Care of pregnant women with epilepsy in the United Kingdom

Taylor, Emily; Junaid, Fatima; Khattak, Hajra; Sheikh, Jameela; Ghosh, Jay; Kemah, Ben-Lawrence; Nelson-Piercy, Catherine; Morley, Kim; Moss, Ngawai; Knox, Ellen; Allotey, John; Thangaratinam, Shakila

DOI:
10.1016/j.ejogrb.2022.06.021

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (Harvard):
Taylor, E, Junaid, F, Khattak, H, Sheikh, J, Ghosh, J, Kemah, B-L, Nelson-Piercy, C, Morley, K, Moss, N, Knox, E, Allotey, J & Thangaratinam, S 2022, 'Care of pregnant women with epilepsy in the United Kingdom: A national survey of healthcare professionals', *European Journal of Obstetrics & Gynecology and Reproductive Biology*, vol. 276, pp. 47-55. https://doi.org/10.1016/j.ejogrb.2022.06.021

European Journal of Obstetrics and Gynecology 276 (2022) 47–55

Contents lists available at ScienceDirect

European Journal of Obstetrics & Gynecology and Reproductive Biology

journal homepage: www.journals.elsevier.com/european-journal-of-obstetrics-and-gynecology-and-reproductive-biology

Care of pregnant women with epilepsy in the United Kingdom: A national survey of healthcare professionals

Emily Taylor [a,*,1], Fatima Junaid [b,1], Hajra Khattak [c], Jameela Sheikh [a], Jay Ghosh [d], Ben-Lawrence Kemah [e], Catherine Nelson-Piercy [f], Kim Morley [g], Ngawai Moss [h], Ellen Knox [e], John Allotey [i], Shakila Thangaratinam [e,i]

[a] University of Birmingham, Birmingham B15 2TT, United Kingdom
[b] Russells Hall Hospital, Pensnett Road, Dudley DY1 2HQ, United Kingdom
[c] Tommy's National Centre for Miscarriage Research, Institute of Metabolism and Systems Research, University of Birmingham, Birmingham B15 2TT, United Kingdom
[d] Worcester Royal Hospital, Charles Hastings Way, Worcester WR5 1DD, United Kingdom
[e] Birmingham Women's and Children's NHS Foundation Trust, Mindelsohn Way, Birmingham B15 2TG, United Kingdom
[f] Guy's & St Thomas' Foundation Trust, London SE1 7EH, United Kingdom
[g] Royal Hampshire County Hospital, Winchester SO22 5DG, United Kingdom
[h] Patient and Public Representative, London, United Kingdom
[i] Institute of Metabolism and Systems Research, University of Birmingham, Birmingham B15 2TT, United Kingdom

ARTICLE INFO

Keywords:
Epilepsy
Pregnancy
Antenatal care
Service provision
Healthcare professionals
Survey

ABSTRACT

Objectives: To map the care provided to pregnant women with epilepsy in UK maternity units and identify future research priorities by conducting a nationwide survey of healthcare professionals.
Study design: A prospective cross-sectional electronic survey was conducted between 29 April and 30 October 2021. The survey included 23 questions developed and refined with relevant stakeholders, including a woman with lived experience of epilepsy and pregnancy. We used descriptive analyses to summarise responses and estimated proportions with medians and interquartile ranges.
Results: 144 individual healthcare professionals from 94 hospitals, representing 77 NHS Trusts, participated in the survey. Obstetricians were the most common responders (45%, 65/144) and almost half (47%, 7/15) of regions had a survey response rate per NHS Trust greater than 50%. Six pregnant women with epilepsy, on average, were booked into antenatal care per hospital per month, and 49% (46/94) of hospitals saw women for specialist antenatal care in the first trimester. The care provided across healthcare systems varied, with multiple pathways for referral to specialist care within regions. Midwife referral was the most used care pathway (80%, 75/94). Less than a third of hospitals (31%, 29/94) ran joint obstetric/neurology clinics for pregnant women with epilepsy. Most survey respondents (81%, 117/144) were confident talking to pregnant women about their risk of seizures but only a minority (20%, 29/144) used validated calculators to assess this risk. There was broad agreement across healthcare professionals that the priorities for research should focus on how to improve communication and address pregnant women's concerns regarding epilepsy and pregnancy, and to develop further understanding on the optimal use and long-term effects of anti-seizure medication.
Conclusion: Our UK nationwide survey of hospital-based maternity services for pregnant women with epilepsy identified wide variation in when, how and by whom these women are seen, with differences between and within the UK regions. This survey highlights areas for improvement in the care of pregnant women with epilepsy.

Introduction

In the United Kingdom (UK), four in 1000 women who give birth have epilepsy [1]. However, one in ten women who die during pregnancy or after childbirth have epilepsy [1]. The main cause of their death is poorly controlled seizures. The 2020 confidential enquiries

* Corresponding author at: College of Medical and Dental Sciences, University of Birmingham, Birmingham B15 2TT, United Kingdom.
E-mail address: emilyct98@aol.com (E. Taylor).
[1] First authors.

https://doi.org/10.1016/j.ejogrb.2022.06.021
Received 16 May 2022; Accepted 24 June 2022
Available online 30 June 2022

(MBRRACE-UK) raised concerns about the significant increase in epilepsy-related maternal deaths, from eight to 18, between consecutive reports [2]. However, management of these women and their condition is complex. Exposure to anti-seizure medication (ASM) in utero increases the risk of fetal congenital malformations and may have long-term neurodevelopmental consequences [3,4]. These risks rise with increased ASM doses and the use of polytherapy [5–7]. Seizures and treatment of seizures also impact women's independence, employment, relationships, and mental health [8–11].

