International Bureau
for Epilepsy

Epilepsy & Pregnancy Toolkit
SURVEY REPORT

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INTRODUCTION

1. While the majority of women with epilepsy will have successful pregnancies, it is vital that women of childbearing age are fully informed on all issues relating to epilepsy and pregnancy. The use of anti-seizure drugs (ASDs) has been associated with an increased risk of birth defects such as cleft palate, spina bifida, autism spectrum disorders or a lower IQ. Nevertheless, seizure control during pregnancy is vital because the risks involved from having uncontrolled seizures can be greater than the risks from ASDs themselves. There is a 25% risk of seizures become more severe during pregnancy and seizures can cause miscarriage, premature labour or affect the baby's heart rate by lowering it to a dangerous level. However, ASDs can also cause issues for pregnant women with epilepsy, with drug levels falling during pregnancy and then rising post-partum so that it is very important for continuous monitoring of levels at this time.
2. Given that up to 50% of pregnancies are unplanned, it is very important for women with epilepsy to talk with their doctors before they consider becoming pregnant so that they are fully informed on the risks involved and, together, they can work to ensure the best possible outcome to a pregnancy. Informing women of child-bearing age about the problems that might arise in a pregnancy, due to their epilepsy, is vital for both the mother and her unborn child. Getting the right message, to the correct audience, in the most appropriate format, is vital.
3. A public hearing, hosted by the European Medicines Agency (EMA) in 2017, reviewed the prescription of medicines containing sodium valproate for women and girls who are of childbearing age. The discussion among the 65 stakeholders who attended the hearing, 28 of whom were people with epilepsy, also looked at the wider issues around epilepsy and pregnancy. At the hearing, IBE emphasised the need for improved public information and health education on all matters relevant to women of childbearing age and pregnancy, advancing advocacy and the exchange of international best practice. It was proposed that a well-organised education campaign was required, in all EU languages, to ensure that as wide an audience as possible was reached. Following on from the public hearing, a stakeholders meeting was organised at which it was agreed that, in ensuring the women of childbearing age were fully informed on the risks associated with epilepsy and pregnancy, personal communication and trust with healthcare professionals should be the basis of the dialogue, with positive messages and explanations as part of this communication.
4. There was agreement that improved information resources had been developed in a number of EU member states. However, these were not reaching the right people at the right time. The distribution and use of these materials, as well as the acceptance of the need for change, had not happened as had been hoped. In addition, risk minimisation had not always been apparent. The consensus was that the status quo was not acceptable, and it was clear that things could, and should, be done better. Two years later, it appeared that there was still little success in getting the message on the risks associated with epilepsy and pregnancy to the right people.
5. his problem was raised by young adults attending an IBE Epilepsy Next workshop in Dublin in 2019. The participants, from 12 different European countries, highlighted the lack of knowledge among many young people with active epilepsy around the issues of contraception, pregnancy and childbirth. They were particularly concerned that young people were often unaware of the associated risks for those with active seizures. The participants discussed how knowledge around this topic differed greatly across Europe and, indeed, even at a country level. The willingness of some doctors to discuss contraception, family planning and pregnancy, national legislation and religious teachings that impacted on safe family planning for people with epilepsy, and the need to support self-empowerment of people with epilepsy to be able to discuss these matters with their care providers were also discussed.

FOCUS OF THE SURVEY

6. The main theme of the survey reported on here was identified as to establish to what extent women with epilepsy of childbearing age are:
   - Aware of all of the risks associated with epilepsy and pregnancy
   - Informed of such risks by their GPs and healthcare specialists
   - Supported by their healthcare providers in making informed choices
   - Where the patient is not provided with information by their healthcare providers, where do they look for this information – internet, social media, epilepsy association, other sources
   - At what point do they look for information – before considering pregnancy, when considering pregnancy, when they become pregnant?
   - How does the information they receive impact on their decisions?

PROPOSED SOLUTION

7. IBE would like to address the knowledge gap around epilepsy and pregnancy by working with its Global Youth Team and with key professionals, including medical professionals:
   - to establish why key messages are not reaching young adults at the time of their lives where information on epilepsy and pregnancy is most urgent;
   - to identify the type of information and the format in which it is delivered that would be effective in closing the gap;
   - to create and deliver key messages in those formats to the widest possible audience.
8. Vital to delivering the message will be the young people themselves. While stigma and medical paternalism have been barriers in the past in involving the most important stakeholder group in raising awareness about epilepsy – persons with epilepsy themselves – the barriers are beginning to come down and there is a rising confidence in this age bracket to discuss their epilepsy and what they need to enjoy the best possible quality of life. They are the most powerful advocates for epilepsy.
9. A key reason for involving the IBE Global Youth Team is because of the importance of informing women about the risks around epilepsy and pregnancy before they reach the stage of planning a family. Once they are aware of the

risks and how best to minimize such risks, they are then forewarned and forearmed for the duration of their child-bearing years. Peer to peer messaging will be important in this work.

10. The organisers of this project agreed that in the initial stage there would be a need to conduct a survey to determine what women with epilepsy and their families knew and understood about the risks associated with antiepileptic drugs and pregnancy.
11. The results of the survey would inform the development of a toolkit. Such a toolkit, which will act as a guide for advocacy planning and an aid to build capacity of the user, will be central to the campaign. It will be developed to be user-friendly, culturally relevant and visually engaging. It will be produced with print, web and social media in mind and with any medical information validated by the medical members of the project team.

PROJECT GROUP

12. Collated responses from each survey provided an overall picture of the situation across Europe and provided the basis to consider where the knowledge gaps lie and which knowledge areas are falling short. A project group, drawn from all relevant stakeholder groups, will then be tasked with developing a programme of materials in a format that is likely to reach its target audience.
13. The group is comprised of members of the IBE Global Youth Team (members drawn from across Europe to ensure a wide focus), IBE President (Prof Martin Brodie), members of Epilepsy Alliance Europe (the joint task force in Europe of IBE and ILAE epilepsyallianceeurope.org), IBE Executive Director Ann Little, President-elect Francesca Sofia and Secretary General-elect Professor Gus Baker.

METHODOLOGY

14. In the first instance the survey was conducted in 9 countries in Europe, with involvement of a number of IBE chapters. In order to ensure maximum take up of the survey, it was necessary to have the content translated to a number of different European languages for those countries where English is not the primary language.
15. The survey ran for eight weeks using SurveyMonkey software, which gathered information on the extent of information available across Europe, and its uptake by all relevant stakeholders. IBE chapters were involved in rolling out the survey at local level to capture data on the knowledge gap that exists.
16. The sampling frame for the study was social media, mailing and IBE databases, website promotion. A self-completion questionnaire addressing a number of epilepsy and pregnancy issues was developed.
17. The questionnaire contained information relating to the following areas:

Demographic details

18. Information was obtained about respondent age, marital and employment status, education, country of origin, and membership of an epilepsy organisation.

Clinical Information

19. This included information in relation to number of years since diagnosis, whether under the care of an epilepsy specialist, pregnancy history, and history of anti-seizure medication.

