

Epilepsy & Behavior

UK framework for basic epilepsy training and oromucosal midazolam administration --Manuscript Draft--

Manuscript Number:	EB-D-21-00379R2
Article Type:	Research Paper
Keywords:	rescue medication; midazolam; community prevention of status; epilepsy safety; basic epilepsy training
Corresponding Author:	Rohit Shankar Plymouth University Peninsula School of Medicine Truro, UNITED KINGDOM
First Author:	Phil Tittensor
Order of Authors:	Phil Tittensor Sarah Tittensor Erica Chisanga Manny Bagary Caryn Jory Rohit Shankar
Abstract:	<p>Background –</p> <p>UK wide Oromucosal Midazolam is used as an emergency treatment in community for seizures administered by family/carers with the right training. The Joint Epilepsy Council (JEC) UK which produced the training guidelines disbanded in 2016.</p> <p>Purpose –</p> <p>Provide standards for basic epilepsy education and rescue medication (Midazolam) administration.</p> <p>Methods -</p> <p>The Epilepsy Nurses Association (ESNA), The International League against Epilepsy, British Chapter (ILAE) and the Royal college of Psychiatrists (RCPsych), used the Delphi process to update guidelines for the administration of oromucosal midazolam including developing a voluntary on-line test for carers. During 2017 -2019 a facilitator worked with two ESNA committees to update the existing guidance and another to develop a question-bank. Both committee outputs were circulated to the ESNA membership, then ILAE and RCPsych for review. Patient-facing organizations and charities opinions were solicited. All feedback was assimilated. A private provider was contracted to deliver the test.</p> <p>Results –</p> <p>A consensus process involving two task and finish groups of 19 people each compared, reflected, debated and engaged with stakeholders across three stages. The updated ratified guidelines were circulated nationally. The Delphi process highlighted many regions and individuals had local assessment tools and procedures in place, while others (around 50%) had no assessment provision. 278 carers with a 95% pass-rate and 100% positive feedback have undertaken the online test (10/2020).</p> <p>Conclusion –</p> <p>The UK-wide care provision gap in basic epilepsy-training and safe rescue medication administration is now addressed. A two-yearly update to the guidelines and test is planned.</p>

Suggested Reviewers:	<p>Matthew Walker m.walker@ucl.ac.uk Professor in Neurology, expert in Status and previous chair of ILAE (UK) and of JEC</p>
Response to Reviewers:	<p>UK framework for basic epilepsy training and oromucosal midazolam administration Responses to reviewer's comments</p> <p>My co-authors and I thank the reviewer for his/her thoughtful feedback. We have considered ALL of the reviewer's comments and incorporated ALL of them.</p> <p>Reviewer 1 - Comment - Thank you for the revised version of this manuscript. The authors have addressed most of my comments. Reply - We are delighted that our changes have met with your approval.</p> <p>Comment - You probably need to address the two outstanding comments: Reply - Of course we would be delighted to</p> <p>1. The figure is not so clear. I would change the color of the background increase the font size (make it simple and clear) Reply - Thank you for highlighting this. We have increased the font size and background colour.</p> <p>2. The citation style is not in the style of Epilepsy and Behavior. You may revise it manually or you may use a software like Endnote or any other software to revise the style Reply - Thank you for your advice – we have revisited this and put it in house style of the journal.</p>

UK framework for basic epilepsy training and oromucosal midazolam administration

Responses to reviewer's comments

My co-authors and I thank the reviewer for his/her thoughtful feedback. We have considered ALL of the reviewer's comments and incorporated ALL of them.

Reviewer 1 -

Comment -

Thank you for the revised version of this manuscript. The authors have addressed most of my comments.

Reply –

We are delighted that our changes have met with your approval.

Comment -

You probably need to address the two outstanding comments:

Reply -

Of course we would be delighted to

1. The figure is not so clear. I would change the color of the background increase the font size (make it simple and clear)

Reply –

Thank you for highlighting this. We have increased the font size and background colour.