Multi-specialist antenatal care is critical in mitigating seizure risk and optimising ASM regimens for women with epilepsy to promote safe outcomes for mother and fetus during pregnancy [12,13]. Consecutive MBRRACE-UK reports highlight the fragmented care received by pregnant women with epilepsy [14], and a continued lack of communication between maternity and neurology services. This is despite the recommendation by the Royal College of Obstetricians and Gynaecologists (RCOG) and MBBRACE-UK reports for joint care models [12]. All maternity departments are required to have access to an epilepsy care team [14].

Much is unknown regarding the care provided to pregnant women with epilepsy across the four UK nations and if this varies by region. We addressed this gap in knowledge and assessed compliance with the current MBRRACE-UK recommendations [14]. We mapped the type of care provided to pregnant women with epilepsy in UK maternity units by undertaking a nationwide survey of healthcare professionals and identified future research priorities.

Materials and methods

The survey was sent electronically to National Health Service (NHS) Trusts across the UK that provide maternity services and open to healthcare professionals who were likely to provide care to pregnant women with epilepsy. The survey was available via a secure online platform between 29 April and 30 October 2021. Information about the survey was disseminated through professional contacts, including obstetrics trainee networks, Epilepsy Action UK's epilepsy specialist nurse newsletter, and social media platforms. Eligible participants were given a maximum of five reminders to complete the survey. The survey comprised of 23 questions, with a combination of multiple choice, Likert scale and ranking questions (Supplementary Material S1). It was designed to be completed within 10–15 min.

The questions on the care provided to pregnant women with epilepsy assessed factors at the level of the maternity hospitals or NHS Trusts (eight questions) and the individual level (15 questions). Questions were developed and refined following discussions with all relevant stakeholders, including one woman with lived experience of epilepsy and pregnancy. Hospital-level questions focussed on the organisation of maternity-epilepsy services, antenatal referral pathways, availability of pre-conception counselling, and protocols used for management. Individual-level questions explored healthcare professionals' experience with referring women to the epilepsy registry, and assessing, managing and communicating seizure risk. We determined future research priority topics by requesting participants to rank questions relevant to improving maternal and offspring outcomes by perceived order of importance.

We performed descriptive analyses to summarise survey responses. Responders were ranked in terms of seniority within the care pathway in the order: consultant obstetrician, consultant neurologist, epilepsy specialist midwife, epilepsy specialist nurse, general midwife, trainee obstetrician, trainee neurologist and general nurse. Responses from the most senior role were used to summarise results at the hospital level. The data were presented to reflect the response rates and the degree of representation across UK regions, starting with high to low response regions. All analyses were conducted and figures produced in Excel Microsoft 365.

Ethical approval for this project was not required, and informed consent was assumed by agreement to participate in and complete the survey.

Table 1
Demographics of survey respondents.

Geographical Spread Region	Response rate of NHS Trusts (Number that completed survey/ number survey was sent to (%))	Number of hospitals that completed survey
West Midlands	14/14 (100)	15
Wessex	5/7 (71)	7
Thames Valley	3/5 (60)	4
Peninsula	3/5 (60)	3
North West	11/19 (58)	11
London	12/21 (57)	13
Kent, Surrey and Sussex	8/15 (53)	9
North East	3/8 (38)	5
East Midlands	3/8 (38)	4
East of England	4/12 (33)	4
Yorkshire and Humber	4/13 (31)	5
Scotland	4/14 (29)	7
Northern Ireland	1/5 (20)	3
Wales	1/6 (17)	2
Severn	1/7 (14)	1
Job Role **Role**	**Number of respondents (% of overall respondents)**	
Obstetrician	65/144 (45)	
Neurologist	13/144 (9)	
Epilepsy specialist nurse/midwife	49/144 (34)	
General midwife	17/144 (12)	

Results

Overall, 159 NHS Trusts were identified that provide maternity services across the UK. Healthcare professionals from 77 NHS Trusts (77/159, 49%) representing 94 hospitals completed the survey. Responses were received from a mean of six (range 1–15) hospitals per Trust. 30% (28/94) of hospitals had more than one individual complete the survey. After excluding the two responses from non-clinical participants (2/146, 1%), 144 valid individual responses were included in the final analysis. The West Midlands region had the highest rate of responses from their Trusts (14/14 Trusts, 100%) and the Severn region, the least (1/7 Trusts,14%). Obstetricians were the most represented profession in the survey (65/144, 45%) (Table 1).

Care provided across healthcare systems

On average, six pregnant women with epilepsy were reported to book for antenatal care in a hospital maternity unit each month across the UK (Fig. 1). This was highest in Scotland (11 women), and lowest in the Thames Valley region (3 women). Participants from 65% (61/94) of hospitals reported that their unit had a care pathway for pre-conception counselling for pregnant women with epilepsy (Fig. 2). Amongst regions with a survey response rate greater than 50%, London hospitals (85%, 11/13) were most likely to have a pre-conception counselling care

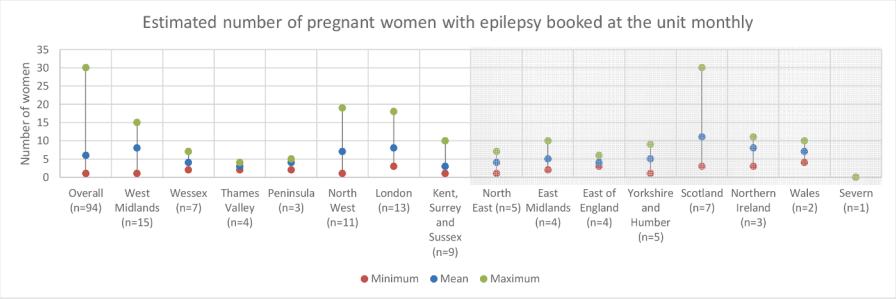


Fig. 1. Monthly booking number of pregnant women with epilepsy. Number of hospitals responding within each region in brackets. Regions with less than 50% response rate in grey shading.