Access to Information about Pregnancy and Epilepsy

20. Information was obtained about access to information about epilepsy and pregnancy. Information was obtained in respect of the source of the information and its value to the respondent. Respondents were asked to consider their level of knowledge of the risks of epilepsy and pregnancy and their decision-making as to whether to have a family or not.
21. Respondents were given the opportunity to provide free comments on many of the aspects covered in the questions.

RESULTS OF THE SURVEY

22. In all, 890 questionnaires were registered on the SurveyMonkey survey. The breakdown by country is shown in figure 1. The majority of respondents (66%) were drawn from four countries, Ireland (11%), United Kingdom (11%), Russia(15%), Czech Republic (14%) and Italy (15%), The other participating countries each contributed <l0% of respondents.

Figure 1 Questionnaires completed by country

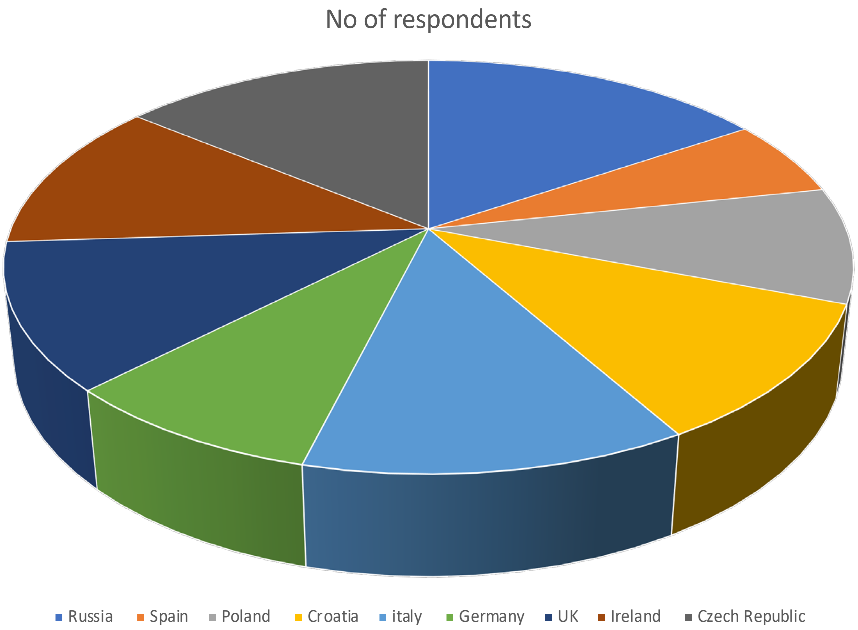
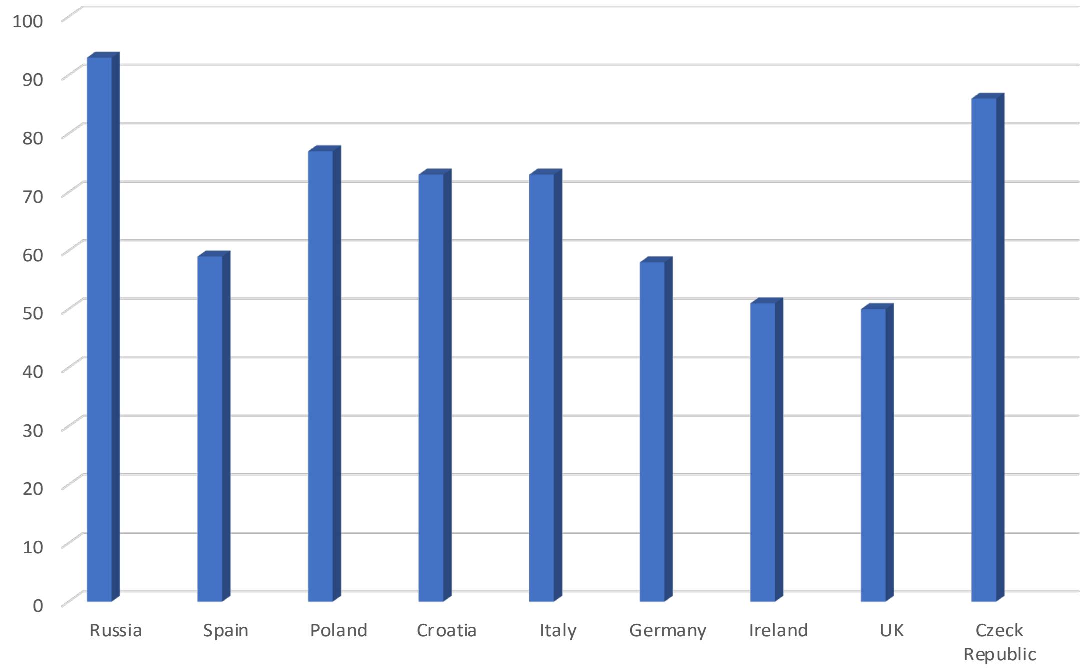


Table 1. Number of respondents by country included in the report

Country	No of Respondents
Russia	136
Spain	52
Poland	78
Croatia	94
Italy	107
Germany	74
UK	99
Ireland	102
Czech Republic	123

Figure 2. Membership of Epilepsy Organisations

Not being a member of an Epilepsy Organisation or Epilepsy Support Group by Country



Demographic and clinical characteristics of respondents

23. The majority of respondents were between 20 and 39 years of age. Twenty-one percent (22%) were single, 71% were married or cohabiting. Sixty-one percent (61%) were educated to college/University level. In terms of employment 60% were currently in employment, of whom the majority working in paid positions as opposed to self-employment.
24. The majority of respondents had been diagnosed with epilepsy for more than two years with 90% reporting a history of epilepsy spanning between 3 and 10 years.

Membership of an epilepsy organisation or epilepsy Support Group [Q8]

25. Membership of an epilepsy support group or epilepsy organisation varied across countries with a mean response of only 37% and the respondents having no membership ranging from 26% to 93%.

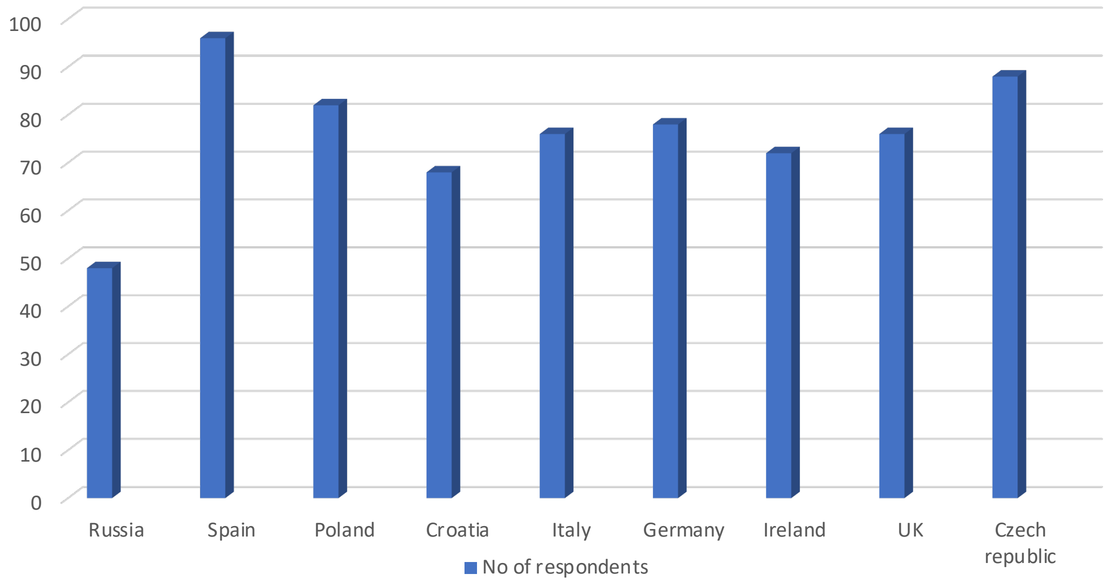
Under the care of a neurologist/epilepsy specialist [Q9]

