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The patient journey during and after a preeclampsia-complicated pregnancy: a cross-sectional patient registry study

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Abstract

Objectives: To gain insight into the patient journey through a preeclampsia-complicated pregnancy

Design: Cross-sectional patient registry study

Setting: Online patient registry initiated by the Preeclampsia Foundation

Participants: Women with a history of preeclampsia enrolled in The Preeclampsia Registry™ (TPR)

Primary and secondary outcome measures: Patient-reported experience measures concerning awareness of preeclampsia, timing and type of information on preeclampsia received, involvement in decision-making regarding medical care, mental/emotional impact of the preeclampsia-complicated pregnancy, and impact on future pregnancy planning.

Results: Of 3,618 TPR-participants invited to complete the Patient Journey questionnaire, data from 833 (23%) responders were available for analysis. Most responders were white (n=795, 95.4%) and lived in the United States (n=728, 87.4%). Before their preeclampsia diagnosis, 599 (73.9%) responders were aware of the term "preeclampsia", but only 348 (43.7%) were aware of its associated symptoms. Women with a lower level of education were less likely to have heard of preeclampsia (OR 0.36, 95% CI 0.21-0.62). Around the time of diagnosis, 29.2% of responders did not feel involved in the decision-making, which was associated with reporting a serious mental/emotional impact of the preeclampsia experience (OR 2.46, 95% CI 1.58-3.84). Over time, there was an increase in the proportion of women who were aware of the symptoms of preeclampsia (32.2% before 2011 to 52.5% after 2016; p-value <0.001) and in the proportion of responders stating they received counseling about the later-life health risks associated with preeclampsia (14.2% before 2011 to 25.6% after 2016; p-value 0.005).

Conclusions: This study demonstrates that improved patient education regarding preeclampsia is needed, that shared decision-making is of great importance to patients to enhance their healthcare experience, and that healthcare providers should make efforts to routinely incorporate counseling about the later-life health risks associated with preeclampsia.

Trial registration: https://clinicaltrials.gov/ct2/show/NCT02020174

Strengths and limitations of this study

Strengths

- A structured questionnaire framework was used to assess three important domains (knowledge/awareness, satisfaction, and emotional impact) along four critical time points during the preeclampsia experience (1. before preeclampsia diagnosis, 2. at the time of diagnosis and management, 3. the immediate postpartum period, and 4. the long-term postpartum period).
- Comprehensive data collection allowed for detailed interpretation of patient responses considering relevant demographic and clinical characteristics.
- Temporal differences in responses were evaluated to reflect changes in patient and provider knowledge and awareness of preeclampsia.

Limitations

- The Preeclampsia Registry™ is enriched for severe disease, thus experiences may not be generalizable to patients with clinically milder forms of preeclampsia.
- There is inadequate racial/ethnic diversity among participants enrolled in the Preeclampsia Registry™, limiting generalizability.

Introduction

Preeclampsia complicates 3-5% of pregnancies, resulting in approximately 150,000 cases per year in the United States alone.[1 2] Preeclampsia often occurs unexpectedly, develops rapidly, and has immediate high acuity impact on both mother and fetus, requiring fast and complex medical decision-making. Patients with preeclampsia often report chronic physical complaints after childbirth (e.g. headache, visual disturbances, tiredness) and are at increased risk for future cardiovascular disease and diabetes.[3-5] Feelings of guilt, shame, lack of control, and symptoms of post-traumatic stress disorder are reported more often by preeclampsia survivors compared to women with uncomplicated pregnancies.[6-8] Preeclampsia survivors also report a poorer health-related quality of life.[9]

Health-related quality of life includes a patient's physical, emotional, and social wellbeing in relation to a medical condition or treatment and is not just a reflection of medical outcomes (e.g. morbidity), but also incorporates the subjective patient experience (e.g. energy level and mood).[10] While patient-centered care focuses on optimizing individual patient-provider communication, even broader impact can be gained by incorporating the patient voice to identify gaps in patient knowledge and patient/provider communication that can be targeted through research and education.[11-13]

By evaluating a patient's journey through a critical health experience, processes worthy of amplifying and areas in need of modifications can be identified so as to improve not only the patient experience, but also the quality of the care provided.[14 15] Recently, a study in which patients completed a questionnaire specific to well-known concerns regarding pregnancy and childbirth prior to a visit with their provider, found that this tool resulted in improved shared decision-making and more personalized care.[16] Given the varied clinical environments in which care for preeclampsia is provided, a comprehensive appraisal of the patient experience is imperative to identify common underlying elements that can be addressed to optimize the immediate and ongoing care of women with this condition. This may allow for a more proactive assessment and addressing of patients' concerns surrounding their preeclampsia diagnosis.

With this study, we sought to ascertain and describe the patient journey in the setting of preeclampsia from the patient's point of view using a structured framework. We hypothesize that a review of patient reported experiences through their journey in a preeclampsia-complicated pregnancy will be instructive to aspects of the care provided before, during, and after this critical obstetric complication. Knowledge regarding baseline awareness of preeclampsia, frequency of provider counseling about preeclampsia before a diagnosis is established, perceived shared-decision making, reproductive planning, long-term implications, and education regarding later-life complications, has the potential to serve as a guide to implement patient-centered care.

Methods

Study population

Participants already enrolled in The Preeclampsia Registry (TPR) (https://clinicaltrials.gov/ct2/show/NCT02020174) who experienced a pregnancy complicated by a hypertensive disorder of pregnancy (HDP) (n=3,618), were invited by email to participate in the Patient Journey Survey to assess the patient journey (from before diagnosis, through management and delivery, and to the post-delivery period) of that pregnancy. The questionnaire was first offered January 2016, and data for this study was retrieved up to 24 November 2020. The questionnaire was only available for women who were not currently pregnant.

We included participants who self-reported a history of at least one pregnancy complicated by the HDP of: preeclampsia, HELLP (hemolysis, elevated liver enzymes, low platelets) syndrome, eclampsia, or preeclampsia superimposed on chronic hypertension. Previous research using TPR data confirmed self-reported HDP diagnoses in 97.7% after validation with medical records in a random sample of over 200 TPR participants.[17] Although we use the term 'preeclampsia' throughout this manuscript, as this was used in the survey given its familiarity with participants, it is intended to include the four abovementioned HDPs. If a HDP recurred in subsequent pregnancies, only responses from the first HDP pregnancy were included. We excluded Patient Journey Survey responses from

pregnancies with a multifetal gestation and pregnancies with gestational hypertension as the reported HDP (Figure 1).

Ethics Approval

The study protocol regarding the Patient Journey was exempted from IRB approval by Chesapeake IRB (now Advarra Institutional Review Board) (Protocol number Pro00015703). The study protocol regarding TPR was approved by Chesapeake IRB (now Advarra Institutional Review Board) (Pro00008369). All participants provided written informed consent at enrollment with TPR through an online process.