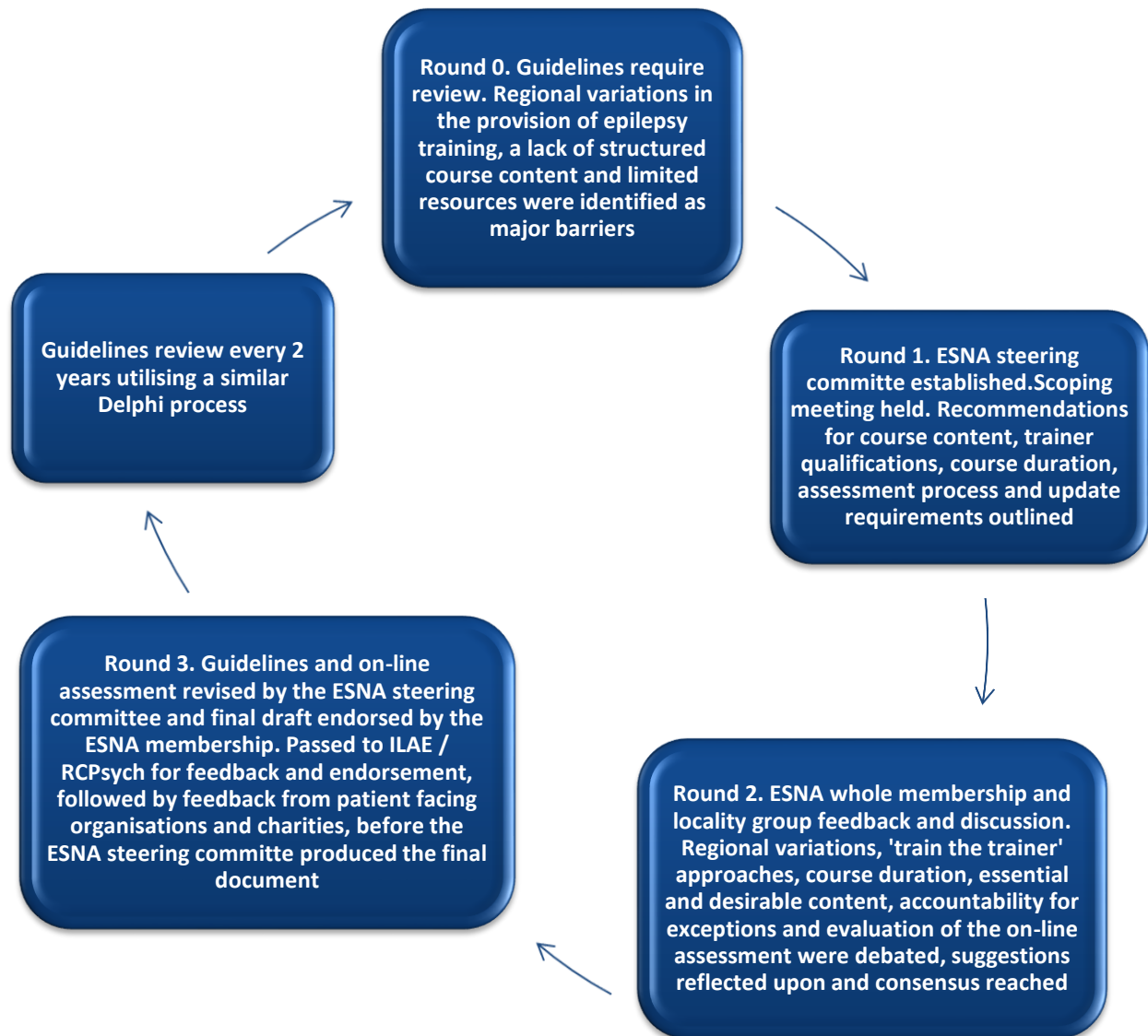
2. The citation style is not in the style of Epilepsy and Behavior. You may revise it manually or you may use a software like Endnote or any other software to revise the style

Reply –

Thank you for your advice – we have revisited this and put it in house style of the journal.

Highlights –

- Oromucosal Midazolam (OM) is used across the UK for seizure emergency in community
- It is expected to be administered by family/carers having undergone bespoke training
- The Joint Epilepsy Council which produced the training guidelines disbanded in 2016
- National epilepsy care organisations updated the guidance using the Delphi process
- This is the 1st evidenced standards for basic epilepsy education and rescue OM use

Figure 1. Process for the guideline's development and review using a modified Delphi process [10]

UK framework for basic epilepsy training and oromucosal midazolam administration

Abstract

Background –

UK wide Oromucosal Midazolam is used as an emergency treatment in community for seizures administered by family/carers with the right training. The Joint Epilepsy Council (JEC) UK which produced the training guidelines disbanded in 2016.

Purpose –

Provide standards for basic epilepsy education and rescue medication (Midazolam) administration.

Methods -

The Epilepsy Nurses Association (ESNA), The International League against Epilepsy, British Chapter (ILAE) and the Royal college of Psychiatrists (RCPsych), used the Delphi process to update guidelines for the administration of oromucosal midazolam including developing a voluntary on-line test for carers. During 2017 -2019 a facilitator worked with two ESNA committees to update the existing guidance and another to develop a question-bank. Both committee outputs were circulated to the ESNA membership, then ILAE and RCPsych for review. Patient-facing organizations and charities opinions were solicited. All feedback was assimilated. A private provider was contracted to deliver the test.

Results –

A consensus process involving two task and finish groups of 19 people each compared, reflected, debated and engaged with stakeholders across three stages. The updated ratified guidelines were circulated nationally. The Delphi process highlighted many regions and individuals had local assessment tools and procedures in place, while others (around 50%) had no assessment provision. 278 carers with a 95% pass-rate and 100% positive feedback have undertaken the online test (10/2020).

Conclusion –

The UK-wide care provision gap in basic epilepsy-training and safe rescue medication administration is now addressed. A two-yearly update to the guidelines and test is planned.

Key words – rescue medication; Midazolam; community prevention of status; epilepsy safety; basic epilepsy training

1. Introduction:

The estimated epilepsy prevalence in the United Kingdom (UK) is around 1%, suggesting that there are about 610,000 people with the condition [1]. Approximately 30% will continue to experience seizures, which can sometimes be life threatening [2]. An average of twenty-one people per week in the UK are thought to die as a result of a seizure [3], thus making epilepsy about nine times riskier than asthma in terms of premature mortality [4]. In addition, people with epilepsy (PWE) tend to die younger, which, in the neurological context, makes stroke the only condition with more years of potential life lost [3].