26. Respondents were asked to report whether or not they were under the care of a Neurologist/ specialist professional in epilepsy or a GP with special interest in epilepsy. Ninety-one percent of respondents on average reported that they were under the care of an epilepsy specialist with a range across the countries from 79-100%.

Information in relation to pregnancy history [Q10-12]

27. A number of questions were addressed to respondents in relation to their experience of pregnancy. Respondents were asked whether they had been pregnant. The mean response across the countries sample was 52% with a range of 44-74%.
28. Respondents were asked to report on whether they were taking antiepileptic medication at the time of the pregnancy [Q11]. There was a significant variation across the countries with Russian respondents reporting as low as 50% and Spanish respondents reporting as high as 96%.

Figure 3. Number of respondents taking anti-seizure medication at the time of their pregnancy

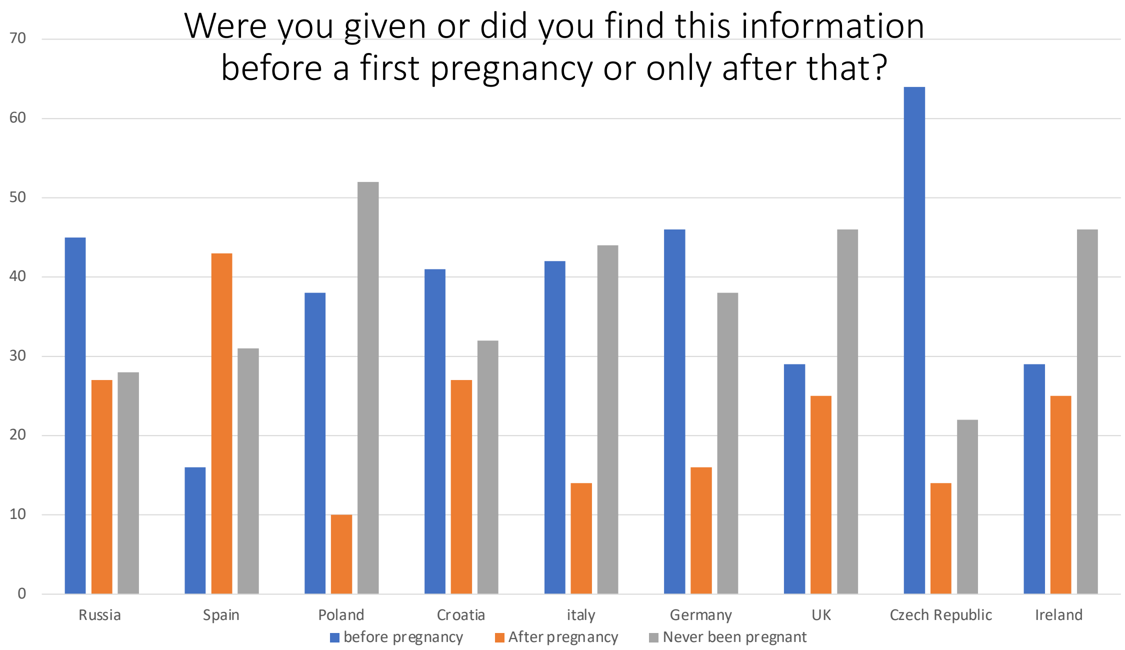


29. In respect of planned or unplanned pregnancy, the mean percentage of respondents reporting a planned pregnancy across the countries was 66% with a range between 46% and 78%. Among those who described their pregnancy as planned, respondents were asked whether the pregnancy reached full term. Responses by country ranged from 78% to 89%. If the respondent answered NO they were asked whether the pregnancy was terminated electively. Responses by country saying NO ranged from 64-100%.

Information relating to advice about epilepsy and pregnancy [Q16-21]

30. A series of questions were provided in relation to information about becoming pregnant while living with epilepsy. Respondents were asked: "Have you ever been given by someone else, or found for yourself, information about becoming pregnant while living with epilepsy?" [Q.16] Respondents providing a YES response ranged from 51% [Russia] to 79% [Czech Republic].
31. Respondents were asked "Were you given or did you find this information before a first pregnancy or only after that?" [Q17]. The results varied across countries and are presented in figure 4.

Figure 4. Timing of information re risks of epilepsy and pregnancy



32. Respondents were asked “In respect of the information you have received, how easy was it to access?” [Q18]. The responses are tabulated in Table 2 below:

Table 2. Access to Information [% responses]

Response	Russia N=136	Spain N=52	Poland N=78	Croatia N=94	Italy N=107	Germany N=99	UK N=99	Czech Rep N=123	Ireland N=102
Very easy	21	10	9	16	15	16	32	18	29
Somewhat easy	29	21	28	22	34	22	27	35	28
Neither easy nor difficult	32	35	46	48	30	48	23	27	26
Somewhat difficult	14	26	14	10	20	10	14	17	14
Very difficult	4	8	3	4	1	4	4	3	3

33. Respondents were asked “In respect of the information you have received, how easy was it to understand?” [Q19]. See table 3

Table 3. Understanding of Information [% responses]

Response	Russia N=136	Spain N=52	Poland N=78	Croatia N=94	Italy N=107	Germany N=99	UK N=99	Czech Rep N=123	Ireland N=102
Very easy	26	15	16	16	21	17	36	21	31
Somewhat easy	32	28	50	29	43	29	29	39	34
Neither easy nor difficult	31	33	26	40	16	40	21	32	21
Somewhat difficult	9	18	8	15	20	14	12	4	13
Very difficult	2	5	0	0	0	0	1	4	1

34. Respondents were asked “In respect of the information you have received, how helpful did you find it?” [Q20]

Table 4. Ease of usefulness of information received [% responses]

Response	Russia N=136	Spain N=52	Poland N=78	Croatia N=94	Italy N=107	Germany N=99	UK N=99	Czech Rep N=123	Ireland N=102
Very easy	39	15	16	38	21	12	30	21	35
Somewhat easy	36	28	50	42	43	33	47	39	38
Neither easy nor difficult	20	33	26	18	16	39	14	32	19
Somewhat difficult	4	18	8	2	20	12	5	4	6
Very difficult	1	5	0	0	0	4	4	4	2

35. Respondents were asked “Did the information make a difference to your decisions about pregnancy and, if so, what?” [Q21] Comments are tabulated below.

