Relevant recommendations from the Epilepsy12 audits:

- Diagnostic pathways: Health Boards and Trusts to review and improve their referral pathways to ensure all first EEGs for CYP with new suspected epilepsy are achieved within a maximum of 4 weeks of request date, and also ensuring that they can provide MRI to children of all ages via a sedation and/or anaesthetic pathway (2020)
- Diagnostic capacity: Hospital commissioners, NHS Regional Offices, Regional Partnership Boards, NHS England and NHS Wales to ensure that there is capacity to provide timely access to necessary epilepsy investigations (such as EEG, ECG, MRI and CT), so that children and young people are not disadvantaged by the variation in availability of diagnostic services (2021).

The Maternal, Newborn and Infant Clinical Outcome Review Programme (MBRRACE-UK) report published in 2021 covered women who died during or up to a year after the end of pregnancy in the UK and Ireland in 2016-18. 22 women died during this time from causes related to epilepsy, giving a rate of 0.91 per 100000 maternities, compared to 13 women in the preceding triennium, giving a rate of 0.52 per 100000 maternities. Of particular concern was that 18 of these 22 deaths were from Sudden Unexpected Death in Epilepsy (SUDEP). In 13 of the 19 women who died whose notes were available for detailed review, improvements in care were identified that would have changed the outcome.

The MBRRACE report made the following recommendations for the care of women with epilepsy in pregnancy:

- Develop guidance to ensure SUDEP awareness, risk assessment and risk minimisation is standard care for women with epilepsy before, during and after pregnancy and ensure this is embedded in pathways of care
- Develop clear standards of care for joint maternity and neurology services, which allow for:
  - early referral in pregnancy, particularly if pregnancy is unplanned, to optimise anti-epileptic drug regimens

    - rapid referral for neurology review if women have worsening epilepsy symptoms
    - pathways for immediate advice for junior staff out of hours
    - postnatal review to ensure anti-epileptic drug doses are appropriately adjusted

- Ensure each regional maternal medicine network has a pathway to enable women to access their designated epilepsy care team within a maximum of two weeks

- Ensure all maternity units have access to an epilepsy team.

2. Recommendations

In light of the findings from these reports a stakeholder meeting was held in May 2021 including representatives from the CYP, maternity, neurology and diagnostics NHSEI teams as well as representatives from interested third parties such as Royal Colleges and relevant charities.

The meeting was well attended and produced the following recommendations:

1. Ensuring timely and equitable access to diagnostic tests
2. Creating clear pathways of care to improve access to epilepsy services
3. Better communication and education for patients with epilepsy about their condition and associated risks.

Why have we focussed on care of patients with epilepsy and what impact will changes have?

There is significant variation in the provision and quality of care for patients with epilepsy across the country. Whilst the reports discussed related to shortcomings in the care provided to children, young people and pregnant women, the stakeholder group agreed that the problem is much wider reaching, affecting the care of all adults with epilepsy too.

Better implementation of existing guidance and use of resources would reduce the variance in quality of care delivered to patients with epilepsy, reducing inequity across the country, and improve overall care for patients with epilepsy.

Ensuring timely and equitable access to diagnostic tests

Almost half of services are not meeting the NICE Quality Standard of CYP having an EEG within 4 weeks of request, and almost one third of children that meet the criteria for an MRI are not having this within their first year of care.

There is a need to increase neurophysiology testing capacity, to include better local access to these investigations in a timely manner to enhance the diagnostic process. It was initially hoped that Community Diagnostic Hubs (CDH) may improve access to diagnostic tests, but neurophysiological tests are not included within the core CDH models. The Director of Diagnostics, Medicines and Pharmacy Improvement and the National Specialty Advisor for Physiological Measurement at NHSEI are aware of this problem and have planned a detailed data collection exercise covering activity, workforce, equipment, estates and digital maturity for autumn 2021. The results will be used to secure investment to enable the development of long-term plans for improving neurophysiology services. To facilitate this, they will be setting up expert reference groups to bring together key stakeholders in the area to advise on plans, work on the transformation of pathways and discuss matters such as improving access and reducing health inequalities.

One of the factors that can slow access to MRI is the need for it to be performed under general anaesthetic in young children. The diagnostic pathway workstream from NHSEI Systems Improvement are aware of this and are formulating a sample care pathway for MRI under GA.

The Neurology GIRFT Programme National Specialty Report, published in September this year, reinforced findings from the NCAPOP programme, and highlighted the need to increase capacity and access to neurophysiology and neuroradiology tests, with wide variation across regions.

Creating clear pathways of care to improve access to epilepsy services

A consistent issue for patients with epilepsy is the barrier to integration between clinicians and care providers in different settings. There is a need for better integration of services between primary, secondary, tertiary and community care, and indeed between clinical teams in hospital – such as obstetrics, neurology and acute physicians. Often these teams are working across different sites (for example children and adult epilepsy services, or maternity and epilepsy services).

Children and Young People

The Children and Young People Transformation Programme (CYPTP) was established to deliver the commitments of the Long Term Plan related to Children and Young People, especially related to improving outcomes for those with long term conditions. Funding has been allocated to improvements in epilepsy care in 20/21.