Data collection

Baseline participant characteristics, medical history, and pregnancy and delivery outcomes, including year of delivery, were collected upon initial enrollment in TPR.

The Patient Journey Survey was chronologically structured to query participants about their experience at critical time points along the preeclampsia course to systematically appraise the patient perspective (questionnaire in Supplemental material). The questions included in the questionnaire were chosen by members of TPR's Scientific Advisory Council with the inclusion of two patient representatives. The questionnaire was then tested by members of the Patient Advisory Council and revised based on input such as relevance and clarity of questions. Questions were crafted to assess baseline awareness of preeclampsia, when and what type of information about the diagnosis was provided, counseling around preeclampsia management, with a targeted focus on shared decision-making, post-delivery management, communication, and future reproductive intentions in light of this experience. Participants answered questions organized into three domains: knowledge/awareness, satisfaction, and emotional impact. To capture their experience, we categorized the data into four distinct and relevant time points: before preeclampsia diagnosis, at the time of diagnosis and subsequent management, the immediate postpartum period, and the long-term postpartum period.

To account for possible temporal changes in practice patterns, we evaluated differences in responses over time by year of delivery: prior to 2011, 2011-2013, 2014-2016, and from 2017 onwards. Since the American Heart Association published their guideline with recognition of preeclampsia as a major risk factor for future cardiovascular disease in 2011, 2011 was used as a break point.[18]

Statistical analysis

Baseline characteristics and outcomes were expressed as number (percentage for total of given answers) and median (interquartile range, IQR). Trends over time by year of delivery were visualized in bar charts and evaluated by linear-by-linear association. We performed univariate logistic regression analysis and multivariate logistic regression analysis with backward selection ($p<0.15$) to relate patient characteristics to the probability of the following outcomes: preeclampsia awareness before diagnosis, serious mental/emotional impact of experiencing preeclampsia, and reproductive planning. Guided by the available literature and reasonable assumptions, we selected the following comprehensive list of covariates for inclusion into our analyses: maternal age (<25 years, 25-30 years, 30-35 years, >35 years), year of delivery (<2011, 2011-2013, 2014-2016, ≥2017), educational level (high school or less and/or technical/vocational school, some college, college, graduate school), parity (1, >1), perinatal loss (yes/no), cesarean delivery (yes/no), maternal intensive care unit (ICU) admission (yes/no), neonatal intensive care unit (NICU) admission (yes/no), and gestational age at delivery (<28+0 weeks, 28+0-31+6 weeks, 32+0-36+6 weeks, ≥37+0 weeks). For analyses pertaining to emotional impact and future reproductive planning, we also considered participants' reported involvement in decision-making (yes/no), preeclampsia awareness (yes/no), knowledge of preeclampsia symptoms (yes/no), whether they reported if the healthcare provider conveyed the seriousness of the condition (yes/no), counseling about preeclampsia recurrence (yes/no), and counseling about long term health risks (yes/no).

Statistical analyses were performed using SPSS 25.0. The number of missing values is reported per variable. Unaltered quotes from free text field answers are included as an adjunct to illustrate the results; no thematic analysis was performed.

Patient and public involvement statement

The Preeclampsia Foundation, established in 2000, is a U.S.-based not-for-profit patient advocacy organization with a key goal of catalyzing research. It established TPR in 2013 to build a resource of data and samples intended to support this goal, and key to TPR was governance by a Patient Advisory Council (PAC) in partnership with other stakeholders. Each member of the PAC is a preeclampsia survivor or a family member of a woman who suffered death or disability as the result of preeclampsia and are chosen through an application and screening process that ensures demographic, geographic, and experiential diversity. Individuals are recruited online to TPR through social media, web searches, and emailed invitations. In some instances, healthcare providers direct eligible patients to the registry. Any questionnaire provided to registry participants is reviewed by the Scientific Advisory Council in consultation with PAC, thereby anchoring patient involvement in the design of this study. A patient representative was involved in the rationale and design of this study, helped with interpretation of the results, and co-authored this manuscript (NAK). Results of this study will also be disseminated by the Preeclampsia Foundation to the PAC and all stakeholders, making the results available to all relevant parties.

Results

Of 3,618 TPR participants, 1,154 (32%) initially responded to the Patient Journey Survey. After exclusion of women without self-reported HDP, multiple gestation pregnancies, and incomplete surveys, questionnaire results were available from 833 (23%) women, from here on referred to in this paper as "responders" (Figure 1). Non-responders were more often younger, non-US residents, non-

white , had a lower family income and educational level, and more often delivered before 2011 (Table 1).

Of the responders, median maternal age at delivery was 30 years (IQR 27-33 years), 795 (95.4%) reported being of white race, 728 (87.4%) lived in the United States, and 753 (90.4%) were nulliparous at the time of their preeclampsia pregnancy. Cesarean delivery rates were high (542, 65.6%) and 456 infants required NICU admission (58.6%). Perinatal loss, defined as stillbirth, termination of pregnancy, or neonatal/infant demise, occurred in 87 (10.4%) cases (Table 1). The median interval between delivery and Patient Journey Survey completion was 2.6 years (IQR 1.1-6.2 years).

Patient experience

Before preeclampsia diagnosis

Before diagnosis, 73.9% of responders reported being aware of the term "preeclampsia", however, only 43.7% were aware of associated symptoms. Symptoms were present in 90.9% before diagnosis and 30.6% of these individuals waited more than 6 days before contacting a healthcare provider. If they had known more about the symptoms, 85.4% indicated they would have acted otherwise, of whom 71.5% would have sought care sooner (Table 2A).

"I wish I had known what to look for. Looking back on it now, I was symptomatic for weeks."

[24 years old, delivered at 23 weeks]

At preeclampsia diagnosis and subsequent management

A little over one-half of responders (58.6%) reported that the first time a healthcare professional provided any information about preeclampsia was at the moment they were diagnosed. Of the responders who received information about preeclampsia at any time, 50.2% were dissatisfied with the information provided. 698 (84.9%) responders reported independently researching additional information about preeclampsia, mostly on the internet. Of all responders, 38.1% felt that their

healthcare provider did not convey the seriousness of the condition. Almost a third (29.2%) reported that they did not feel involved in the medical decision-making regarding their care, which they attributed to having a poor understanding of what was happening, lack of time before delivery, and inadequate communication from the healthcare provider (Table 2B).

"I wasn't given any detailed information - perhaps I want more than what is normal, but I felt left out of my care to a degree."

[22 years old, delivered at 37 weeks]

Immediately postpartum

Only 30.7% of the responders indicated that they were provided with information about preeclampsia before being sent home and almost a third of responders (29.7%) reported not being instructed to follow-up with their healthcare provider regarding their diagnosis of preeclampsia.