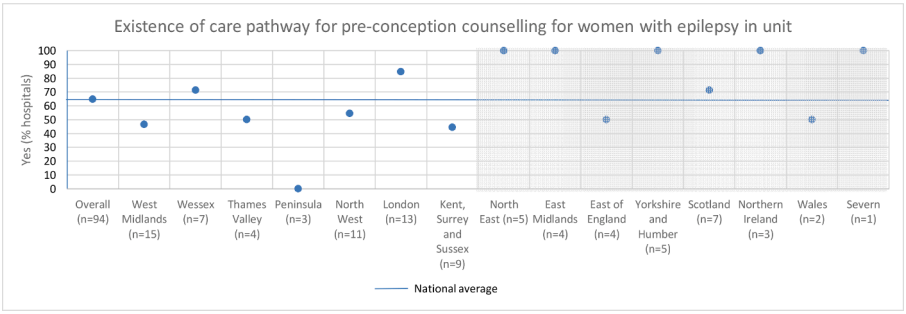


Fig. 2. Prevalence of care pathway for pre-conception counselling. Number of hospitals responding within each region in brackets. Regions with less than 50% response rate in grey shading. Blue line denotes national average. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

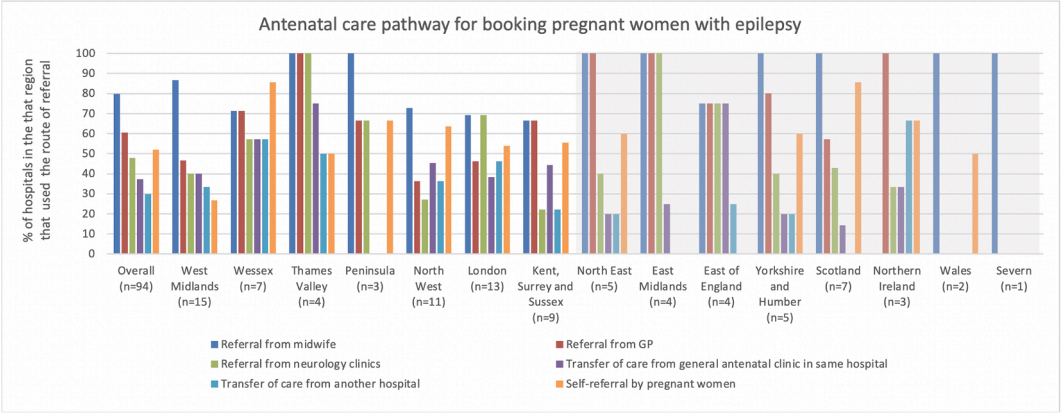


Fig. 3. Antenatal care pathways for booking pregnant women with epilepsy. Number of hospitals responding within each region in brackets. Regions with less than 50% response rate in grey shading.

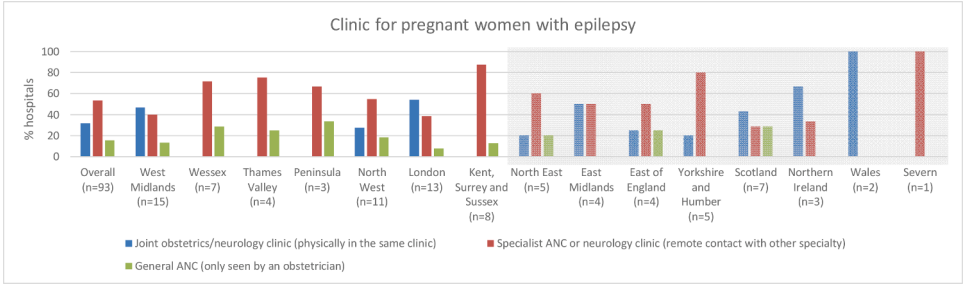


Fig. 4. Clinics for pregnant with epilepsy. Number of hospitals responding within each region in brackets. Regions with less than 50% response rate in grey shading.

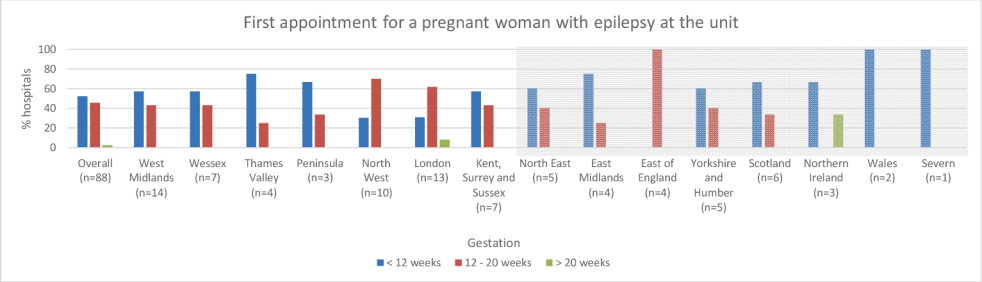


Fig. 5. Timing of first specialist antenatal appointment for pregnant woman with epilepsy. Number of hospitals responding within each region in brackets. Regions with less than 50% response rate in grey shading.

pathway for pregnant women with epilepsy. Across the UK, most pregnant women with epilepsy were referred for specialist care by their midwife (75/94 hospitals, 80%), followed by their GP (57/94, 61%), then by self-referral (49/94, 52%). Multiple referral pathways for booking pregnant women with epilepsy were also reported across the regions (Fig. 3).