Status Epilepticus (SE), is defined as a continual seizure lasting longer than 30 minutes, or multiple seizures, without recovery in between, again lasting half hour [5]. SE has a mortality rate of up to 20%, as well as significant, often long term, morbidity. SE can be broken down into four stages; premonitory, early, established and refractory [6]. There is evidence to suggest that intervention in the premonitory stage of SE, especially in the community, could largely prevent progression to other stages [7]. Thus, good knowledge and training of carers and family members of PWE at risk of SE in the community could significantly reduce mortality, morbidity and resource costs. Central to the mitigation of this risk is the use of emergency epilepsy medication. In the UK, it is standard practice to use oromucosal midazolam. In recent years, formulations have been developed in prefilled syringes, making administration much easier in emergency situations. However, midazolam in the UK is unlicensed for this purpose in adults and is a controlled drug, which can create prescribing and administration challenges. The use of midazolam requires bespoke training and governance, which until recently was not available in the UK or globally [7].

The use of midazolam by appropriately trained carers at the right time for the right purpose can significantly reduce negative outcomes, and ultimately deaths. Historically, The Joint Epilepsy Council of the UK and Ireland (JEC), a voluntary body composed of interested stakeholders, such as epilepsy charities, the International League against Epilepsy, British Branch (ILAE) and the Epilepsy Nurses Association (ESNA), took responsibility to ensure that educational guidance on this complex area was available [8]. However, due to funding and resource concerns, it was disbanded in 2015 with its last report being in 2012 [8]. Since then, there has been no clear guidance, standards or pathways to ensure safety of the patient, carer or professional, leaving a vacuum in this vital area of epilepsy care [7]. This has led to a multifactorial problem (Appendix 1).

ESNA is an UK wide organisation, founded in 1992, with a current membership of 430 nurses with competencies in epilepsy care and working professionally with PWE. The majority of the membership is involved in basic epilepsy awareness and administration of midazolam training. ESNA, along with its affiliates the ILAE and the Royal College of Psychiatrists (RCPsych), sought to develop an up to date, nationally evidence based protocol and pathway, to enable best practice for basic epilepsy training and midazolam administration, to address the lack of best practice guidance.

2. Methods -

The project ran from February 2017 to June 2019, from when the update began to the publication of the Guidelines [9]. A three-stage Delphi process was utilised identifying from previous similar exercises undertaken specifically in epilepsy (figure 1) [10, 11, 12, 13, 14, 15]. This begins with idea generation, followed by an assessment, in this case undertaken by two task and finish group's made up of experienced epilepsy nurses. There then follows feedback and discussion with a wider cohort to compare and debate the outcome of the assessment, reflect on the comments made and engage with the process prior to reassessment and a final strategy.

2.1 The Delphi Process [10, 11, 12, 13, 14, 15]

The idea generation [11], was begun by the Council of the ILAE, who felt that it was important to have robust guidance available for the training of carers in basic epilepsy awareness and midazolam administration. They recognised that, in the UK, the remit for such training would normally lie with the nursing profession. Additionally, many of the carers requiring such training would be looking after the needs of people with intellectual disabilities (ID). Therefore, the ESNA Executive Committee, and the Intellectual Disability Faculty of the RC Psych were approached to begin a three-way dialogue to discuss how best to address this issue. ESNA agreed to lead the initiative, as the primary nursing organisation for epilepsy in the UK. It was recognised that there were major regional differences in the provision of epilepsy training for carers. There were challenges about the availability of suitably qualified trainers, with again a large regional variability. While many epilepsy specialist nurses (ESNs) undertake epilepsy awareness and midazolam training as part of their NHS role, there are simply too few of them in the UK to provide all of the training required. This has led to a proliferation of (mainly) independent training organisations and individuals, with widely varying experience and education in epilepsy, filling in the gaps. Serious concerns have been raised about the provision and quality of education being provided, and this has been highlighted in a series of reports from the learning disabilities mortality review programme (LeDeR), as a major risk factor in

the premature death of people with epilepsy and intellectual disability in the UK [16]. Variations in the expertise of professionals providing services for PWE and ID have been recognised for some time, with a recent report continuing to highlight difficulties [17]. Following the dissolution of the JEC, a vacuum had been left in the guidance underpinning basic epilepsy training courses. The three organisations began to work together to build a fresh consensus regarding the content, level and duration of this vital education.

Two parallel task and finish groups, consisting of 19 members, identified by a general call out to the ESNA membership, and led by two experts in the field (ST and EC), was set up to assess the recommendation to develop training standards. All regions of the UK and different stakeholder specialties (Intellectual disability, adult, paediatrics) were represented. They were mandated to form a consensus on the minimum standards of epilepsy training required for paid carers, as well as to devise and revise the available learning resources, using the JEC guidelines as a template [8]. The outputs of the two groups were subject to an extensive, multi-professional, UK wide consultation, utilising stage 2 of the Delphi process, to compare, reflect, debate and engage with stakeholders to refine the assessment process [10]. The outcomes from this process were drafted and sent to expert practitioners from the ILAE, Royal College Nursing (RCN) and the RCPsych, external from ESNA, for peer review as part 3 of the Delphi process. This was supplemented with feedback from patient facing organisations such as national charities (SUDEP Action, Epilepsy Society, Epilepsy Action etc.).