Almost half of the responders (49.0%) indicated that the experience of having preeclampsia seriously impacted their mental/emotional well-being, with the vast majority reporting a negative impact (70.3%). Additionally, 49.3% reported symptoms of postpartum depression after this pregnancy, and 17.3% reported being diagnosed with postpartum depression (Table 2C).

"I felt robbed of what should have been such an amazing experience."

[39 years old, delivered at 40 weeks]

Long-term postpartum

With respect to long-term management, 36.6% of responders reported not being counseled about preeclampsia recurrence risk and 79.1% indicated that they did not receive any counseling regarding later-life health risks associated with preeclampsia. For 626 (81.3%) responders, the experience of preeclampsia influenced their future pregnancy planning, with 24.3% deciding not to pursue another pregnancy and 13.1% considering (or had already pursued) adoption and/or surrogacy (Table 2D).

"I will have another child, but I have this fear of dying."

[31 years old, delivered at 38 weeks]

Differences in responses over time

A sequential increase in the proportion of positive responses over time was observed across critical parameters (Figure 2A-D). Of responders who delivered before 2011, only 32.2% reported being aware of the symptoms of preeclampsia before diagnosis, which increased to 52.5% in those who delivered after 2016 (Figure 2A, p<0.001). Of the responders who delivered before 2011, 60.5% felt involved in the decision-making about their care, which increased to 77.1% after 2016 (Figure 2B, p<0.001). Also, an increase was seen in the percentage who reported receiving instructions to follow up with their healthcare provider regarding their diagnosis of preeclampsia: from 52.1% in the period before 2011 to 85.0% after 2016 (Figure 2C, p<0.001). A small, but still significant, increase was observed in the proportion of responders indicating that they were counseled about the later-life health risks associated with preeclampsia (14.2% before 2011 to 25.6% after 2016) (Figure 2D, p=0.005). No significant interaction was observed between year of delivery and the interval between delivery and survey completion.

Associations between patient characteristics and outcomes

Results of univariate logistic regression analysis are reported in Supplemental Table 1 and the results of the multivariate analysis are reported in Table 3. Responders who delivered before 2011 and those with only high school or vocational training were less likely to have been aware of preeclampsia before their diagnosis compared to responders who delivered after 2016 (OR 0.28, 95% CI 0.17-0.47) and those with college level education (OR 0.36, 95% CI 0.21-0.62), respectively. Graduate level education was associated with a higher likelihood of being aware of preeclampsia (OR 2.05, 95% C 1.35-3.11) (Table 3A).

Perinatal loss (OR 8.26, 95% CI 3.06-22.38), NICU admission (OR 1.81, 95% CI 1.19-2.76), and not feeling involved in the decision-making about their care (OR 2.46, 95% CI 1.58-3.84) were all independently associated with the preeclampsia experience having a serious impact on the responders' mental/emotional well-being (Table 3B).

Responders over the age of 35 years at delivery (OR 1.72, 95% CI 1.02-2.89; reference group 25-30 years) and who were multiparous (OR 1.80, 95% CI 1.02-3.18) were more likely to decide not to pursue another pregnancy. Conversely, responders who experienced perinatal loss were less likely to avoid future pregnancies (OR 0.20, 95% CI 0.06-0.64) (Table 3C).

Discussion

Main findings

In this study of women with a history of preeclampsia, we describe the patient journey before, during and after diagnosis. In our study population, knowledge about preeclampsia improved over time, but still more than half of the responders were unaware of the associated symptoms before diagnosis. Experiencing preeclampsia had a notable mental/emotional impact and women who did not feel involved in medical decision-making were twice as likely to report a serious negative impact. Moreover, a quarter of the responders desired more children, but elected not to pursue another pregnancy due to the preeclampsia experience. Most responders were instructed to follow up with their healthcare provider regarding preeclampsia after discharge, however, counseling about related future health risks was reported in only a quarter of the population, despite the evidence supporting an increase in risk for cardiovascular disease in women with prior preeclampsia.[4 19] Although several assessed parameters had more positive responses with more recent deliveries, results from this study demonstrate concrete areas for improved patient-provider communication.

Comparison with literature

The perceived lack of knowledge regarding the symptoms associated with preeclampsia is in accordance with other, smaller studies.[20 21] Approximately 85% of responders in our study indicated that they would have acted differently and, for example, sought medical care earlier, had they known more about preeclampsia, highlighting the importance of better patient education. We also found that patient-specific characteristics, such as education level, influenced the likelihood of having heard of preeclampsia and its symptoms. Given that easily-accessible and reliable tools to predict preeclampsia, especially in nulliparous women, remain elusive[22], education regarding preeclampsia should be provided to all obstetric patients and the development of education tools should take these patient level factors into consideration.

Our finding of a significant association between not feeling involved in the medical decision-making and experiencing a more serious mental/emotional impact from the preeclampsia-complicated pregnancy is in line with the principles of patient-centered health care.[11] Indeed, patient reported outcomes are substantively important in judging the quality of care, along with purely medical outcomes. As new preeclampsia diagnosis may require urgent action and, therefore, comprehensive involvement of the patient in shared-decision making may not always be feasible. This potential constraint, however, underscores the need for rigorous and effective communication. Importantly, inadequate communication was one of the most commonly mentioned reasons for not feeling involved in obstetrical care. This lack of effective communication during a stressful event may contribute to feelings of being unprepared, adding to a lingering dissatisfaction conveyed by the women included in our study, even several years after the HDP pregnancy. Shared decision-making is positively associated with patient-satisfaction[23], and our results suggest that effective communication by the health care team can crucially augment the patient experience with a preeclampsia pregnancy.

In 2011, the American Heart Association (AHA) recognized preeclampsia as a major risk factor for future cardiovascular disease, recommending an annual cardio-metabolic assessment.[18 24 25] Despite these recommendations, only 25.6% of women in our study who delivered after 2011 were counseled

about these long-term risks. A German study from 2013 found that, although the majority of obstetricians were aware of the higher risk of cardiovascular disease after preeclampsia, knowledge of current guidelines among these physicians was low, suggesting that improved evidence-based counseling is needed in geographically diverse locations.[26] Previous research showed that, even when obstetricians are aware of the long term effects of preeclampsia, they often do not take action on management to reduce risk.[27] Most women in our cohort were instructed to follow up with their healthcare provider regarding their HDP diagnosis, suggesting that most providers are aware of the possibility for postpartum complications, but they may not have appropriate guidance regarding who is responsible for the long-term counseling and the optimal timing to inform women of these specific risks. To meet these needs, individual healthcare systems should develop evidence-based care pathways and processes for transition of care that are in line with the local health care landscape.