The CYPTP held a roundtable in August alongside Young Epilepsy, with a range of stakeholders, including the Royal College of Paediatrics and Child Health, Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) and the Royal College of Nursing.

Following this, the CYPTP has distributed to regional CYP Transformation Leads in October an information pack summarising priority areas based on the Epilepsy12 Audit.

These are:

- access to mental health screening and psychosocial support
- access to tertiary services including epilepsy surgery
- transition from paediatric to adult epilepsy services
- variation in care provided.

Funding has been distributed to regions with the expectation that regions will:

- establish clinical leadership and governance at system/regional level with responsibility for paediatric epilepsy care
- understand variation in service delivery and pathways of care for CYP with epilepsy. This may include reviewing paediatric epilepsy care pathways and commissioning arrangements and a focus on the priority areas identified above
- work with key stakeholders across the region to develop a plan for improving epilepsy care and outcomes for CYP at a system/regional level, with evidence of co-production with CYP and a commitment to share good practice across the region. This may include planning the restoration and recovery of paediatric epilepsy services, including access to necessary

epilepsy investigations; a focus on reducing any health inequalities; and identifying regional variations.

The CYP Transformation Programme has established in Q3 a national CYP epilepsy oversight group, co-chaired with Young Epilepsy, to oversee a programme of work focused on paediatric epilepsy care. The group will hold its first meeting in December 2021 and will meet bimonthly thereafter. It is anticipated that outputs from this group will support regions in improving the quality of epilepsy care for CYP.

In addition to the above, The CYP Transformation Programme has also funded expansion of the RCPCH epilepsy improvement programme to further support providers to make improvements against the findings of the paediatric epilepsy audit.

Maternity

NHSEI is in the process of setting up Maternal Medicine Networks to ensure equity of access for all women to appropriately constituted multi-disciplinary teams for all medical conditions, including epilepsy. Funding has been made available to establish core teams, comprising an obstetric physician, obstetrician and senior midwife who will be employed in a maternal medicine centre to provide leadership across a system.

There is a national service specification with clear guidance on where to manage patients with medical conditions, including epilepsy, in pregnancy. If the local offer to women with epilepsy in pregnancy does not meet the standards set by the network, then the core Maternal Medicine Centre team will work with local physicians to provide such a service, ensuring that women are seen centrally until the local service is fully established.

Networks are fully established in some areas and in the process of being established in others. They will also be responsible for collecting outcome metrics to demonstrate action against the MBRRACE-UK recommendations.

General resource

An existing resource available to guide regional and local service provision is the RightCare Epilepsy Toolkit, which was developed by NHS England in partnership with Epilepsy Action, SUDEP Action and Young Epilepsy.

This is designed to support systems to understand the priorities in epilepsy care and key actions to take. It provides opportunity to assess and benchmark current systems to find opportunities for improvement. It covers support to children and young people, people with learning disabilities and pregnant women, as well as personalised care and education.

Better communication and education for patients with epilepsy about their condition and associated risks

Neurological causes are the second most common indirect cause of maternal death and in 2020 there was a significant increase in maternal mortality due to Sudden Unexpected Death in Epilepsy (SUDEP).

It is clear that there is work to be done to improve access to, and personalisation of communication about risk, particularly risk of mortality in epilepsies with patients and carers. The National Clinical Audit of Epilepsy-Related Death from almost 20 years ago made recommendations to improve the communication of risk of death to patients, yet it is evident this is still not happening widely.

SUDEP Action have a checklist for clinicians to support clinicians in discussing risk with people with epilepsy. This is evidence-based, validated, and recommended best practice by the NHS RightCare toolkit, amongst others. Over 1200 clinicians already use the checklist, and there is evidence demonstrating this helps reduce risk among those previously flagged to be at risk[i], and can help make sure people with epilepsy are accessing the appropriate services at the right time to suit their current risks[ii].

EpSMon is an epilepsy self-monitoring app also created by SUDEP Action. This assesses risk and provides recommendations to patients about actions to take. 4000 people with epilepsy have downloaded EpSMon.

The group felt that rather than creating new resources, support to better implement existing resources and tools, making them more accessible to clinicians and patients would be one approach to help drive improvements in care.

It is proposed that the RightCare Epilepsy Toolkit is spread more widely through maternity and CYP Networks and that local systems are encouraged to use it to improve the care for people with epilepsy.

How will success be measured?

Epilepsy-12 remains an important part of the national audit programme and will continue to monitor important metrics in the care of children and young people with epilepsy. Equally MBRRACE-UK continues to review all maternal deaths in the UK and Ireland.

Timely access to appropriate diagnostic tests and to specialist advice and treatment should continue to be monitored to evaluate the impact of the changes being introduced through maternity and CYP networks.

3. Summary

This paper highlights important concerns about the care of patients with epilepsy identified by the Epilepsy12 audit and the Maternal, Newborn and Infant Clinical Outcome Review Programme, and the resultant actions being taken to address them.

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[i] https://doi.org/10.1111/ene.13651
[ii] https://doi.org/10.1016/j.yebeh.2020.107637