During the initial idea generation stage of the Delphi process, importance was attached to the assessment of any training provided, in order to ensure uniform quality. Therefore, it was decided that a second task and finish group should be established, in parallel to the guideline consultation, to explore remote assessment. A UK wide group of epilepsy specialist nurses (ESN's), from paediatric, Intellectual disability and neurology services, were brought together to devise an on-line test in order to evaluate carer knowledge of epilepsy following the completion of a local training program. A successful pilot project, undertaken in the UK county of Cornwall (pop: 538,000), using the 'teach and test' model, demonstrated proof of principle and formed the basis of the assessment tools [7]. Questions devised and submitted by ESNA members were edited, quality checked and ratified by an oversight group of medical practitioners and educationalists assembled by the ILAE. Responsibilities for hosting the test and creating a suitable online platform were handed to Virtual College (VC), an education organisation with experience in providing on-line education and assessment in the field of healthcare [18]. A pilot test was sent for the ESNA membership to try, and adjustments made

according to the feedback received. The full test was launched in conjunction with the guidelines. It is hosted by VC (<http://epilepsyassessment.virtual-college.co.uk/>).

2.2. Ethics and participation consent

No ethical permission was sought as no patients were involved. Consent was implicit by participation for the clinical practitioners group. All participants were advised at the start of the project that contributions were voluntary and their replies, i.e. data, would be anonymised. The project was reviewed by the participating organisations.

3 Results

Regional differences in the approach to epilepsy training emerged during the Delphi process (table 1). Some areas of the UK, most notably Scotland and Cornwall, have very well established procedures to deliver effective epilepsy awareness and midazolam courses to care staff. However, these arrangements only cover around 10% of the UK by population.

Initial discussions proposed that all training should be undertaken by qualified nurses or doctors. This was amended to state that trainers without a nursing or medical qualification or nurses/doctors, who have no epilepsy experience in the last two years, must have attended a train the trainer course. There are additional safeguards to allow for deviation from the guidelines, provided there are clear lines of accountability set in place locally. Changes made to the previous JEC guidelines have been clearly highlighted in the new document [9].

The duration of the training courses was scrutinised during all stages of the Delphi process. The JEC guidelines [8] mandated that epilepsy awareness and midazolam training combined should last between four and six hours. Task and finish group members were concerned that this may be too long to allow care organisations to release staff to attend courses. However, the aim of the educational guidelines and associated assessment, was to provide carers with an adequate knowledge of epilepsy to enable them to act confidently when asked to manage someone having a seizure, and to practice the technique for administering midazolam. It was also recognised that these are best practice guidelines, so to recommend a shorter course, which by definition would require content to be omitted, was contrary to the project brief. Indeed, the task and finish groups identified topics missing from the last iteration of the JEC guidelines [8], which they felt were essential, for example sudden unexpected death in epilepsy (SUDEP).

There was broad agreement in the multi-agency consultation with the content of the training courses, but disagreement about which elements should be essential, and which desirable. Following extensive consultation, all elements of the midazolam training were considered to be essential, while flexibility was allowed with regard to content of epilepsy awareness courses. Allowance was also made for bespoke training, tailored to the needs of a particular individual [9], providing the care and training organisations had clear lines of accountability, justifying deviation from best practice. An example might be a school setting with only one child who has epilepsy. Bespoke training for the staff in that situation could be delivered in a shorter timeframe, as they would need to respond to an individual's needs, rather than having to address the varying needs of a cohort of people. The key points of the guidelines are set out in appendix 2 and the final published guidelines available freely from www.ESNA-online.org. The list of participants in the different Delphi stages and their professional roles is provided in table 2.

During the Delphi process, it became apparent that many regions and individuals had local assessment tools and procedures in place, while others (around 50%) had no assessment provision. A need to establish a national, minimum assessment was agreed, with local assessments taking place alongside the online test hosted by VC [9, 18].

The Delphi process brought the following key elements of the on-line assessment into focus: the need for the test to comprise three broad sections: epilepsy awareness, safety and seizure treatment, first aid and emergency medication administration. Pass rates were set at 80%, 100% and 100% respectively. Candidates needed to pass each section in order to progress to the next level. A bank of 110 questions was produced from members' submitted questions. This meant that anyone re-taking the test would not have the same questions the second time, and that delegates on the same course would also, largely, have different questions to their colleagues. Example questions are provided in table 3.

By 10/2020, 278 people had attempted the online test. 96% had taken the full test (it is possible to choose epilepsy awareness only). The average time to complete the full test was 27 minutes while the epilepsy awareness section took 7 minutes. The pass rate pre-set for the full test was 95%, with 100% pass rate for the epilepsy awareness section. Of all assessments 71 are incomplete. Of these, 10 learners are 'in progress' and 61 'not started'.