Strengths and limitations

We used a large patient cohort with structured and comprehensive data collection, allowing for detailed interpretation of patient responses in light of relevant demographic and clinical characteristics. Our ability to incorporate temporal differences in responses is also important given the rapidly changing landscape of preeclampsia research and awareness. Importantly, patient involvement at the time of study design allowed for appropriate centering of the core concepts of the survey and for them to be in line with relevant metrics. Self-report of the diagnosis of preeclampsia was proven to be very accurate, since prior work through TPR has confirmed excellent concordance between patient-reported diagnoses and those confirmed by medical record review.[17] Since TPR is an initiative by the Preeclampsia Foundation, patient involvement in TPR design and data use is the basis of TPR and this paper.

Our study is not without limitations. First, given the relatively low response rate, selection bias and lack of representation are a concern as almost all women in our study were non-Hispanic white and highly educated. At 18.5%, Hispanic individuals make up the largest minority in the United States,

but only 6% of responders self-identified as Hispanic in our study.[28] TPR and the Patient Journey Survey are not available in Spanish, possibly contributing to this lack of representation. Significant differences between responders and non-responders (i.e. age, country of residence, racial background, family income, and educational level) were observed, thus limiting incorporation of experiences across populations. TPR is notably enriched for severe disease, thus the experiences of included participants may not be generalizable to patients with clinically milder forms of preeclampsia. Second, recall bias may have influenced results given the interval from delivery to survey completion (median 2.6 years). As such, for virtually all questions, 'I don't know' or 'I'm not sure' were included as answer options. Literature, however, suggests that emotionally stirring life events are unlikely to be forgotten and that the memory of these events is accurate.[29 30]

Conclusion and future perspectives

By providing a comprehensive insight into the patient journey before, during, and after a preeclampsia pregnancy, this study adds to a growing body of literature establishing the importance of a patient-centered approach to healthcare. In our study population of women with a prior preeclampsia pregnancy, a large proportion reported being unaware of this condition and its associated symptoms prior to diagnosis and many indicated not feeling involved in the decision-making regarding their care. In turn, they noted that their preeclampsia experience had a serious negative impact on their mental/emotional wellbeing and influenced their future pregnancy planning. Counseling regarding the long-term health risks associated with preeclampsia was reported to occur infrequently. This systematic assessment of the patient perspective through a preeclampsia-complicated pregnancy provides invaluable insights to catalyze enhanced education, communication and counseling for this common obstetric complication associated with significant morbidity. Future research should be replicated in a more diverse population. Such knowledge can help develop targeted tools for improving the experienced patient journey and augmenting preeclampsia knowledge based on community level characteristics. Counseling regarding postpartum complications and follow-up clearly

needs to be initiated by obstetric providers. Mechanisms to support ongoing counseling and management of this population at risk for long-term morbidity are best established at the local level, however, blueprints from successful programs in current practice can be leveraged and tailored to regional needs.[31-34]

Author contribution statement

RS, HSG, EZT, MPHK and EWS designed this study. AB collected the data. Analysis and interpretation of the data was performed by RCB, SB, RS, MPHK and EWS. RCB, SB and RS wrote the first draft of the manuscript. Critical feedback was provided by AB, NAK, EZT, MPHK and EWS. All authors contributed to reviewing and editing the manuscript

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Competing interests statement

None declared.

Data sharing statement

Data that support the findings of this work are available upon reasonable request from the corresponding author.

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Table 1. Baseline characteristics responders and non-responders

Individual characteristics	Responders (833) *Median (IQR) / N (%)*	Non-responders (2,161) *Median (IQR) / N (%)*	p-value
Maternal age (years)	30 (27; 33)	29 (26; 33)	<0.001
<25	97 (11.7%)	393 (18.3%)	
25-29	265 (31.9%)	700 (32.6%)	
30-34	305 (36.7%)	744 (34.6%)	
≥35	163 (19.6%)	312 (14.6%)	
	Missing: 3	*Missing: 12*	
Country of residence			0.012
United States	728 (87.4%)	1,796 (83.1%)	
Other	105 (12.6%)	365 (16.9%)	
	Missing: 0	*Missing: 0*	
Race			0.001
White	795 (95.4%)	1,990 (92.1%)	
Non-white	38 (4.6%)	171 (7.9%)	
	Missing: 0	*Missing: 0*	
Ethnicity			0.281
Non-Hispanic	781 (94.0%)	1,967 (92.9%)	
Hispanic	50 (6.0%)	151 (7.1%)	
	Missing: 2	*Missing: 43*	
Totally family income per year (USD)			0.020
Less than 25.000	66 (13.2%)	264 (18.1%)	
25.000-99.999	259 (51.9%)	745 (51.2%)	
100.000-249.999	149 (29.9%)	401 (27.6%)	
250.000 or more	25 (5.0%)	45 (3.1%)	
	Missing: 334	*Missing: 706*	
Highest level of education completed			<0.001
High school or less and technical/vocational school	74 (9.0%)	277 (13%)	
Some college	117 (14.2%)	368 (17.3%)	
College	341 (41.4%)	885 (41.7%)	
Graduate school	292 (35.4%)	593 (27.9%)	
	Missing: 9	*Missing: 38*	
Marital Status			0.978
Married or in a relationship	795 (95.8%)	2,056 (95.8%)	
Divorced/single	35 (4.2%)	90 (4.2%)	
	Missing: 3	*Missing: 15*	

(Continues on next page)

Pregnancy details	*Median (IQR) / N (%)*	*Median (IQR) / N (%)*	p-value
Parity			0.622
1	753 (90.4%)	1,966 (91.0%)	
>1	80 (9.6%)	195 (9.0%)	
	Missing: 0	*Missing: 0*	
Mode of delivery			0.731
Vaginal birth	284 (34.4%)	747 (35.1%)	
Cesarean section	542 (65.6%)	1,384 (64.9%)	
	Missing: 7	*Missing: 30*	
Gestational age at delivery (weeks+days)	35+2 (32+1; 38+3)	34+5 (31+1; 37+3)	0.566
<28+0	99 (12.2%)	266 (12.6%)	
28+0 - 31+6	117 (14.4%)	334 (15.8%)	
32+0 - 36+6	306 (37.6%)	815 (38.5%)	
≥37+0	291 (35.8%)	704 (33.2%)	
	Missing: 20	*Missing: 42*	
Year of delivery			<0.001
Before 2011	187 (22.4%)	623 (28.8%)	
2011-2013	174 (20.9%)	456 (21.1%)	
2014-2016	286 (34.3%)	507 (23.5%)	
From 2017 onwards	186 (22.3%)	574 (26.6%)	
	Missing: 0	*Missing: 1*	
Pregnancy outcome			0.238
Living child	746 (89.6%)	1,931 (89.4%)	
Live birth with subsequent infant death	52 (6.2%)	119 (5.5%)	
Stillbirth(s)	33 (4.0%)	88 (4.1%)	
Miscarriage	0 (0%)	1 (0%)	
Induced pregnancy termination	2 (0.2%)	22 (1%)	
	Missing: 0	*Missing: 0*	
Birthweight child (grams)	2,359 (1,452; 3,039)	2,268 (1,406; 3,036)	0.188
	Missing=14	*Missing: 56*	
Maternal ICU-admittance	156 (19.6%)	413 (20.2%)	0.730
	Missing: 37	*Missing: 114*	
Baby admitted to the NICU	456 (58.6%)	1,208 (60.6%)	0.334
	Missing: 55	*Missing: 168*	