Overall, 11% (10/94) of hospitals reported that their unit did not have a protocol for managing pregnant women with epilepsy. Of the hospitals reported to have a protocol, almost two-thirds (63%, 46/72) used multiple guidelines. Amongst the protocols used, 74% (53/72) used the RCOG guidelines, 64% (46/72) used the National Institute for Health and Care Excellence (NICE) guidelines, and 19% (14/72) used the Scottish Intercollegiate Guidelines Network (SIGN) guidelines.

Across the UK, 31% (29/94) of hospitals had joint obstetric-neurology clinics caring for pregnant women with epilepsy, where both obstetricians and neurologists were physically present (Fig. 4). Over half of hospitals (52%, 49/94) nationally ran either a specialist antenatal clinic (led by an obstetrician, with remote contact with a neurologist) or neurology clinic (led by a neurologist, with remote contact with an obstetrician). In 16% (15/94) of hospitals, women were only seen by an obstetrician in a general antenatal clinic. Amongst hospitals that ran joint clinics, these were held weekly in 8% (2/26), fortnightly in 38% (10/26) or monthly in 46% (12/26). Women were seen for antenatal epilepsy management before 12 weeks' gestation in 52% (46/88) of hospitals, and before 20 weeks' gestation in 98% (86/88) of hospitals. Women tended to be seen earlier in Thames Valley (75%, 3/4 less than 12 weeks) and Peninsula (67%, 2/3), as compared to London (31%, 4/13) and the North West (30%, 3/10).Fig. 5..

Care provided by healthcare professionals

Two-thirds of all participants (67%, 97/144) referred women with epilepsy to the national epilepsy register (Fig. 6). Epilepsy specialist nurses/midwives were most likely to do so (98%, 48/49), followed by neurologists (85%, 11/13). Only 51% (33/65) of obstetricians had referred a woman to the epilepsy register, but the proportion varied between consultants (74%, 28/38) and trainees (19%, 5/27). The maternity epilepsy shared care toolkit [15] was used by only 38% (55/144) of respondents (Fig. 7). It was, however, popular with epilepsy specialist nurses/midwives, with more than twice the survey average (78%, 38/49) having used it.

Just over half of respondents (56%, 75/144) felt that the risk of seizures in pregnant women with epilepsy should be first documented at their booking appointment. However, 41% (55/144) felt this should occur when they first see an obstetrician or neurologist (Fig. 8A). Almost two-thirds of respondents (65%, 93/144) communicated seizure risk to pregnant women both verbally and with written information (Fig. 8B). There was variation in practice amongst trainee and consultant obstetricians. Trainees were more likely to communicate verbally only compared to consultants (56%, 15/27 and 29%, 11/38 respectively), and less likely to use both verbal and written methods (33%, 9/27 and 71%, 27/38 respectively). Most respondents (81%, 117/144) were confident talking to pregnant women about their risk of seizures (Fig. 8C). 71% (27/38) of consultant obstetricians and 80% (8/10) of consultant neurologists were very confident, compared to 11% (3/27) of trainee obstetricians and no (0/17) general midwives.

Seizure risk calculators were poorly used amongst respondents overall, with only 20% (29/144) aware of and using them, while 72% (47/65) of obstetricians and 94% (16/17) of general midwives were not aware of any such tool. Of those who did use a calculator, the Empire calculator was most commonly cited (7/17 responses, 41%), followed by the ASM withdrawal risk and EpSMon/SUDEP calculators (5/17 responses, 29% each). The EpSMon/SUDEP calculator was popular amongst epilepsy specialist nurses/midwives who used a risk calculator (5/9 midwives, 56%) but not used by any obstetrician or neurologist.

The majority of respondents agreed on what they thought the top three concerns for pregnant women with epilepsy were (Table 2). In

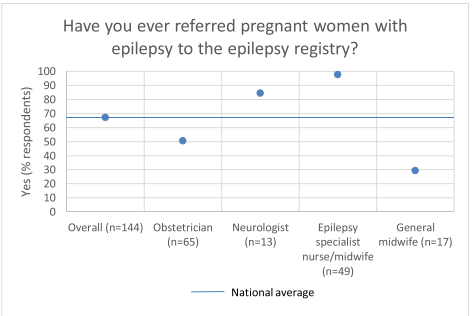


Fig. 6. Referral rate to epilepsy register. Blue line denotes national average. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