4. Discussion

The training of carers for PWE in the UK was fragmented, patchy and inconsistent. The ESNA guidelines [9] allow care providers to critically evaluate the content of their training providers. The guidelines are freely available from the ESNA website, (www.ESNA-online.org) the ILAE, RCPsych and leading epilepsy charities. They were disseminated electronically to all ESNA/ILAE/RCPsych members and, via the Epilepsy Action newsletter and Nursing Times [19].

The use of a nationally accredited, standardised test, gives care providers' confidence that their staff have received adequate education to safely manage PWE. Carers are assured that they have correctly understood the course and are better prepared to manage seizures. The test is free to avail but a £5.00 fee is charged for certification. This allows professional care organizations to ensure their employed carers are trained while families and private carers can use the test for knowledge updates. The collected fees go to further question bank update and development.

The challenge is to incorporate these guidelines and the associated on-line test, into routine service delivery. Safety is a key component in recent UK policy documents such as NHS Right Care [20] and Step Together [21]. While applicable in all care settings, the guidelines will be of most benefit to ID services. The Learning Disability Mortality Reviews, which looks into causes of premature mortality in people with ID, highlight the disproportionate epilepsy related deaths (5%) and epilepsy as a contributory factor (40%), pointing out gaps in training [16]. The guidelines along with other similar safety initiatives could improve patient safety [22].

5. Acknowledgements

ESNA Task and finish group members (excluding co-authors)

Mel Goodwin, Fiona Hughes, Lynda Morris, Jill Conium, Hazel Thomas, Jackie Scott, Alison Holmes, Shelley Brett, Marie Synott- Wells, Martin Smith, Mary Codling, Pam Iddon, Lesley Alexander, Jan Bagshaw.

ESNA executive committee (excluding co-authors)

Carrie Burke, Catherine Doherty, Marie Hooper

International League against Epilepsy British Chapter executive committee and Juliet Solomon
director of ILAE British Chapter.

Royal College of Psychiatrists Intellectual Disability Faculty

Royal College of Nursing

Epilepsy Action UK

SUDEP Action UK

6. References

1. Joint Epilepsy Council of the UK and Ireland (JEC). Epilepsy prevalence, incidence and other statistics. https://www.epilepsyscotland.org.uk/wp-content/uploads/2019/05/Joint_Epilepsy_Council_Prevalence_and_Incidence_September_11_3.pdf 2011 [accessed 18/02/2021]
2. Brodie, Martin J. Road to refractory epilepsy: The Glasgow story. *Epilepsia*. 2013; 54: 5–8
3. Thurman DJ, Hesdorffer DC, French JA. Sudden unexpected death in epilepsy: assessing the public health burden. *Epilepsia* 2014; 55: 1479-85.
4. SUDEP Action. Prevent21 Summit on Tackling Epilepsy Deaths: Consensus Recommendations Summary. https://sudep.org/sites/default/files/sudep_action_prevent21_summit_report_-_outcomes_recommendations_1.pdf 2018 [accessed 20/02/2021]
5. Trinka E, Cock H, Hesdorffer D, Rossetti AO, Scheffer IE, Shinnar S, Shorvon S, Lowenstein DH. A definition and classification of status epilepticus – Report of the ILAE Task Force on Classification of Status Epilepticus. *Epilepsia*. 2015; 56: 1515–1523. doi:10.1111/epi.13121
6. Walker M, Shorvon S. Treatment of tonic-clonic status epilepticus. Epilepsy Society. <https://www.epilepsysociety.org.uk/sites/default/files/2020-08/Chapter33Walker2015.pdf> 2015 [accessed 20/02/2021]
7. Shankar R, Jory C, Mclean B, Tittensor PA, Walker M. Epilepsy awareness and rescue medication training: Ignorance is bliss. *Epilepsy and Behaviour*. 2017; 70 (2017) 212–216.
8. Joint Epilepsy Council of the UK and Ireland (JEC). Guidelines on the administration of buccal midazolam. JEC. 2012. PO Box 186, Leeds, LS20 8WY.
9. Epilepsy Nurses Association (ESNA). Best practice guidelines for training professional carers in the administration of Buccal (Oromucosal) Midazolam for the treatment of prolonged and / or clusters of epileptic seizures in the community. <https://www.esna-online.org/wp-content/uploads/2019/06/ESNA-Midazolam-Guidelines.pdf> 2019 [accessed 20/02/2021]
10. Khodyakov, D., Grant, S., Denger, B. *et al*. Practical Considerations in Using Online Modified-Delphi Approaches to Engage Patients and Other Stakeholders in Clinical Practice Guideline Development. *Patient*. 2020; **13**, 11–21. <https://doi.org/10.1007/s40271-019-00389-4/> [accessed 24/05/2021]
11. Khodyakov D, Denger B, Grant S, *et al*. The RAND/PPMD Patient-Centeredness Method: a novel online approach to engaging patients and their representatives in guideline development. *European Journal for Person Centered Healthcare*. 2019; 7(3) 470-475 (accessed 24/05/2021)