Table 5. Comments from respondents on their experiences of receiving information in respect of epilepsy and pregnancy

COMMENT
No, I’m still confused as to whether it is safe for me to get pregnant especially risks around SUDEP, and congenital malformations when taking newer anti-epileptic medication. I do think, it is important to carry out more research in this area even though there is an Epilepsy Pregnancy Registry, there remains unanswered questions around new drugs for example Rufinamide, and Lacosamide. I think there are also concerns about an increase in seizures due to extra hormones when pregnant. [UK]
The information made it easy to monitor certain things happening with and to my body. Made me feel a lot more comfortable knowing that my epilepsy wasn’t a problem during pregnancy. [Italy]
Yes, I fear pregnancy because of my medications [Italy]
Yes, it did. Prepare for it more thoroughly [Russia]
Yes, I have had to come off and change seizure medication twice before planning pregnancy, have also had to have abortion as became pregnant once on Epilim, decision may have been different if Epilim was not dangerous.[UK]
I postponed the planned pregnancy for several years after the start of treatment [Russia]
It’s fundamental to know that pregnancy needs to be planned and that my life-saving medication would be extremely harmful for the foetus. Any decisions about having or not having a child cannot be taken light-heartedly anymore!!! Lots of aspects must be factored in for oneself and the prospective newborn! [Italy]
One doctor advised against getting children. Another doctor said it`s no problem. [Germany]
Yes, it was not so scary for my children that they could inherit epilepsy or not! [Russia]
More than anything the information given by my epilepsy nurse team was frightening. A lot of ‘Do not’ ‘you can’t’ ‘you shouldn’t’ without offering alternatives. The information was valid and worth knowing but daunting for an expectant mother when offered with no ‘Instead try..’ [UK]
“I am afraid of getting pregnant. I am afraid that the child will be” damaged” or will not survive.” [Poland]
The information received is too little for making decisions: breastfeeding, taking vitamins and additional medications, which doctors to visit. I’m afraid to face the negative. I will go specifically for a consultation before becoming a mother. [Russia]
After the clarification with a specialist for epilepsy the decision to get pregnant was strengthened in a positive way. [Germany]
I found out what medications I can take, that I need to take folic acid. I know that I can breastfeed and give birth naturally. I’m not afraid of getting pregnant. [Poland]
There is very little information on this matter, the doctors themselves know very little (Russia)
The low, non-absent, risk of teratogenicity caused a sort of psychosis in me that made me consider to voluntarily interrupt the pregnancy. Luckily, everything ended up well. [Italy]

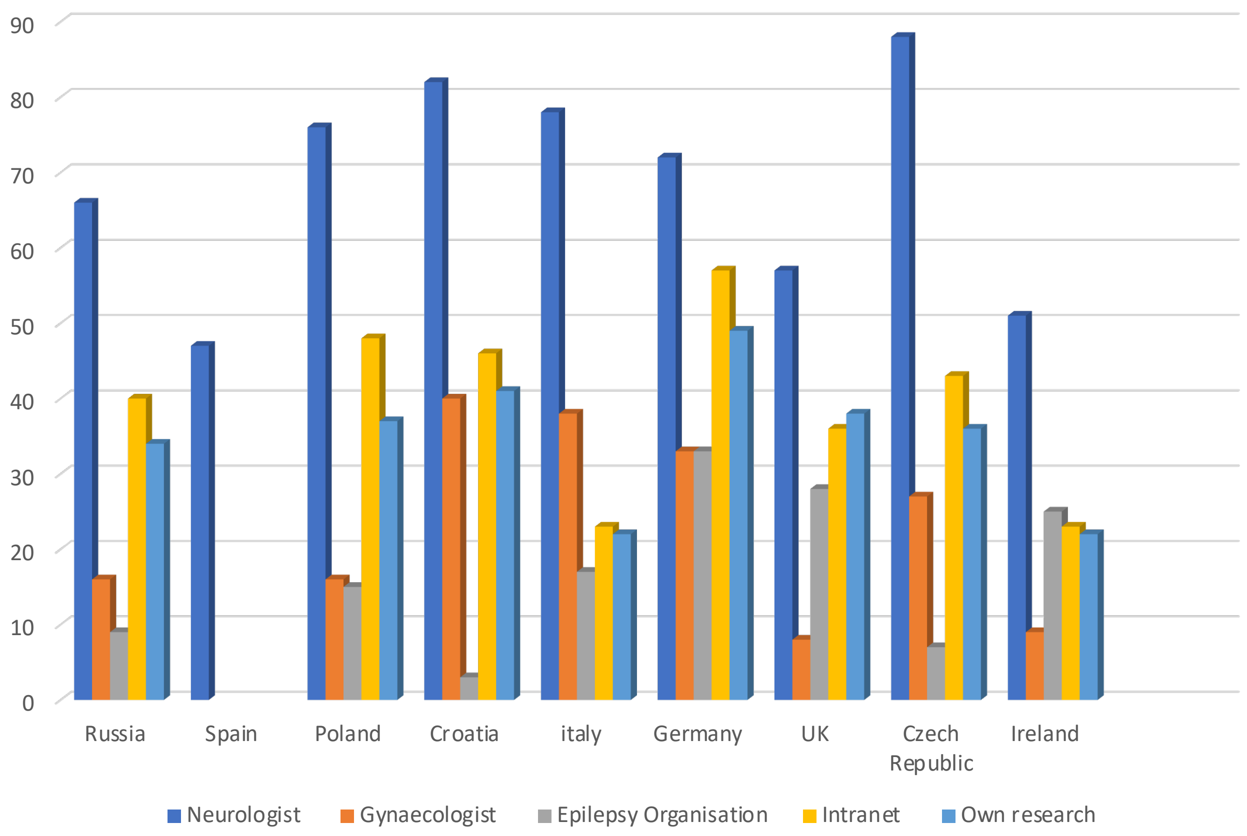
COMMENT
It was reassured that a pregnancy isn`t a problem while taking lamotrigine. It strengthened my decision to get pregnant. [Germany]
No it didn’t, but in some ways it made me more apprehensive and worried about pregnancy and being a mum because of all the risks of seizures etc. [UK]
When I first found out about the risk, I was in a deep emotional depression and I was seriously considering with my partner that we would never have children (or adopt) because it could be too dangerous. [Poland]
The information I received has been fundamental in deciding not to have children. [Italy]
It made me aware I had to take a higher dose of folic acid and the possibility of risks [UK]
I don`t want children because I`m scared and I have a lack of trust in my neurologist. [Germany]
The information I received made me feel more secure in myself and about the pregnancy, ESPECIALLY the pregnancy. I had several “fears”, since the father of the baby was not by my side, but thanks to my family and to my physicians some of the biggest fears gradually disappeared! [Italy]
Yes I had been taking sodium valproate and while I was doing a research proposal for my degree I decided to do it on the effects of anticonvulsants during pregnancy. After my findings I asked GP for a referral to neurologist. I discussed my plans with him and he changed me over to Keppra. [UK]
The information had impact on the decisions to be pregnant. They made me realize how important it is to properly plan and manage pregnancy in a correct and responsible way. [Poland]
I’ve always wanted several children. I discovered I suffer from epilepsy at the third month of gestation and I immediately started a treatment with Keppra, which is still ongoing. I carried the high-risk pregnancy to term giving birth to a healthy baby. With the information I have now I don’t think I’ll opt for a second child. I’m too scared of the outcome. [Italy]
The information that women with epilepsy can give birth to healthy baby made me decide to become pregnant. [Poland]
Since been diagnosed at age 11, I have always taken folic acid and have been on Keppra which is safe to use at child bearing age. I was reassured when epilepsy nurse told me that 94% of women with epilepsy do not have a seizure during labour/birth. I was told to bring additional medication in case I vomit through birth. Told not to bathe baby alone, wear a sling with baby alone. All common sense but helpful all the same! [UK]
Yes, because my neurologist reassured me that given my non-severe form of epilepsy and with appropriate treatment and a good gynaecologist my pregnancy would run its course peacefully. [Italy]
I was terrified, it reassured me that all would be okay which it was [UK]
I decided to have an abortion, before I got married my husband had a brother and a cousin who died from leukaemia. I didn’t want children with possibly two diseases, especially leukaemia. I received information about epilepsy and pregnancy 12 years later. If I had had the opportunity of talking about this with somebody I probably wouldn’t have interrupted the pregnancy. [Italy]
Information was hard to get from doctors on this. It was also difficult to even get appointments to see the neurologist without waiting months [UK]