IQR=interquartile range; USD=United States dollars; ICU=intensive care unit; NICU=neonatal intensive care unit

Table 2. Patient Journey *(N=833)*

A. Before preeclampsia diagnosis	N(%)
Heard of preeclampsia	599 (73.9%)
Missing: 22	
Aware of the symptoms associated with preeclampsia	348 (43.7%)
Missing: 36	
Experienced any symptoms	746 (90.9%)
Missing: 12	
Symptoms length before reaching out to a healthcare provider	
<1 day	244 (37.7%)
2-5 days	206 (31.8%)
≥6 days	198 (30.6%)
Missing: 185	
Would have done anything differently if had more knowledge about symptoms	536 (85.4%)
Missing: 205	
Would have sought care sooner	383 (71.5%)

(Continues on next page)

B. At preeclampsia diagnosis and subsequent management	N(%)
Healthcare provider asked for a family history of preeclampsia	248 (39.6%)
Missing: 207	
Moment at which a healthcare provider first shared information about preeclampsia	
During or after a previous pregnancy	15 (2.0%)
During a prenatal visit for this pregnancy	258 (33.9%)
After I was diagnosed with preeclampsia in this pregnancy	356 (46.8%)
After delivery in this pregnancy	64 (8.4%)
At discharge from the hospital	3 (0.4%)
During a postpartum check-up after this pregnancy	12 (1.6%)
Sometime later	11 (1.4%)
Never	42 (5.5%)
Missing: 72	
Satisfied with the provided information	325 (49.8%)
Missing: 180	
Researched preeclampsia by themselves	698 (84.9%)
Missing: 11	
Healthcare provider conveyed the seriousness of the condition	
Yes	460 (61.9%)
No, even though it was serious	283 (38.1%)
Missing: 90	
Degree of mental or emotional impact of preeclampsia diagnosis	
No Impact	26 (3.1%)
Minimal Impact	96 (11.6%)
Some Impact	321 (38.8%)
Serious Impact	385 (46.5%)
Missing: 5	
Healthcare provider indicated why delivery was necessary	751 (93.1%)
Missing: 26	
Did not feel involved in making decisions	212 (29.2%)
Missing: 107	
Reasons why women felt not involved *(Multiple answers possible)*	
I was unconscious or in a coma	10 (4.7%)
I was "out of it''	65 (30.7%)
I did not understand what was happening	86 (40.6%)
There was no time before delivery	62 (29.2%)
I did not want to be involved	0
My family was involved instead of me	20 (9.4%)
Inadequate communications from healthcare provider(s)	86 (40.6%)
Other	28 (13.2%)

(Continues on next page)

C. Immediately postpartum	N(%)
Provided with information about preeclampsia before being sent home	220 (30.7%)
Missing: 116	
Instructed to follow up with a healthcare provider regarding preeclampsia	543 (70.3%)
Missing: 61	
Degree of mental or emotional impact	
No Impact	38 (4.6%)
Minimal Impact	76 (9.2%)
Some Impact	308 (37.2%)
Serious Impact	406 (49.0%)
Missing: 5	
Pregnancy negatively affected the emotional/psychological wellbeing	565 (70.3%)
Missing: 29	
Believed they had postpartum depression	382 (49.3%)
Missing: 58	
Officially diagnosed with postpartum depression	131 (17.3%)
Missing: 74	

D. Long-term postpartum	N(%)
Counseled about the risk of having preeclampsia in future pregnancies	505 (63.4%)
Missing: 36	
Counseled about later-life health risks associated with preeclampsia	165 (20.9%)
Missing: 43	
Preeclampsia affected relationship with family or friends	392 (54.2%)
Missing: 110	
How did preeclampsia affect the relationship with your partner?	
For the better	163 (41.6%)
For the worse	97 (24.7%)
Both for the better and worse	132 (33.7%)
Missing: 0	
Influenced decision to become pregnant again	
My decision to become pregnant again has not been influenced	144 (18.7%)
My decision to become pregnant again has been influenced	626 (81.3%)
I wanted more children but decided not to have another pregnancy	187 (24.3%)
I am considering (or already pursued) adoption and/or surrogacy	101 (13.1%)
I will seek (or already sought) preconception counseling by a high risk pregnancy specialist	246 (31.9%)
If I get pregnant I will be seen by a specialist at that point	217 (28.2%)
With time my perspective on this question has changed	150 (19.5%)
Other	143 (18.6%)
Missing: 63	

**Indentations: this question only applies when a specific answer was given to the previous question; percentages are provided for total of given answers*

Table 3. Associations between patient characteristics and outcomes

A. Heard of preeclampsia before first diagnosis	*OR*	*95% CI*	*p-value*
Year of delivery			
<2011	0.28	0.17-0.47	<0.001
2011-2013	0.64	0.37-1.11	0.111
2014-2016	0.66	0.40-1.09	0.106
≥2017	ref		
Highest level of education completed			
High school or less and technical/vocational school	0.36	0.21-0.62	<0.001
Some college	0.72	0.45-1.16	0.182
College	ref		
Graduate school	2.05	1.35-3.11	0.001
Multiparity	1.65	0.88-3.08	0.118

Covariates removed by backward selection: maternal age

B. Serious mental/emotional impact	*OR*	*95% CI*	*p-value*
Year of delivery			
<2011	0.89	0.49-1.64	0.718
2011-2013	0.54	0.29-1.02	0.056
2014-2016	1.20	0.70-2.05	0.508
≥2017	ref		
Perinatal loss	8.26	3.06-22.28	<0.001
Cesarean section	0.7	0.45-1.09	0.112
Baby admitted to the NICU	1.81	1.19-2.76	0.006
Not involved in making decisions	2.46	1.58-3.84	<0.001

Covariates removed by backward selection: gestational age, parity, maternal age, maternal intensive care admittance, healthcare provider conveyed the seriousness of the condition, aware of preeclampsia symptoms before diagnosis, heard of preeclampsia before diagnosis

C. Family planning: wanted more children but decided not to pursue another pregnancy	*OR*	*95% CI*	*p-value*
Maternal age (years)			
<25	0.57	0.27-1.19	0.134
25-29	ref		
30-34	1.07	0.68-1.68	0.773
≥35	1.72	1.02-2.89	0.040
Multiparity	1.80	1.02-3.18	0.041
Gestational age at delivery (weeks+days)			
<28+0	2.00	0.94-4.26	0.072
28+0 - 31+6	1.72	0.98-3.01	0.057
32+0 - 36+6	1.11	0.72-1.72	0.632
≥37+0	ref		
Perinatal loss	0.20	0.06-0.64	0.007

Covariates removed by backward selection: child admitted to neonatal intensive care unit, counseled about risk of experiencing preeclampsia in future pregnancies, maternal intensive care admittance

Results are from multivariate logistic regression analysis. OR=Odds Ratio; 95% CI=95% confidence interval; NICU=neonatal intensive care unit

Figures

Figure 1: Flowchart of responders Patient Journey questionnaire in the Preeclampsia Registry™.