12. Shawahna, R., Abbas, A. & Ghanem, A. Medication transcription errors in hospitalized patient settings: a consensual study in the Palestinian nursing practice. *BMC Health Serv Res.* 2019; 19, 644.
13. Shawahna R, Abdelfattah B, Shafei M, Ruzzeh S. Therapeutic monitoring of antiepileptic drugs: Recommendations to improve care of patients with epilepsy in the Palestinian practice. *Epilepsy Behav.* 2020; 107215, <https://doi.org/10.1016/j.yebeh.2020.107215>
14. Shawahna, R. Merits, features, and desiderata to be considered when developing electronic health records with embedded clinical decision support systems in Palestinian hospitals: a consensus study. *BMC Med Inform Decis Mak.* 2019; 19, 216-9.
15. Shawahna R, Development of key performance indicators to capture in measuring the impact of pharmacists in caring for patients with epilepsy in primary healthcare: A Delphi consensual study, *Epilepsy & Behavior.* 2019; 98 (A), 129-38
16. The Learning Disabilities Mortality Review (LeDeR). Annual report http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf 2019 [accessed 20/02/2021]
17. Kerr MP, Watkins LV, Angus-Leppan H, Corp A, Goodwin M, Hanson C, Roy A, Shankar R; British Branch of the International League Against Epilepsy (ILAE) Working Group on services for adults with intellectual disability and epilepsy. The provision of care to adults with an intellectual disability in the UK. A Special report from the intellectual disability UK chapter ILAE. *Seizure.* 2018; 56: 41-46.
18. Virtual College. Homepage. <https://www.virtual-college.co.uk/> 2020 [accessed 20/02/2021]
19. Tittensor PA, Tittensor SL, Chisanga E *et al.* Managing patients at risk of epileptic seizures in the community. *Nursing Times.* 2019; 115: 11, 34-5.
20. NHS Right Care. Epilepsy Toolkit. <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2020/03/rightcare-epilepsy-toolkit-v2.pdf> 2020 [accessed 20/02/2021]
21. Shankar R, Scheepers M, Liew A, Cross H, McClean B, Tittensor P, Slowie D, Toker-Lester H, Pullen A (2020). Step together: integrating care for people with epilepsy and a learning disability. BILD. <https://www.bild.org.uk/wp-content/uploads/2020/11/Step-Together-17-November-2020-Download-Link-.pdf> 2020 [accessed 20/02/2021]
22. Shankar R, Ashby S, McLean B, Newman C. Bridging the gap of risk communication and management using the SUDEP and Seizure Safety Checklist, *Epilepsy & Behavior.* 2020; (103B), 106419

Appendix 1- Examples of concerns surrounding the administration of emergency medication for PWE⁷

Patient concern-The ability of carers to respond appropriately in an emergency especially if the patient is unconscious

Professional carer concerns - When to give the medication, and when/if to withhold it

Prescriber concerns – A lack of confidence in the competence of carers to administer medication as prescribed, a potential to cause iatrogenic harm and lack of regulation clarity.

Appendix 2 – Key messages from the ESNA best practice guidelines [8]

The recommended content for epilepsy awareness and midazolam administration courses
Face to face training to be delivered by qualified nursing or medical practitioners, with a minimum of two years' experience working with people who have epilepsy, evidence of continued professional development (CPD) and a minimum of one year experience delivering training/facilitation courses with a recognised teaching and assessment qualification.
Trainers without a nursing or medical qualification and/or who do not have two years' experience working with people who have epilepsy, must attend a 'train the trainer' course, facilitated by a practitioner meeting the above requirements.
Initial training should last 4 to 6 hours, with a minimum of two yearly refreshers lasting 2 to 3 hours (this should be tailored to individual needs and could therefore vary).
Carers should complete a national, online test, in addition to any local assessment requirements

Table 1 - Delphi results

Round 1 – scoping meeting	Round 2 – ESNA membership engagement, comparison, reflection and debate	Round 3 – final outcome ⁹
Trainer experience and competence	Did this person have to hold a medical or nursing qualification? What experience/qualifications in epilepsy, training and assessment was required?	Hold a nursing or medical qualification, a recognised qualification in teaching and assessing, 2 years recent experience of working with PWE. Trainers without the above must have attended a train the trainer's course facilitated by a person meeting the requirements.
Duration of courses	JEC guidelines recommended 4-6 hours to teach epilepsy awareness and midazolam administration to professional carers with no prior knowledge, with refreshers lasting 2-3 hours. Debate whether this was too long, would prove difficult to implement due to staff availability to attend and therefore increase the risk of no education being delivered.	Not possible to teach required epilepsy awareness in less time. Unsafe to train professional carers with no prior knowledge of epilepsy to administer midazolam without underpinning knowledge of epilepsy. Course duration recommended to be 4-6 hours with 2-3 hour refreshers <i>unless</i> bespoke training required for an individual, in which case the duration could vary depending on the complexity of needs.
Course content	Delegates felt that the JEC content was still applicable, but that there were significant omissions (e.g. SUDEP). Extensive debate produced a list of required topics.	Significant further debate about course content. Decision made to have essential and desirable elements. For example, recognising common seizure types was considered essential, whereas psychosocial aspects of epilepsy were desirable.
Refresher course frequency and content	JEC guidelines recommended a refresher course every 2 years. Consideration given to 12 month refreshers. Concerns about capacity versus safety.	Carers should attend a refresher course every 2 years.
Mode of delivery (face to face or remote)	Consensus quickly reached about midazolam administration, which needed to be taught face-to-face due to practical administration. Considerable debate about	Final position was that all of the course should be taught face-to-face. This was to be reviewed formally as part of the guidelines evaluation process.