COMMENT
I was always unsure if I would have children but thought someday I would. I changed Neurologist to an epilepsy specialist recently and the discussion came up around Epilim as I was on it when I was 15/16. Given recent reports of the effects of Epilim on pregnant woman my new neurologist was keen to know how long I was on it for. The only reason I was taken off it was due to weight gain. I'm still not clear on what effects Epilim can have if you were on it in the past but I have also been informed that my epilepsy is hereditary and there's approximately a 17% chance that my child would get it. I'm currently on Lamictal, Keppra and Frisium and still having seizures. If I was someone who really wanted children I would potentially take the risk, however given that I was unsure it's highly doubtful that I will have children. I am 30 years old. [UK]
I received the information from my epilepsy nurse and neurologist and it made a difference as it made me plan ahead to talk to my neurologist to plan each pregnancy with regard to the medications I was on and the dosage. During my last pregnancy I was hospitalised as I had pre-eclampsia and low sodium levels and as a result I had to monitor my fluid intake and output. My medication was also reduced due to this issue. I was induced at 36 weeks due to issues with blood supply to the baby as a result of pre-eclampsia. [UK]
Yes, it reassured me I don't know any other epileptics so knew nobody who was pregnant and have birth so I liked to read success stories to know it is possible [UK]
I was on an old epilepsy drug and had to come off it as one of the side effects was birth defects so came off it before I got pregnant and went on a lighter dose of a completely different drug. [UK]
Yes. The sodium valproate scandal meant that I was aiming to cut my AED medication (Lamictal) and be off it completely for at least 6 months before trying to become pregnant. A combination of information that I received from 1. a presentation for women run by Epilepsy Ireland, 2. an appointment that a specialist nurse kindly gave me after the presentation when I asked to speak with her (the appointment was a phone call to answer all the questions my husband and I had), and 3. the MHRA report from January 2021 'Antiepileptic drugs: review of safety of use during pregnancy' (it was mentioned in the presentation), resulted in me deciding to stop doing this, as I learnt that actually having any sort of seizure is far more dangerous for the baby than taking Lamictal could have been." [UK]
Yes, being better informed meant I could make better choices and was prepared if/when my seizures returned. My epilepsy nurse specialist and consultant were outstanding in the care and guidance given pre pregnancy. They did everything in their power to keep myself and baby well and as safe as is/was possible. [UK]
I decided to terminate my pregnancy because I had not been taking folic acid and was currently taking a med that is not safe for pregnant women. I was also finishing school and thought it would be too much for my body in regardless to controlling my seizures. So with all that information, I was able to make an informed decision for my abortion. [UK]
It made me realise it's not a decision I can just make easily and quickly like many women can, it takes a lot of planning with healthcare providers to make sure risks are minimised. [UK]
Information I've accessed made me question whether I'd ever want to become pregnant due to the risks involved, though that might be more of a personal thing. Although you see examples of pregnancies going to full-term and hear of good experiences, it's very hard to trust that my experience will be the same. Each person's experience of epilepsy as a condition is different, so how would I know if I was going to be ok? Looking at the facts and figures that are out there, I should feel reassured. I can tell that my consultants are always trying to approach the topic in a reassuring manner but don't find this all that encouraging. I don't know if I'd be brave enough to take the risk of becoming pregnant after recently seeing the figures related to epilepsy and pregnancy, I've thought about adoption instead. It feels as though the chances of a successful pregnancy are half science and half luck. The luck being who your healthcare provider is, how long waiting lists are, capacity and understanding. [UK] Yes. I'm afraid to have children now. This was when I was on Epilim this was the only time I was given information about pregnancy. I know no information about getting pregnant and the medication I am on now. [UK]
I made a decision to become more insistent on reducing Epilim which my neurologist and nurse were happy to go with. I understand Keppra is slightly safer but will consider these risks. I want to reduce my Vimpact also. Overall, the information has probably caused more concern and frustration because my wish for children is strong but has certainly made me think what the best decision for me and potential children would be. [UK]

Who provided the information in respect of epilepsy and pregnancy [Q22-27]

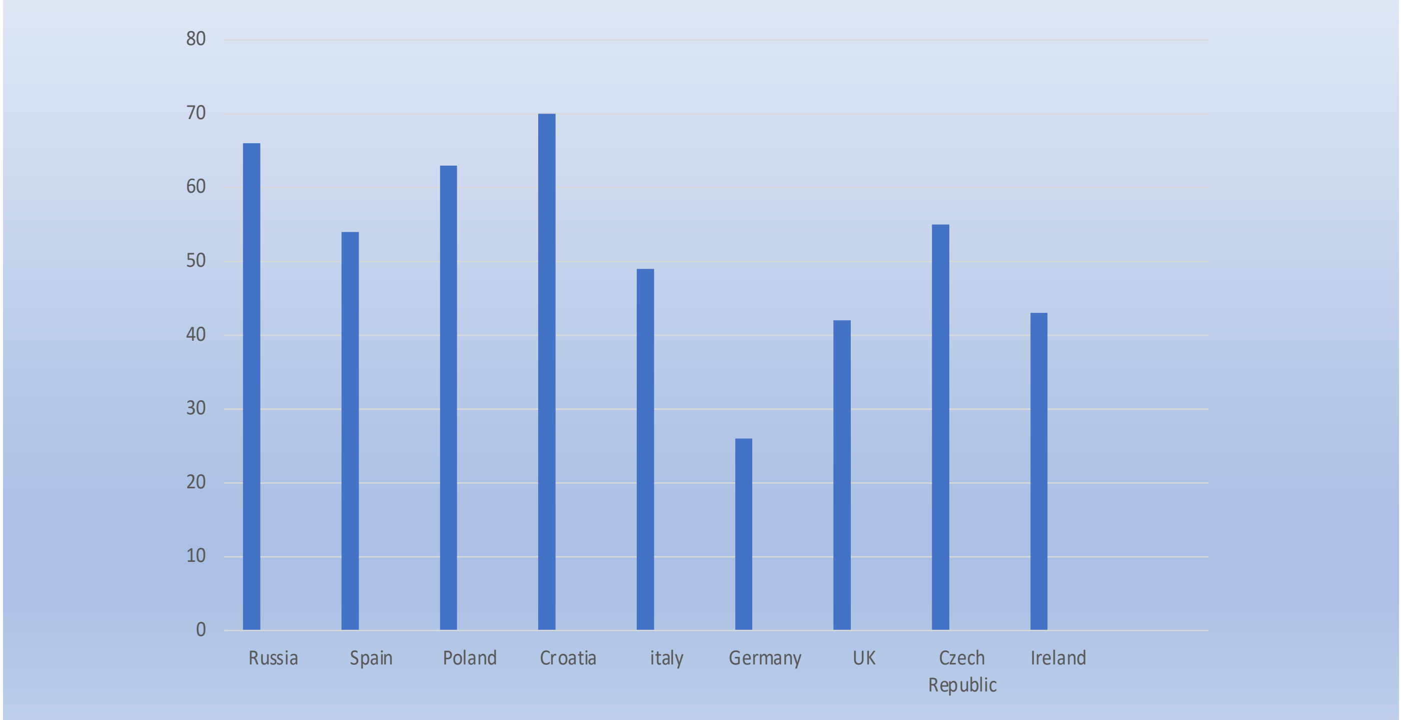
36. The respondents were asked to comment on who provided the information [Q22]. A list of professions were provided. The majority of the respondents identified that neurologists were likely to be the main provider, followed by gynaecologists, the internet or they found it for themselves [see figure 5].