Abbreviations: TPR=The Preeclampsia Registry; HDP=Hypertensive disorder of pregnancy, defined as preeclampsia, HELLP (hemolysis, elevated liver enzymes, low platelets) syndrome, eclampsia, or preeclampsia superimposed on chronic hypertension.

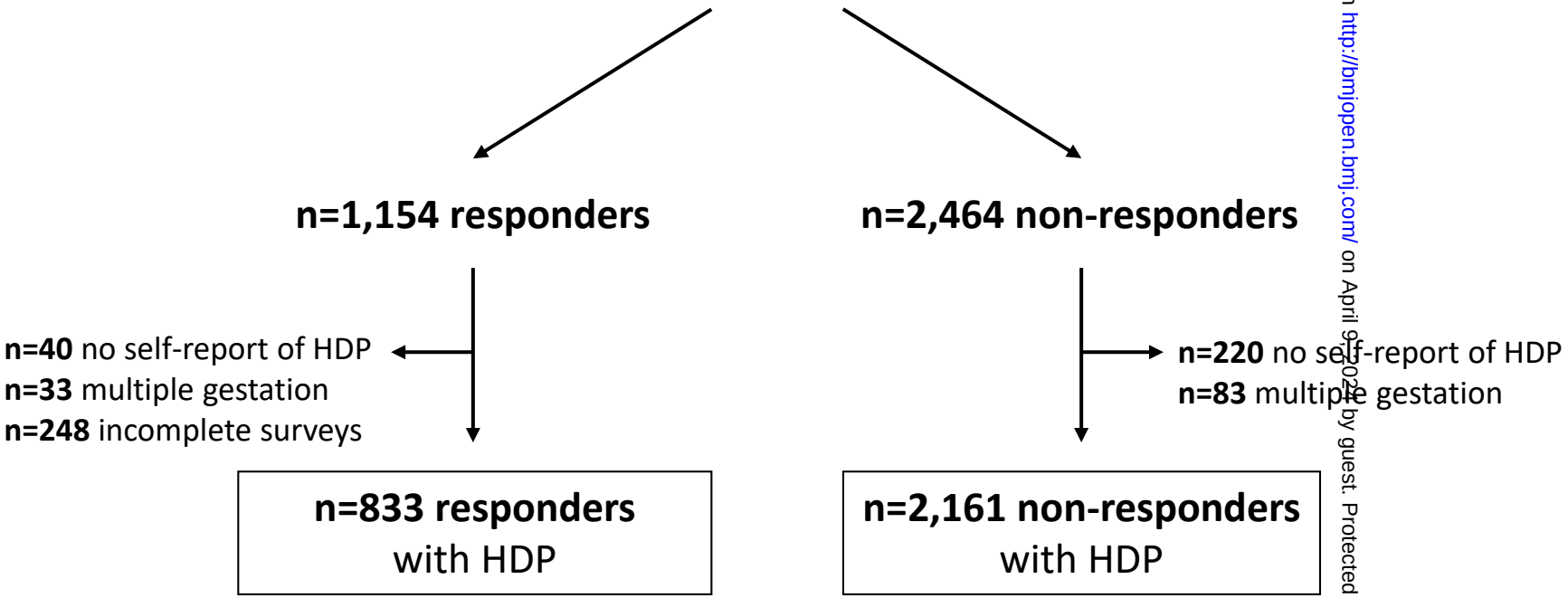
Figure 2: Differences in responses over time

A: Were you aware of the symptoms associated with preeclampsia before you were diagnosed with preeclampsia in this pregnancy?

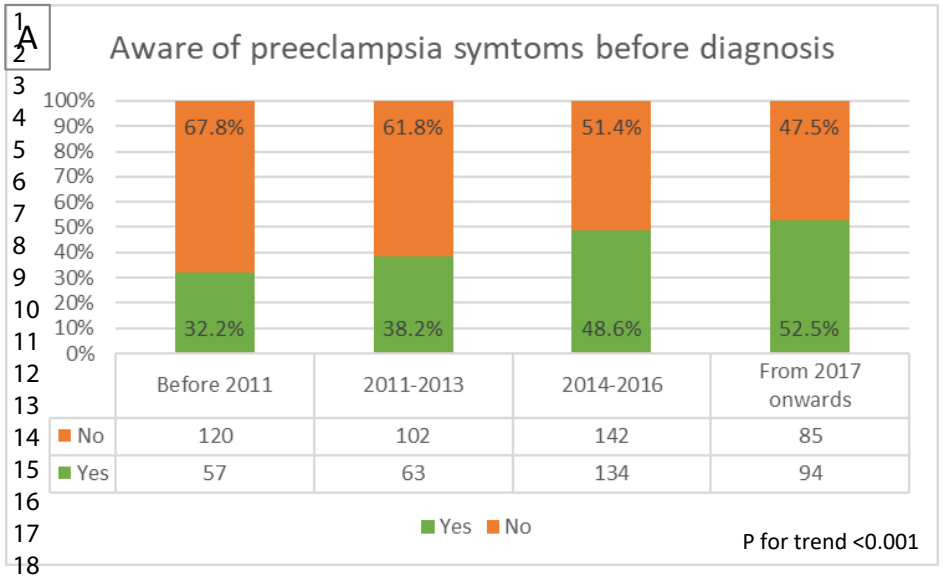
B: Did you feel that you were adequately involved in making decisions about your care?

C: Were you instructed to follow up with your healthcare provider regarding your diagnosis of preeclampsia?

D: Did anyone speak to you about the potential long-term health consequences as a result of preeclampsia?