	whether epilepsy awareness could be taught remotely.	
Indemnity	How to ensure indemnity insurance to protect practitioners and organisations from malpractice claims related to training provided.	Vicarious liability from employing organisation, or obtained independently. Up to date professional development (in the UK, this is regulated by statutory bodies for nursing and medical professionals). Following best practice teaching guidelines ⁹
Care plan documentation	Important for robust documentation outlining when emergency intervention is required, midazolam dose and frequency. Important to make an example care plan available as part of the guidelines.	Care plans in use by wider ESNA membership considered. Commonalities identified and draft produced. Final version appended with the guidelines ⁹ .
Accountability	Lots of interregional variability surrounding the delivery of epilepsy awareness and midazolam training. Concerns about professional accountability and indemnity if full guidelines not followed. No resolution at stage 2 and question debated by wider membership.	There are some areas of the UK with well established procedures for delivering epilepsy training, but which vary from the consensus guidelines. The final resolution was to outline the training organisation's responsibilities and specifically that deviations from the recommendations made in the guidelines ⁹ must have clear lines of accountability.
Assessment content	Debate around whether there should be a single assessment covering all aspects of epilepsy awareness and midazolam administration, or whether the assessment should be divided into sections in an incremental manner, so that one section needs to be passed before the next is attempted. The wider membership were invited to produce relevant questions (table 3), which was subsequently reviewed in a two-stage process by ESNA and the ILAE.	The assessment was divided into three sections; epilepsy awareness, safety and seizure treatment, first aid and emergency medication administration. Each section has to be passed before moving onto the next in an incremental manner. Pass rates were set at 80% for epilepsy awareness, with 100% for safety and seizure treatment.
Assessment format	Many individual assessments were evaluated. A consensus formed around a single unified test to help promote uniform	Consensus formed around the benefits of remote testing with audit facilities. Virtual College

	standards. Some debate about whether this could be delivered face-to-face or by electronic means. Remote assessment held advantages in terms of audit. Promising results from a pilot in Cornwall. Debate about hosting the assessment.	(VEC) chosen as host for the online test.
Assessment methods	Many methods in use. Written tests, with multiple choice or longer written answers were commonly in use, sometimes alongside quizzes, verbal and practical assessments.	Recommendation that all course delegates take the online test. This can be supplemented by local testing arrangements, mandated by the care organisation and/or the training organisation.
Cost of assessment	Delegates felt that the ideal would be to provide a free online assessment. However, this proved impossible to achieve in practice with no organisations been able to provide free technical support and hosting. There was considerable disagreement about whether to mandate a purchased test.	The benefits of providing a uniform test with a stable platform provided by an organisation with considerable online health education experience and incorporating an audit function was felt to outweigh the nominal cost of £5.00 per test. This was therefore adopted as best practice.

Table 2 – Panellists for the Delphi process

Name	Title	Affiliated organisation
Phil Tittensor	Consultant Nurse, Honorary lecturer, Chairperson of ESNA,	ESNA - project lead for ESNA – task and finish group member
Sarah Tittensor	ESN, adult,	ESNA - lead of the on-line assessment task and finish group
Erica Chisanga	Consultant Nurse,	ESNA - lead of the guidelines task and finish group
Marie Hooper	ESN, adult	ESNA – task and finish group member
Alison Holmes	ESN, adult	ESNA – task and finish group member
Shelly Brett	ESN, adult	ESNA – task and finish group member
Marie Synnott-Wells	ESN, adult	ESNA – task and finish group member
Martain Smith	ESN, paediatrics	ESNA – task and finish group member
Mary Codling	ESN, intellectual disabilities	ESNA – task and finish group member
Lynda Morris	ESN, adult	ESNA – task and finish group member
Jill Conium	ESN, adult	ESNA – task and finish group member
Hazel Thomas	ESN, paediatrics	ESNA – task and finish group member
Jackie Scott	ESN, adult	ESNA – task and finish group member
Mel Goodwin	ESN, adult	ESNA – task and finish group member
Caryn Jory	ESN, intellectual disabilities	ESNA – task and finish group member
Fiona Hughes	ESN, adult, Chairperson ESNA Scottish locality group	ESNA – task and finish group member
Pam Iddon	ESN, adult, epilepsy commissioning support	ESNA – task and finish group member
Lesley Alexander	ESN, adult, lead representative for Northern Ireland	ESNA – task and finish group member
Jan Bagshaw	Independent epilepsy consultant nurse	ESNA – task and finish group member
Mathew Walker	Professor of Neurology, Consultant Neurologist, President ILAE (Europe)	ILAE – special advisor
Manny Bagary	Consultant Neuropsychiatrist President ILAE (British Chapter)	ILAE – project lead for ILAE
Juliet Solomon	Director ILAE	ILAE – special advisor