Figure 5. Sources of information regarding epilepsy and pregnancy



37. Respondents were asked whether they had ever received information from a medical practitioner in relation to the need to consider contraception while taking anti-seizure medication [Q23]. The majority of respondents were either provided by a neurologist, gynaecologist or individuals found the information for themselves or via the internet. Epilepsy organisations, in the main, was not a frequent source of information.

Figure 6. Number of respondents who reported that they were not provided with information in respect of contraception



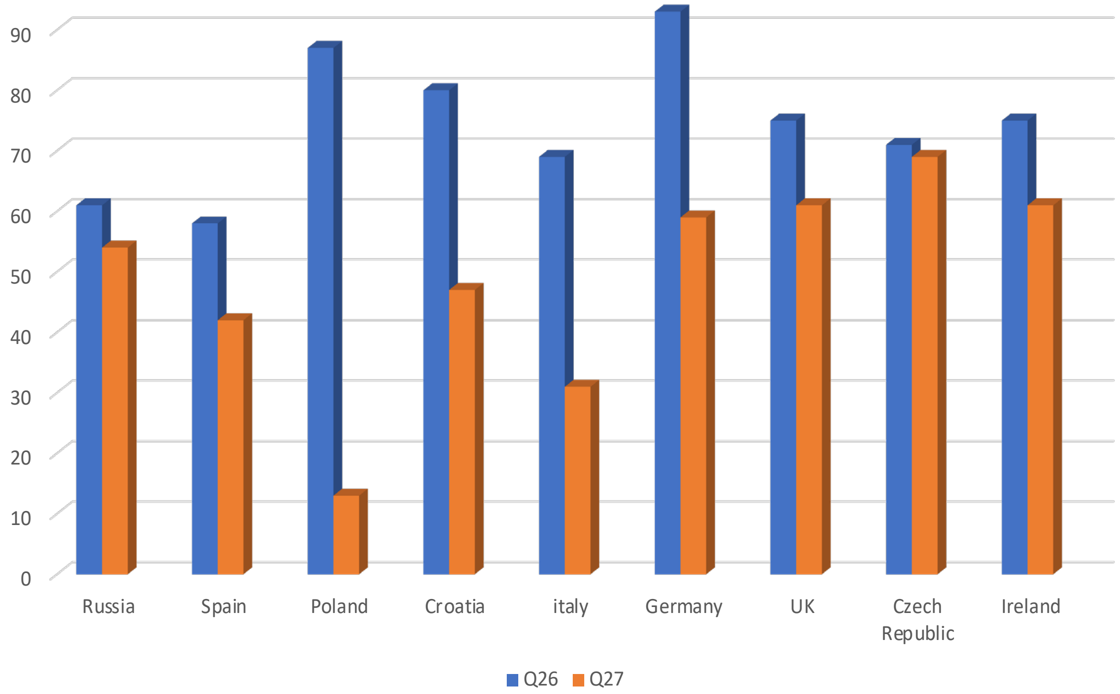
38. Respondents were asked “Have you ever been referred by a neurologist or GP to additional social and medical supports available in your community for women with epilepsy?” The response rate varied from 76% to 93% of respondents reporting that they had not been referred for additional support.

39. Respondents were asked to address the following questions in respect of the risk of pregnancy and planned pregnancy:
    - Have you been made aware of the risks associated with taking some anti-seizure medication while pregnant? (Q26)
    - Have you been advised to plan pregnancy by a medical professional? (Q27) There was a significant variation by country as displayed in the following figure.

Figure7. Responses to the risks of pregnancy and whether respondents had been advised to plan their pregnancy

Q26. Have you been made aware of the risks of taking AEDs while pregnant? [Yes]

Q27. Have you ever been asked to plan your pregnancy by a medical specialist? [Yes]



40. Respondents were asked if they were provided with advice about planning their pregnancy, who provided such advice. The majority of respondents reported that their neurologist was the person to have given them advice, with a range across the countries from 72% to 96%. The second most commonly cited professional involved in advising about pregnancy was the gynaecologist, with a wide range across the countries between 10% and 70% of respondents. [Q28]

41. Respondents were asked “If you were pregnant tomorrow would you contact a medical professional before making any decision about whether or not to stop taking medication?” [Q29]. The following table provides individual country responses:

Table 6. Response in respect of medication decisions if pregnant

Country	% response answering YES
Russia	84
Spain	100
Poland	74
Croatia	82
Italy	91
Germany	74
UK	90
Czech Republic	92
Ireland	92

42. Respondents were asked to document their responses to the following question, "Are you aware of the registries that exist in Europe/UK for women with epilepsy who are pregnant." [Q30] A significant number of respondents reported that they were not aware of such registries.

43. Respondents were asked "In your opinion, is clear and concise information available for women with epilepsy who are considering becoming pregnant? [Q31]. There was a wide range of responses from the countries with between 18 to 75% responding that no there is not enough clear and concise information available.

Table 7. Responses to availability of clear and concise information by country

Country	**% response answering YES**	**% response anwering NO**
Russia	35	65
Spain	25	75
Poland	41	59
Croatia	82	18
Italy	37	63
Germany	48	52
UK	40	60
Czech Republic	65	35
Ireland	32	68

44. Respondents were asked to respond to the Question "Would you avoid becoming pregnant if you were on anti-seizure medication?" [Q32]. The responses are tabulated below.