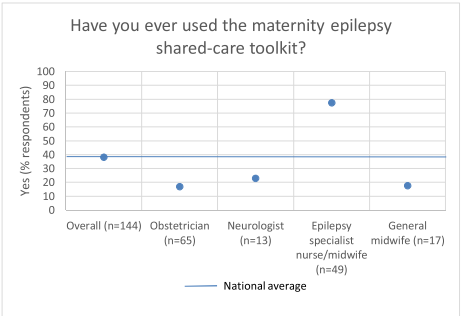
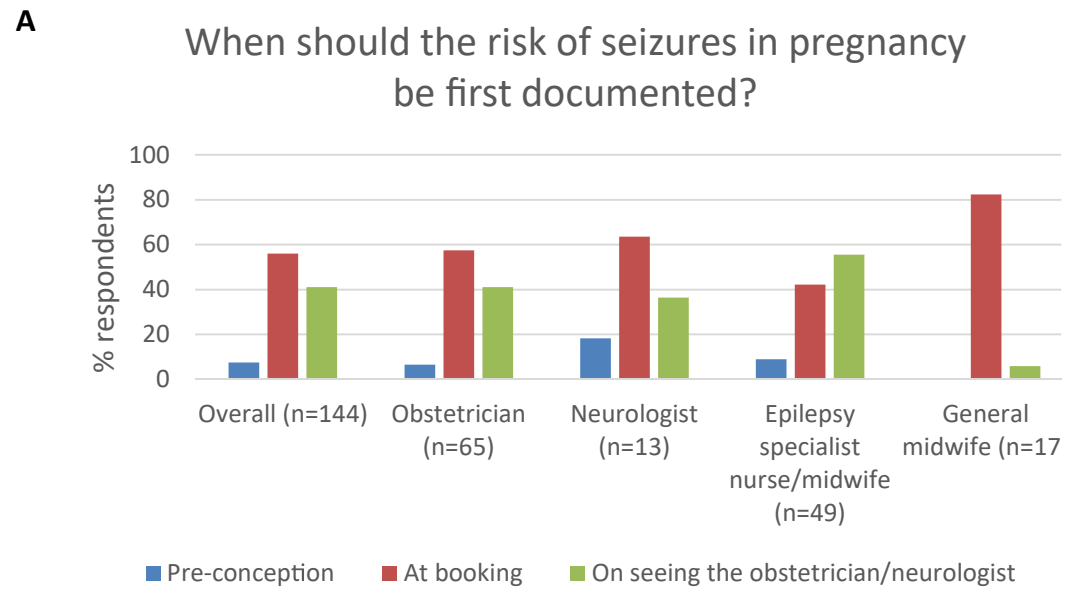


Fig. 7. Use of maternity epilepsy shared-care toolkit. Blue line denotes national average. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)



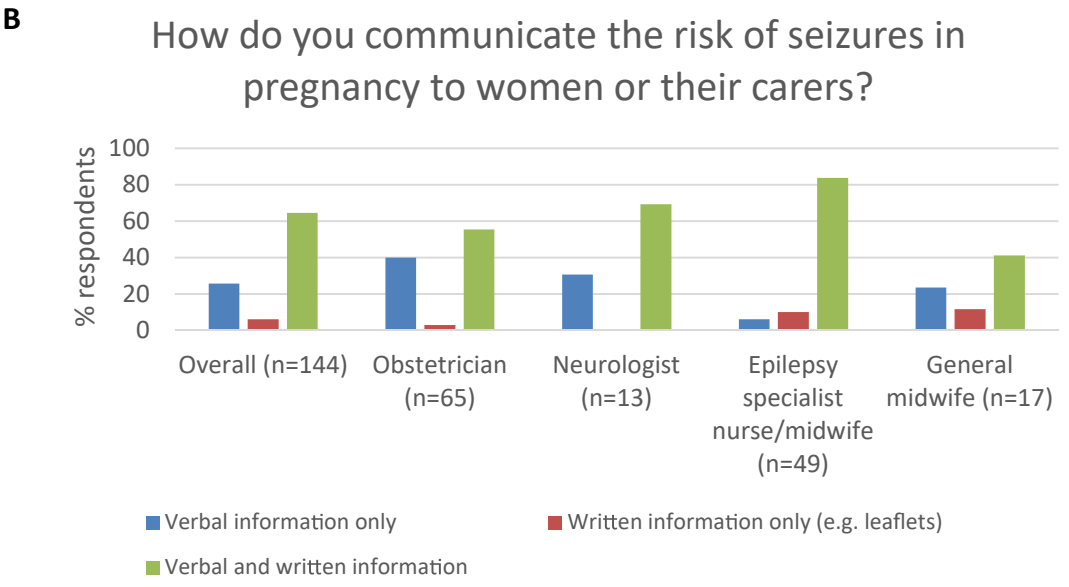


Fig. 8. Seizure risk communication. A. Opinion of healthcare professionals when seizure risk should first be documented in a pregnancy. B. Methods of communication of seizure risk to pregnant women. C. Confidence of healthcare professionals in communicating seizure risk to pregnant women.

addition to these common responses, consultant obstetricians reported a concern of what factors increased triggers for seizures during pregnancy (e.g. tiredness), and consultant neurologists noted the concern of whether the woman would pass on epilepsy to her child.

There were similar opinions across respondents about the research priorities for improving outcomes for mothers and babies, with most specialities selecting the same top three (Table 2). In addition to these common responses, consultant neurologists and trainee obstetricians added whether there was a role for drug monitoring for newer ASMs. General midwives wanted to prioritise how to increase awareness amongst healthcare professionals of a mother's seizure risk status. Communication with mothers and families regarding potential complications in babies born to mothers with epilepsy was also deemed important by epilepsy specialist nurses/midwives.