A



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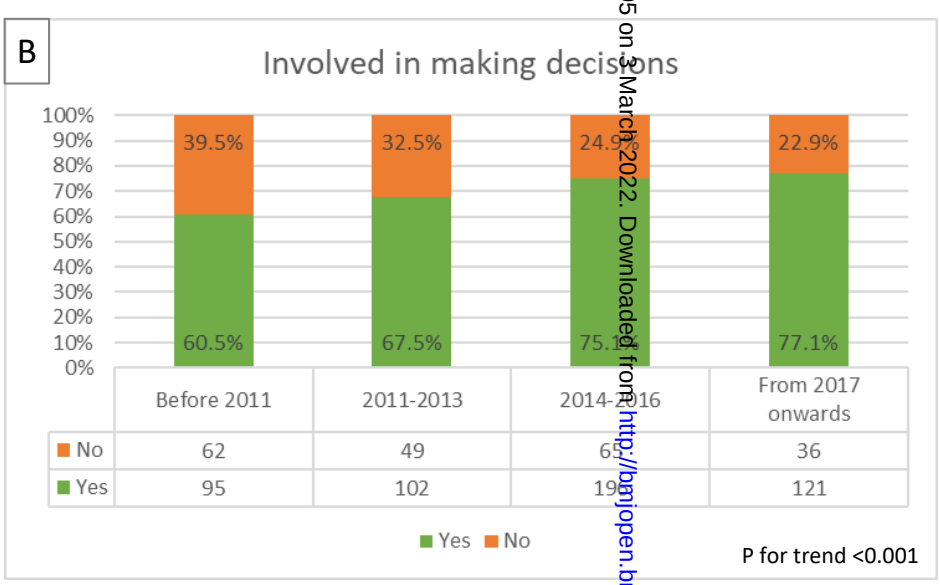

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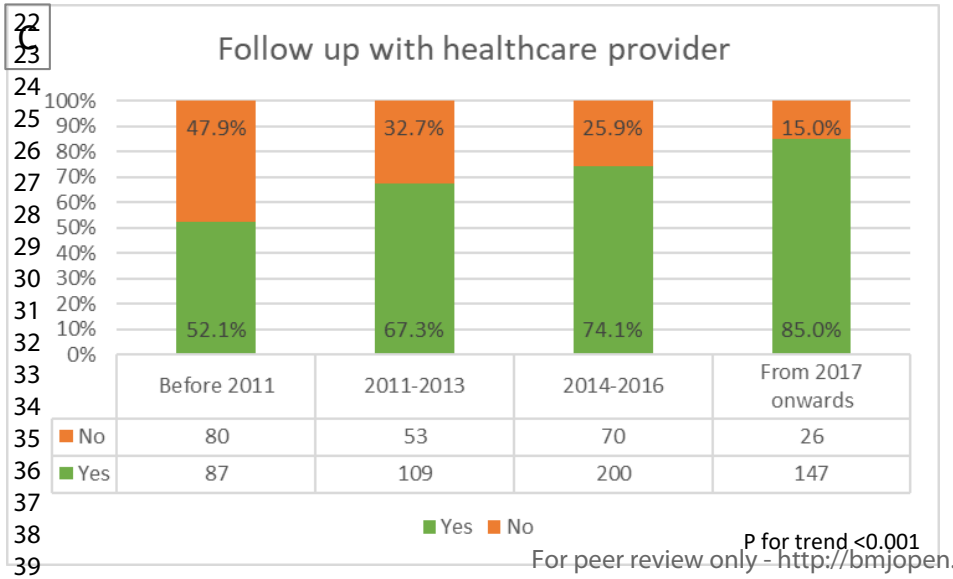

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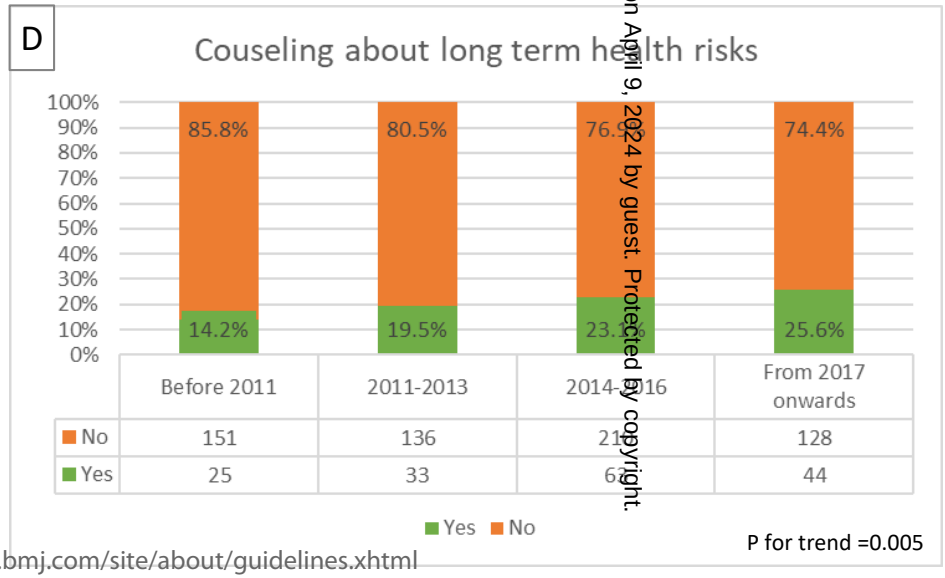

Patient Journey Survey

The following survey has been added to The Preeclampsia Registry to better understand the patient journey including diagnosis, management, treatment, and delivery. This research is being conducted by the Preeclampsia Foundation, in collaboration with rEVO Biologics, a biotechnology company that is developing therapies to treat uncommon conditions, including early onset preeclampsia, and under the supervision of Dr. Ellen Seely (Brigham & Women's Hospital, Harvard University) and Drs. Hilary Gammill and Swati Shree (University of Washington). The information collected in this survey will be de-identified and then used by rEVO Biologics to more effectively address the needs of women with preeclampsia and their healthcare providers. In addition, it will be used by the Preeclampsia Foundation to improve patient education and support, and advocate for better healthcare practices. Other investigators may also use this information for additional research studies. You do not have to answer these questions in order to continue your participation in The Preeclampsia Registry.

You can learn more about rEVO Biologics at their website www.revobiologics.com and more about the Preeclampsia Foundation at their website www.preeclampsia.org.

The information you provide in the survey will be de-identified. The Preeclampsia Registry will *not* give anybody your name, contact information, or any information that can identify you.

This survey will take approximately 30 minutes to complete. Some of these questions relate to how you felt about your experience and some relate to the sequence of events. You do **not** need to complete it all at one time. If you are not comfortable answering any question, please skip ahead to the next question. If you don't know the answer to a question, you may select "I'm not sure".

If you have any questions or concerns, you may contact The Preeclampsia Registry Research Coordinator at (800) 665-9341 or by email at Registry@preeclampsia.org.

Thank you.