Table 8. Responses to decisions about becoming pregnant if on anti-seizure medication

Country	**% response answering YES**	**% response aswering NO**
Russia	43	57
Spain	53	47
Poland	41	49
Croatia	38	62
Italy	41	49
Germany	28	72
UK	34	66
Czech Republic	16	84
Ireland	36	64

45. Respondents were asked “Would you consider the information given to you on the issue of epilepsy and the risks associated with pregnancy has helped you to decide whether to become pregnant?” [Q33]. The responses are tabulated below with a wide variation of responses from 17-50% of respondents reporting that they had never been provided with information about the risks associated with pregnancy. .

Table 9. Responses to adequacy of information provided in respect of planned pregnancy by country

Country	% response answering YES	% response answering NO	% response answering Information has never been provided
Russia	48	18	34
Spain	29	21	50
Poland	70	17	13
Croatia	56	17	27
Italy	51	29	20
Germany	62	20	18
UK	62	16	22
Czech Republic	63	20	17
Ireland	54	18	28

46. Respondents were invited to comment on whether there was any other information that they had found helpful and if so what?

Table 10 Comments by respondents on whether other information had been helpful

COMMENT
I think looking on the SUDEP Action website has been a useful resource and their research around pregnancy in women, as I think a lot of neurologists are scared (understandably so) to discuss this openly with women. There is also a section on the Epilepsy Action website which includes stories from women with Epilepsy and their experiences of pregnancy which I found helpful. [UK]
This information led me to choose a physician who would explain things thoroughly to me. [Italy]
Today I want to be a mother and I can’t get anyone to guide me [Spain]
There is no clear understanding of which drugs can be taken and which cannot be taken. There is also no clear understanding of what the use of drugs can lead to during pregnancy and lactation. (Russia)
I didn’t receive much information on epilepsy from my neurologist. The yearly follow-up visit is used mainly to have updates on my health status. [Italy]
I think there is a lack of positive stories, attitudes and information concerning epilepsy and pregnancy and parenting. Parenting specifically. [UK]
It gave me some peace of mind knowing that despite epilepsy I can have a normal pregnancy and a healthy and beautiful baby [Spain]
The information that women with epilepsy can give birth to healthy baby made me decide to become pregnant. [Poland]

COMMENT
Unfortunately, there are very few qualified doctors in our country. I found my epileptologist, who has been leading me for many years, only 2 years after the onset of seizures. In hospitals (DIFFERENT!) I was told that I was in my puberty age and everything would go away by itself. Articles on the topic of epilepsy are very necessary and important, how to identify it, to which medical centers to run for help. In fact, only such sites helped me find the right people who made the correct diagnosis and treatment. Now it is not so scary to become pregnant with epilepsy and appear with unqualified specialist. [Russia]
"I had my first tonic clonic seizure 5 years ago and my second whilst heavily pregnant a week before my due date. I was diagnosed a week before birth and was told to start taking AED's. I felt I didn't know enough about it, was in shock and didn't plan on taking them until baby was here as I wanted to breastfeed and I wasn't aware of any risks (or no risks) regarding the AEDS and breastfeeding. When in labour, I was told I must start taking the medication right then and now, my partner had to go home and get the medication and I started in labour. This was awful adjusting to AED's whilst going through a traumatic birth. Hospital doctors wanted to give me an epidural straight away as they were worried pain would cause another seizure, this was the total opposite of the birth I had imagined and unfortunately the whole experience has left me totally traumatised and I plan on having no more children." [UK]
There is a lack of reputable information online. Often you found discussion forums and they are very different/subjective. [Germany]
List of antiepileptic drugs that are safe or less harmful to the unborn child. I understand that research on pregnant women is not carried out, but nevertheless, a lot of women give birth, taking different drugs. Are there any drug statistics? (Russia)
"It is a very small percentage that the child is born with a deficiency compared to other women. Taking the precautions of the neurologist and gynaecologist, I see that there is not too much problem." [Spain]
All information is very important. I still wish I had more children. Unfortunately, drug-resistant epilepsy is the barrier. I am waiting for a miracle or a drug that will guarantee no seizures. I would like to have the comfort of life and know that if I take this drug I will not have seizures - I will be able to get a driving license and at least partially become independent and function more freely ... [Poland]
I'm lucky to be followed up at a regional epilepsy centre. However, gynaecologists are not informed about all this and should interact with epileptologists. [Italy]
I would love to know how to get pregnant with a diagnosis of epilepsy (Russia)
My neurologist and gynaecologist examined me good/often and make me aware of everything before and during the pregnancy. [Germany]
"The neurologist informed me that the pregnancy had to be planned, a higher dose of folic acid was ordered, but I did not receive full information about the risk of my medications, the dose was not reduced. I gave birth to a child with a neural tube defect - spina bifida. In my opinion, I was not properly guided by a neurologist before and during pregnancy." [Poland]
"I was told if I got pregnancy I would want an abortion which was inappropriate." [UK]
Complete terror of dying and malformations, total ignorance of what pregnancy would be like [Spain]
"I'd like to point out that I hold a degree in Neurosciences, for me it's been easy to understand what the neurologist says and finding information on medications and their effects. For other women it's probably not the same because epilepsy is scarcely, and often poorly, discussed." [Italy]
No all medication will affect pregnancy. Having a good doctor and epilepsy nurse and neurologist makes a huge difference - nothing is impossible. [UK]
"I found looking on websites where children are impacted by anticonvulsant medications very informative. They give out clear information on what may happen to the unborn child." [UK]

COMMENT
“Yes, my neurologist and my gynaecologist explained to me that I should take care with contraceptives until the day I want to have a baby because it must be very planned. My neurologist also told me the risks of medication in a baby, but on my own I wanted to know more in detail, and I decided to search a lot in books, and on the internet to know exactly what the risks were for the baby and for me . And I was able to find the answer. I suppose that they would explain it to me when it was time to want to conceive. They gave me peace of mind knowing that always planning and controlling everything would be fine and that they (my doctors) were going to accompany me at all times. I feel calm when the moment comes, although I must admit that insecurity will always be in me.” [Spain]
I have decided to never become pregnant due to the risks involved. I would like there to be more research done and a focus by neurologists etc. on menstruation and epilepsy. [UK]
I am lucky to have a good relationship with my neurologist and GP. Any life decisions I make I have always discussed with them to make sure I always am able to make an informed decision. [UK]
I know that there are medications that are toxic to the foetus, as well as these can be avoided during pregnancy, the first thing is to go to the neurologist and then to the gynaecologist, the most important thing is to take care of yourself. [Spain]

DISCUSSION

47. This survey was conducted to understand the experiences of women with epilepsy of child-bearing age. The survey aimed specifically to gather information on their understanding of the risks of epilepsy and pregnancy; determining the degree to which women were informed of the risks and by whom; their perceptions of the adequacy of any information provided; and whether or not this informed their decisions in relation to having a child or not.

48. The survey set out to collect information from women with epilepsy across Europe. At the outset of the survey it was agreed to limit the duration of the survey to a period of eight weeks. The sampling frame was social media, mailing and IBE databases and website promotion. There were 890 valid responses from 11 countries

Limitations of the Survey

49. There are a number of limitations to the study that include the following:

[1] There were only 9 countries involved in the study and membership was influenced by the ability to identify chapters willing to participate in the country. There was a lack of response from Scandinavian countries.