Richard Hills	General Practitioner, GP lead for ILAE	ILAE – special advisor
Ashok Roy	Consultant Psychiatrist, RC Psych lead for Intellectual Disability Faculty	RC Psych – special advisor
Rohit Shankar	Professor of Neuro psychiatry Consultant Psychiatrist,	RC Psych - Medical advisor and project lead for RC Psych.
Jean O’Hara	FRC Psych, National clinical director for learning disabilities, Consultant Psychiatrist, Visiting Senior Lecturer	RC Psych – special advisor
Eileen Joyce	Professor of Neuropsychiatry, Chair or RCPsych neuropsychiatry group Consultant Psychiatrist	RC Psych – special advisor
Maria Oto	Consultant Psychiatrist, executive member of RCPsych Neuropsychiatry group & ILAE British Chapter executive member	RC Psych – special advisor
Mike Wilcock	Pharmacist, head of prescribing support unit	Special advisor
Reena Tharain	Community pharmacist	Special advisor
Dominic Slowie	General practitioner, National Clinical Advisor (learning disability and premature mortality) NHS England	Special advisor
Epilepsy Action	National Charity	Stakeholder group
SUDEP Action	National Charity	Stakeholder group

Table 3 – Example questions from the on-line test

Epilepsy awareness						
Question	A	B	C	D	E	Correct answer/s
What is epilepsy?	A tendency to have recurring seizures	A nervous tick	A reaction to a stressful situation	A mental health condition		A
What is true about anti epileptic medications? (tick all that apply)	Seizure medications may have side effects that upset the patient	Seizure medications will reduce the frequency of seizures in many patients	Seizure medications may reduce the severity of seizures	Seizure medications can cure epilepsy		ABC
Can you catch epilepsy?	Yes	No				B
Safety						
Question	A	B	C	D	E	Correct answer/s
If you are with a person who is in the bath, what should you do to help them?(select all that apply)	Keep the warm water topped up to stop them getting cold	Lift them out of the bath and lay them on the floor as soon as possible	Pull the plug and allow the water to drain	Use towels around the side of the bath and over the person to prevent injury and maintain dignity	Leave them and go and get help quickly	CD
What must be recorded in the event of a seizure?	Room temperature	First aid intervention	How many people	The length of time of the seizure	Description of the seizure	BDE

(select all that apply)		including any medication	witnessed the seizure			
When supporting someone DURING a seizure you should (select all that apply)	Restrain the person during the seizure	Protect their head with something soft or your hands	Loosen restrictive clothing	If the person is in bed remove the pillows	Place some gauze between the teeth to prevent the tongue being bitten and remove false teeth	BCD
Seizure treatment, first aid and emergency medication administration						
Ann is a 50 year old lady with learning disabilities who is refusing to take her medication. Her relatives say it is fine to hide her medication in her food. \What do you do?	Agree and do as hr relative asks. Ann obviously doesn't know what is good for her	Tell the relative Ann must have a mental capacity assessment to see if she can understand about the consequences of not taking her medication	Tell her relative Ann has the right to refuse her medication and if she doesn't want to have them not to give them			B
What are the circumstances to call an ambulance when a person has a convulsive seizure? (select all that apply)	If the seizure lasts longer than 5 minutes and you don't know the person	If it is the first convulsive seizure	If the seizure has happened in water and the person may have inhaled some water	if you are concerned about their breathing or an injury	Whatever your care plan states	ABCDE

What would you check before you administer Buccal Midazolam? (select all that apply)	Is it the right person's Midazolam	Has it been stored correctly (i.e. not in a fridge)	Are the tamper seals in place	Has the person met the criteria for administration in their care plan	If you might need it later and don't have any more in stock	ABCD
--	------------------------------------	---	-------------------------------	---	---	------

UK framework for basic epilepsy training and oromucosal midazolam administration

Phil Tittensor^{1,2}, Sarah Tittensor³, Erica Chisanga⁴, Manny Bagary⁵, Caryn Jory⁶, Rohit Shankar^{6,7*}

¹Royal Wolverhampton NHS Trust United Kingdom

²University of Wolverhampton United Kingdom

³University Hospitals Birmingham NHS Foundation Trust United Kingdom

⁴Cambridge University Hospital NHS Foundation Hospital Trust United Kingdom

⁵Birmingham and Solihull Mental Health Foundation Trust, United Kingdom

⁶Cornwall Partnership NHS Foundation Trust United Kingdom

⁷Cornwall Institute of Intellectual Disability Equity Research (CIDER) University of Plymouth Medical School United Kingdom

***Corresponding author:**

Professor Rohit Shankar MBE, email address: Rohit.shankar@nhs.net, Threemilestone Industrial Estate, Truro, UK.

PT has received honoraria for talks from Arvelle, Bial, Eisai, Sanofi, UCB Pharma and Veriton, ST honoraria for talks from Arvelle and Veriton CJ has received honoraria for talks from UCB, Arvelle and Veriton. RS has received institutional and research support from LivaNova, GW pharma, UCB, Eisai, Special Products, Averelle and Destin outside the submitted work. We all have the disclosure of being authors of the ESNA guidance which is referenced and used in this paper. It is free to download and use.

Funding sources:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

All authors have the disclosure of being authors of the ESNA guidance which is referenced and used in this paper. It is free to download and use.