C

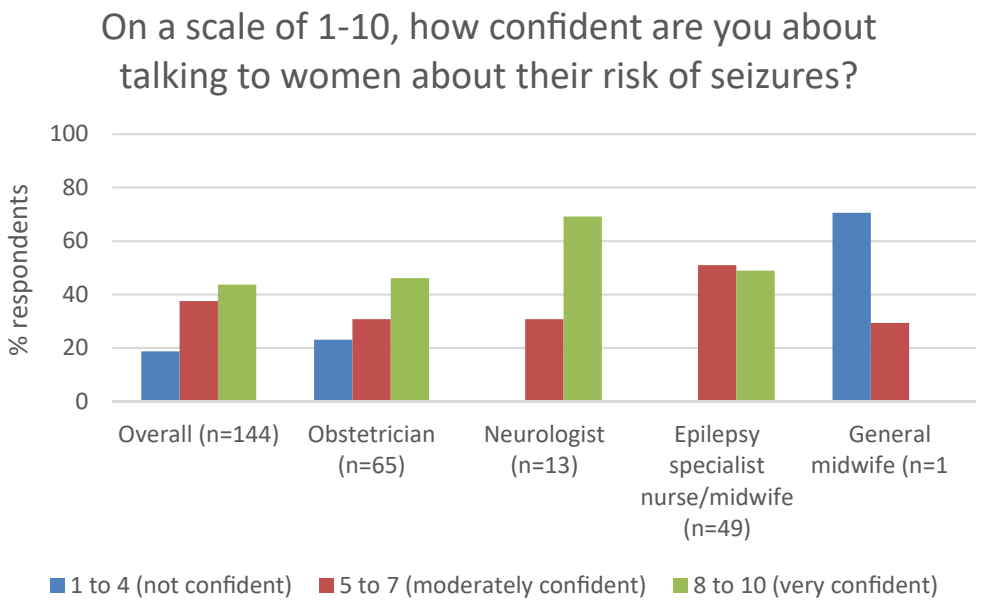


Fig. 8. (*continued*).

Discussion

This is the first nationwide study assessing hospital-based specialist maternity services for pregnant women with epilepsy in the UK. We identified widespread variation in when, how and by whom these women are seen, with differences between and within regions. While most respondents were aware of how to care for pregnant women with epilepsy, a sizeable minority were unaware of any pre-conception care or antenatal referral pathways or protocols within their hospitals. Once referred, only a minority of women nationally were seen at joint clinics with obstetrics and neurologists, and many were first seen in their second trimester. The survey further identified how practice and confidence in managing pregnant women with epilepsy varied among individuals and between different specialities, with epilepsy specialist nurses/midwives most likely to use epilepsy toolkits and feel confident discussing seizure risk with pregnant women. We also noted differences in experience, practice and confidence between trainee and consultant obstetricians, which highlights an area for improvement. The questionnaire was also useful in identifying research priorities regarding optimising the care of pregnant women with epilepsy based on the experience of healthcare professionals working closely with them.

Responses were gathered from a range of healthcare professionals in all four UK nations and several English regions, covering a broad range of perspectives, experiences, and geographical contexts. A strength of the survey was identifying what respondents understood the provision in their hospital to be, therefore likely to be reflective of their practice in managing pregnant women. Therefore, it is a more pragmatic evaluation of services rather than a necessarily comprehensive one. For example, how many hospitals have pre-conception counselling pathways or what guidelines were used in their local hospital. The survey also captured individual practice and confidence, illustrating what tools are currently being used and by which group of healthcare professionals.

However, a key limitation of this study is the difference in response rates between different regions, making accurate and quantitative geographical comparisons in provision particularly difficult. The resulting data is more English-centric due to limited responses from other UK nations. An added difficulty was processing multiple responses from the same unit when seeking to evaluate services at a hospital level. Prioritising responses based on those most likely to directly oversee antenatal management, like a consultant obstetrician may have given an accurate overview of the hospital but removed alternative experiences of provision within the same unit. The survey also focussed on the experience and understanding of healthcare professionals, rather than that of the pregnant women themselves in order to evaluate how

Table 2
Identified concerns and research priorities for pregnant women with epilepsy.

What do you think are the top 3 concerns for pregnant women with epilepsy?
Impact of epilepsy medication on their unborn baby (e.g. abnormalities or long-term effects)
Impact on the baby from having a seizure (e.g. miscarriage, foetal oxygen supply)
Managing their medication (e.g. dosage changes, stopping medication)
What are the top 3 research questions for improving maternal outcomes in women with epilepsy?
How can we accurately predict seizure risk in pregnancy?
How can we best address women's concerns regarding epilepsy medicines to reduce change in adherence?
How can we optimise communication of seizure risk to pregnant women with epilepsy and families?
What are the top 3 research questions to improve baby outcomes in pregnant women with epilepsy?
What is the association between the type and dosage of epilepsy medications and congenital abnormalities?
How can we predict any adverse outcomes in children born to women with epilepsy?
What is the association between epilepsy medications and neurodevelopment outcomes beyond 5 years of age?

professionals understand and utilise protocols in their hospitals.

Despite repeated studies on the importance of improving maternal outcomes for women with epilepsy, maternal deaths from epilepsy have risen in the UK and Ireland [14]. Of those who died, very few had documented pre-pregnancy counselling, and fewer than half saw an epilepsy specialist during pregnancy. Independent reviewers thought there may have been an alternative outcome in 68% of cases if these women received different care, giving a strong impetus to improve provision. Hence, women with epilepsy should receive holistic, multidisciplinary care during and prior to pregnancy [12,13]. Based on our survey, it is evident that not all UK units or healthcare professionals involved in maternity services for pregnant women with epilepsy are following these guidelines. Maternal medicine networks should aim to address regional differences and prioritise the provision of equitable, accessible care and education. Local audits of practice would be useful in reviewing adherence to national standards and identifying areas for improvement.

This survey identifies several areas that units can consider for improving their services for pregnant women with epilepsy. This may include targeted measures such as evaluating staff training to increase awareness of provision and protocols or educational sessions for trainee obstetricians on management and communication with pregnant women with epilepsy. It is hoped that this survey can encourage more interdisciplinary teamwork, utilising the experiences and varied expertise of obstetricians, neurologists and specialist nurses/midwives in providing comprehensive care for pregnant women.