[2] The responses from a number of countries were so low as to necessitate excluding them from the analysis e.g. Greece [N=4], France [N=8] and Georgia [N=13].

[3] A significant proportion of the respondents were either college or university educated suggesting that the survey did not capture the views of individuals who were less educated.

[4] Given the limitation on resources it was not possible to conduct forward or backward translation of the questionnaire. However, native speakers with an excellent command of English were utilised in the forward translation process.

[5] As a result of the above some caution should be taken when generalising the results to all women with epilepsy of child-bearing age

MAIN SURVEY FINDINGS

50. The main findings of the results of the survey can be summarised as follows:

- The majority of respondents were educated to College or University level.
- The majority of respondents had been diagnosed with epilepsy for more than 2 years
- A significant proportion of the respondents were not members of an epilepsy organisation or support group
- The majority of respondents were under the care of a neurologist independent of their country of origin.
- Between 44% and 75% had reported having at least one pregnancy.
- There was a significant variation by country as to whether respondents were on anti-seizure medication at the time of the pregnancy, with 96% of respondents from Spain on medication and 50% from Russia.
- According to responses, the majority of pregnancies were planned with a mean of 66% and a range of 64-78%.
- Between 51% and 79% of responders, depending on the country of origin, reported that they had accessed or been provided with information about becoming pregnant with epilepsy.
- Many respondents reported that they did not receive information about the risks of pregnancy until after their first pregnancy
- Respondents in the main reported that the information they received was easy to access, easy to understand and generally helpful.
- Information was generally provided by neurologists or gynaecologists, followed by the Internet or finding the information for themselves.
- Only a small percentage of responders accessed Epilepsy organisations or epilepsy support groups for information about epilepsy and pregnancy.
- A third to two thirds of respondents reported that they did not receive information in respect of contraception.
- Few respondents reported that they had been referred for additional social and medical support.
- Between 60-90%, depending on country of origin, of respondents reported that they had been made aware of risks of taking antiseizure medication whilst pregnant.
- Between 40% and 66% of respondents reported having ever been advised to plan their pregnancy by a medical specialist.
- Any medical advice provided to women with epilepsy of childbearing age was likely to come from the treating neurologist or gynaecologist
- The majority of respondents reported that they would take medical advice before stopping medication if they found themselves to be pregnant.
- Respondents were asked about the availability of clear and concise information in their country in respect of epilepsy and pregnancy. There was significant variation in the responses with between 35% and 65% responding yes.
- Between 16% and 53% of respondents reported that they would avoid becoming pregnant if they were on anti-seizure medication.
- Between 17% and 50% reported that the information they had received had helped them making a decision whether to become pregnant.

KEY POINTS

Key Point 1. The Survey

51. The aims of the survey were clearly identified as documenting the following: an understanding of the experience of women with epilepsy; their information needs; the support received from professionals and the degree to which the information they received impacted upon their decision. The survey, administered through 'survey monkey', was constructed to address the afore mentioned aims. Forward translations was provided by the project group membership. The survey was administered through Social media and IBE distributions lists. The limitations of the study have been discussed above. Despite these limitations the general impression from the responses was that the survey was fit for purpose.

Key Point 2. The Responses

52. There were 890 responses from 9 different countries subject to reporting. The majority of respondents were women with epilepsy between the age of 20 and 39 with 71% being married. Sixty-one percent of the respondents were educated to College or University level. The majority had been diagnosed with epilepsy more than two years ago. Between a half and two-third of the respondents had been pregnant. While the results are not perhaps surprising in terms of educational levels of the respondents, it does raise issues about ensuring that when a tool kit is rolled out it is tested on a range of women with varying educational levels to ensure that it is easily and fully understood.

Key Point 3. Membership of an epilepsy organisation or epilepsy support group

53. he mean number of respondents who were member of an epilepsy support group or Organisation was extremely variable. In Russia only 10% of respondents were members while in Italy the figure was as high as 75%. This will have implications for rolling out of a tool kit and limiting the roll out to IBE Chapters only. It also highlights the need for the IBE to make greater strides in improving our communications with our chapters.

Key Point 4. Who provides the care?

54. The majority of the respondents were under the care of a neurologist or a gynaecologist. It will be important when the kit is rolled out to ensure that that these two professional groups are made aware of its existence, and able to signpost potential benefactors to it. Further to include materials in the toolkit aimed at the professionals.

Key Point 5. Experience of epilepsy

55. The majority of respondents were taking anti-seizure medication at the time of their pregnancy apart from respondents from Russia who were equally likely to be or not to be taking medication during their pregnancy. Most pregnancies were planned independent of the country of origin. Information was available to women with epilepsy but, quite worryingly, ***many of the respondents did not receive that information until they were already pregnant***. The toolkit will have to be specifically targeted at women before their first pregnancy if it is to be of use.

Key Point 6. Information

56. When women with epilepsy do receive information the general perception held that the information is easy to understand, relevant and helpful. These need to be essential characteristics for the development of the tool kit.

Key Point 7.

57. There was a range of comments with a number of themes including: [1] the need to investigate all anti-seizure medication for their risk to those women who are pregnant or plan to become pregnant; [2] endorsement that information received was generally helpful; [3] comments that the information could be frightening and confusing; endorsement that information on the risks to the unborn child has influenced some to make the decision not to have children; [5] that some women would be fearful to undergo a pregnancy.

Key Point 8. Who provided the information about the risks of epilepsy and pregnancy?

58. The main providers of information relating to the risks of epilepsy and pregnancy were neurologists and gynaecologists and women with epilepsy themselves. Epilepsy organisations did not appear to be an important source of information provision. The authors are cognisant that IBE chapters are seen as providers of advice on the social aspects of epilepsy while epilepsy & pregnancy is a medical issue? Further there may be a tendency for people whose epilepsy is controlled to not join (or to leave) an epilepsy association because of the stigma associated with epilepsy?

Key Point 9. Information and advice on contraception

59. High level of respondents reported not receiving information in relation to contraception in the majority of those countries surveyed. There were significant numbers of respondents who reported that they were not given advice about planning their pregnancy by a medical specialist. However, many respondents reported that they would contact a medical professional about stop taking their medication if they were wanting to become pregnant.

Key Point 10.

60. In the main between a third and a half of the respondents would avoid becoming pregnant if they were on anti-seizure medication. These results are in contradiction to the evidence from published trials that for the majority of women they can have a successful pregnancy whilst taking anti-seizure medication if well advised and supported by neurological and gynaecological staff.

Key Point 11

61. There is clearly a significant number of respondents, between a fifth and a half, who were of the opinion that they were not provided with adequate information to make a decision about whether or not to become pregnant. This is not a finding that should be acceptable to the epilepsy community.

Members of the Epilepsy and Pregnancy Group

- Professor Gus Baker, Chair
- Mrs Ann Little Co-Chair
- Mrs Tea Bobinac-Krivacic
- Prof Martin Brodie
- Ms Elizabeth Cunningham
- Ms Erin Davies
- Dr Joanna Jedrzejczak
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