Further research areas include maternal and fetal outcomes based on the type of antenatal clinic pregnant women with epilepsy attend and the woman's experience during pregnancy. Capturing the experience of pregnant women in their interactions with different healthcare professionals would also be informative in targeting staff training and education. Finally, this survey identified clear research priorities that would be of most use to staff and pregnant women in improving the management of this key obstetric demographic such as ASM, seizure-risk prediction, and optimising communication with pregnant women regarding their epilepsy.

Conclusion

Epilepsy is often a debilitating condition, especially for pregnant women. By conducting a national survey of healthcare professionals, we were able to map the type of care delivered to pregnant women with epilepsy in UK maternity hospitals and identify priorities for future research and education of both healthcare professionals and women with epilepsy. It is evident that despite the guidance by RCOG and recommendations in the MBRRACE reports, there is a sheer discrepancy in how care is provided to these high-risk pregnant women in the UK. There is a need for standardised, accessible care to prevent morbidity and mortality in this group of pregnant women. Predicting seizure risk during pregnancy and understanding the impact of anti-seizure medications on babies born to women with epilepsy are two of the top research goals for healthcare practitioners. Finally, differences in experience, practice and confidence amongst trainee and consultant obstetricians calls for improving the training of those involved in the care of women with epilepsy.

Funding

No sources of financial support were obtained for this work.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We thank all the healthcare professionals who completed this survey. We thank Epilepsy Action UK, The Royal College of Midwives, Wessex Epilepsy Nurse Forum, RCOG National Trainee's Committee, MacDonald Obstetric Medicine Society and the Epilepsy Nurses Association for helping to disseminate this survey. We also thank the Dame Hilda Lloyd Medical Student Champions (Ella Marson, Isobel Trout, Millie Manning and Adeolu Banjoko) for their support with survey recruitment.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejogrb.2022.06.021.

References

[1] The UK Epilepsy and Pregnancy Register [last accessed 25/03/2022]. Available from: http://www.epilepsyandpregnancy.co.uk.
[2] Knight M, Bunch K, Tuffnell D, et al. on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care: Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2017-19. Oxford: National Perinatal Epidemiology Unit, University of Oxford; 2021.
[3] Tomson T, Battino D, Bonizzoni E, Craig J, Lindhout D, Sabers A, et al. EURAP study group. Dose-dependent risk of malformations with antiepileptic drugs: an analysis of data from the EURAP epilepsy and pregnancy registry. Lancet Neurol 2011;10(7):609–17.
[4] Bromley R, Weston J, Adab N, Greenhalgh J, Sanniti A, McKay AJ, et al. Treatment for epilepsy in pregnancy: neurodevelopmental outcomes in the child. Cochrane Database Syst Rev 2014;2020(6). https://doi.org/10.1002/14651858.CD010236.pub2.
[5] Hill DS, Wlodarczyk BJ, Palacios AM, Finnell RH. Teratogenic effects of antiepileptic drugs. Expert Rev Neurother 2010;10(6):943–59. https://doi.org/10.1586/ern.10.57.
[6] Meadow R. Anticonvulsants in pregnancy. Arch Dis Child 1991;66:62–5. https://doi.org/10.1136/adc.66.1_Spec_No.62.
[7] Rosa FW. Spina bifida in infants of women treated with carbamazepine during pregnancy. N Engl J Med 1991;324(10):674–7. https://doi.org/10.1056/NEJM199103073241006.
[8] Thangaratinam S, Marlin N, Newton S, Weckesser A, Bagary M, Greenhill L, et al. AntiEpileptic drug Monitoring in PREgnancy (EMPiRE): a double-blind randomised trial on effectiveness and acceptability of monitoring strategies. Health Technol Assess 2018;22(23):1–152.
[9] Weckesser A, Denny E. Women living with epilepsy, experiences of pregnancy and reproductive health: a review of the literature. Seizure 2013;22(2):91–8. https://doi.org/10.1016/j.seizure.2012.11.001.
[10] Weckesser A, Denny E. the EMPiRE Collaborative Network. Re-working biographies: Women's narratives of pregnancy whilst living with epilepsy. Soc Sci Med 2017;185:100–17. https://doi.org/10.1016/j.socscimed.2017.05.036.
[11] Loring DW, Meador KJ, Lee GP. Determinants of quality of life in epilepsy. Epilepsy Behav 2004;5(6):976–80. https://doi.org/10.1016/j.yebeh.2004.08.019.
[12] The Royal College of Obstetricians and Gynaecologists. Epilepsy in pregnancy: Green-top Guideline No. 68. London: Royal College of Obstetricians and Gynaecologists; 2016.
[13] Knight M, Kenyon S, Brocklehurst P, et al. on behalf of MBRRACE-UK. Saving lives, improving mothers' care: lessons learned to inform future maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2009-12. Oxford: National Perinatal Epidemiology Unit, University of Oxford; 2014.
[14] Knight M Knight M, Bunch K, Tuffnell D, et al. on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care: Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2016-18. Oxford: National Perinatal Epidemiology Unit, University of Oxford; 2020.
[15] Morley K. Maternity epilepsy shared-care toolkit. Women with epilepsy. 2021 [last accessed 4/01/2022]. Available from: https://www.womenwithepilepsy.co.uk/pregnancy-toolkit/.

Emily Taylor: Emily Taylor is a final year MBChB student at the University of Birmingham and a BSc Urgent and Emergency Care graduate from the University of Plymouth. She has an interest in obstetrics and gynaecology and is the clinical lead for the West Midlands Dame Hilda Lloyd maternal health network.

Fatima Junaid: Fatima Junaid is a junior trainee in obstetrics and gynaecology based in the West Midlands. She is an MB/PhD graduate from the University of Cambridge, completing her doctorate in cancer and stem cell biology in the mechanisms of metastasis. She has developed a broad base of experience in research, public health and quality improvement including involvement in clinical projects from recruiting patients for research through to adapting guidelines. She has a particular interest in understanding the attitudes and experiences of women in their health and healthcare.

Hajra Khattak: Hajra is a registrar in obstetrics and gynaecology in the West Midlands. She is currently undertaking a PhD in female fertility preservation using ovarian tissue cryopreservation and transplantation techniques. Through her research, she has developed skills in various research methodologies including evidence synthesis, laboratory techniques specific to female fertility preservation and qualitative research methods. Hajra is the education lead for trainees' tier for the West Midlands Dame Hila Lloyd Network, as well as the director of trainees' mentorship academy.

Jameela Sheikh: Jameela Sheikh is a fourth-year MBChB student at the University of Birmingham and has completed BMedSc Clinical Sciences: Reproduction and Women's Health in 2021. She has a keen interest in obstetrics and gynaecology, and academia. She is the publicity and liaison lead for the West Midlands Dame Hilda Lloyd maternal health network.

Jay Ghosh: Jay Ghosh is an ST5 O&G trainee in the West Midlands deanery currently at Worcester Royal Hospital. He obtained his MBBS from Imperial College London, a BSc in Healthcare management from Imperial College Business School and a PhD in Risk factors and management of miscarriage from the National Centre for Miscarriage Research at the University of Birmingham funded by Tommy's. He is current Chair of O&G Trainee's in the West Midlands sitting on the RCOG National Trainees Committee and Co-Trainee Lead for the Dame Hilda Lloyd network.

Ben-Lawrence Kemah: Ben-Lawrence Kemah is a registrar in Obstetrics and Gynaecology in the West Midlands Deanery. He has a Master's in Public Health (International) from the University of Nottingham. He leads the Health Education and Research Organisation (HERO), Cameroon which is an early career researcher initiative which adapts WHO health tools as well as conceptualising, implementing and monitoring & evaluation of public health interventions for resource limited settings alongside international stakeholders.

Cathy Nelson Piercy: Catherine Nelson-Piercy is a Consultant Obstetric Physician at Guy's and St. Thomas' Hospitals Trust and the Lead Obstetric Physician for the South East London Maternal Medicine Network. In 2010 she was awarded the title of Professor of Obstetric Medicine at King's College London. Professor Nelson-Piercy is past President of the International Society of Obstetric Medicine (ISOM). She was founding co-editor in chief of the journal *'Obstetric Medicine: the medicine of pregnancy.'* ". She has over 250 publications and has edited five books and written the successful *Handbook of Obstetric Medicine*, now in its sixth edition. She is also one of the central physician assessors for the UK Confidential maternal deaths enquiry.

Kim Morley: Kim Morley is an epilepsy specialist midwife/nurse and INP specialising in antiseizure medicines. She has a MSc in ACP and published her dissertation on Reducing risks for pregnant women with epilepsy: A qualitative study exploring experiences of using a toolkit at the antenatal booking appointment. Kim designed the maternity epilepsy toolkit available from www.womenwithepilepsy.co.uk. She established a thriving pre-conception and pregnancy epilepsy midwifery service, a community and hospital-based epilepsy nursing service. Kim has written multiple publications and guidelines, is as an assessor for MBRRACE and midwifery representative on the valproate committee (MHRA). She was awarded RCM mum's midwife of the year (2016) & focuses on sharing her expertise with women with epilepsy, their families, healthcare professionals and charities, nationally and internationally to improve knowledge, reduce risks and optimise outcomes.

Ngawai Moss: Ngawai Moss is a women's health advocate interested in research following her participation in a number of studies during pregnancy (including one on epilepsy and pregnancy). Ngawai now advises on patient and public involvement in health research, including the UK National Institute for Health Research. She is also the Chair of the Clinical Reference Group for the National Maternity & Perinatal Audit. Ngawai is a founding member of Elly Charity which works internationally to protect women's health - through education and patient centred research ensuring the voices of women, their families and communities shape the research agenda.

Ellen Knox: Ellen Knox is a consultant obstetrician (maternal medicine, subspecialty trained in maternal fetal medicine) at Birmingham Women's and Children's and obstetric lead for the West Midlands Maternal Medicine Network. She leads joint obstetric maternal medicine clinics and MDTs providing regional and supraregional coordination of care for women prior to, during and after pregnancy. She is an associated postgraduate dean responsible for postgraduate doctors in training engagement and training and training programme director for obstetrics and gynaecology and current RCOG Workplace Behaviours Advisor.

John Allotey: John Allotey is a lecturer in epidemiology and women's health at the WHO Collaborating Centre for Global Women's Health within the Institute of Metabolism and Systems Research. He has almost a decade of experience in academic clinical research, primarily in the field of maternal health. His research interests lie in the development, evaluation and implementation of prognostic models and evidence synthesis using aggregate data and individual participant data meta-analysis.

Shakila Thangaratinam: Shakila Thangaratinam is Professor of Maternal and Perinatal Health at University of Birmingham and leads the Maternal and Reproductive Health Theme. She is the co-Director of WHO Collaborating Centre for Global Women's Health and academic lead for Women's Health in Birmingham Health Partners. As Consultant Obstetrician she is involved in the care of high-risk mothers at Birmingham Women's and Children's NHS Foundation Trust. She is the founder of the Dame Hilda Lloyd Network, which brings together medical and midwifery students and trainees, school students, and senior clinical academics involved in Women's Health Research in the West Midlands.