"Start Survey"

Form 2

We will be asking about your pregnancies that were complicated by preeclampsia. This includes postpartum preeclampsia that continued after pregnancy or new onset shortly after pregnancy.**

****Throughout this questionnaire, the term "preeclampsia" will be used as an overall description of all Hypertensive Disorders of Pregnancy, such as preeclampsia (sometimes referred to as toxemia or PIH), HELLP syndrome, gestational hypertension, preeclampsia superimposed on chronic hypertension. We are aware these are different complications of pregnancy.**

Information and Awareness

Had you heard of preeclampsia before your first diagnosis?
(check boxes single response)

- Yes
- No
- I'm not sure

If Yes, What did you know about preeclampsia before you were first diagnosed with the condition? *(text box)*

Have you ever done any research on preeclampsia on your own?
(check boxes single response)

- Yes *(skip logic)*
- No *(skip logic)*
- I'm not sure

(If No) Why? Check all that apply. *(multiple response)*

- No access to internet or library
- I was too scared to learn more
- I was content with what I knew
- Other (*text box*)
- I'm not sure

(If Yes) When did you do this research? Check all that apply. *(multiple response)*

- Before conception
- During pregnancy *if checked (multiple response)*
  Check all that apply.
  - Before I was diagnosed
  - When I experienced symptoms
  - After I was diagnosed
- Immediately after delivery (within 48 hours or during hospitalization) *if checked (multiple response)*
  Check all that apply.
  - Before I was diagnosed
  - When I experienced symptoms
  - After I was diagnosed
- Later after delivery (up to 6 weeks later) *if checked (multiple response)*
  Check all that apply
  - Before I was diagnosed
  - When I experienced symptoms
  - After I was diagnosed
- Much later after delivery (more than 6 weeks)
- Other *(text box)*
- I'm not sure

(If Yes) What sources of information did you use? Check all that apply.

(multiple response)

- Website
  - Which website? *(text field)*
- Mobile app
  - Which mobile app? *(text field)*
- Pregnancy Books
- Pamphlets/handouts from the hospital
- Family member/spouse/friend
- Social Media
- Chat rooms/Message boards
- Nurse or other hospital staff
- Additional medical opinions (i.e., “second opinions”)
- Other *(text box)*
- I’m not sure *(single response if selected)*

(If Yes) How satisfied were you with the information that you found? Select the one best choice.

(single response)

- Not satisfied
- A little satisfied
- Very satisfied
- Completely satisfied

(If Yes) How did the information make you feel? *(text box)*

(If Yes) What is your primary mode of electronic research? Select the one best choice.*(single response)*

- Mobile phone
- Tablet
- Laptop computer
- Desktop computer
- Other (*text box*)
- I’m not sure

Based on your experience, what information would be most useful to women with preeclampsia that was not available to you? *(text box)*

What word(s) would you use to describe the emotion(s) you felt *during* your first experience with preeclampsia? *(short text box & limit characters to 117)*

What word(s) would you use to describe the emotion(s) you felt *after* your first experience with preeclampsia? *(short text box & limit characters to 117)*

Did preeclampsia affect your relationship with your family or friends? *(single response)*

- Yes
- No
- I’m not sure

(If Yes) How were your relationships affected? (Check all that apply) *(multiple response)*

- Changed my relationship with my partner for the worse
- Changed my relationship with my partner for the better
- Distanced me from some or all family members
- Brought me closer to some or all family members
- Ended friendships
- Brought me closer to friends
- Other (please specify)

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Form 3

Long-term Health

What NEW lingering effects do you believe preeclampsia had on you? That is, issues you did not have (or were not diagnosed with) before pregnancy. Check all that apply *(multiple responses)*

- Fatigue, beyond "new mother" sleeplessness
- Pain
- Emotional/psychological (e.g. anxiety, depression, intense feeling of loss)
- Kidney disease
- Liver disease
- Multiple hospitalizations resulting from condition(s) associated with pregnancy
- Heart conditions or heart disease
- Stroke
- High blood pressure
- Clotting disorders
- Autoimmune disorders (e.g. lupus, arthritis, etc.)
- Thyroid problems
- Diabetes
- None
- Other *(text)*

(Asked once if any of the above are checked except for "None") Did or do you receive medical care for this problem(s)?*(single response)*

- Yes
- No
- I'm not sure

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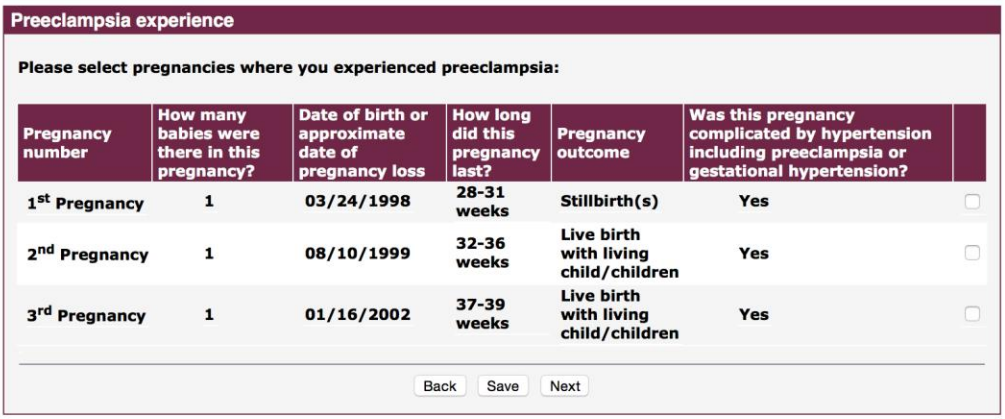
Form 4

This is the pregnancy history we have on file for you. You will be given the option to provide details about each of the pregnancies in which you experienced preeclampsia. If there are any mistakes in this information please contact registry@preeclampsia.org.

This will determine how many times this questionnaire can loop and for what pregnancies.



Preeclampsia experience

Please select pregnancies where you experienced preeclampsia:

Pregnancy number	How many babies were there in this pregnancy?	Date of birth or approximate date of pregnancy loss	How long did this pregnancy last?	Pregnancy outcome	Was this pregnancy complicated by hypertension including preeclampsia or gestational hypertension?	
1st Pregnancy	1	03/24/1998	28-31 weeks	Stillbirth(s)	Yes	☐
2nd Pregnancy	1	08/10/1999	32-36 weeks	Live birth with living child/children	Yes	☐
3rd Pregnancy	1	01/16/2002	37-39 weeks	Live birth with living child/children	Yes	☐

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Looping begins here:

Begin looping with oldest pregnancy checked

Form 5

Demographics

The following questions are about your pregnancy in *mm/yyyy*.

Because you are enrolled in The Preeclampsia Registry, we already have most of the basic information we need about you and your pregnancy(s).

1. Where did you live during this pregnancy with preeclampsia?
   City: *(text)* Country: *(dropdown countries)* State/Province: *(Dropdown US States if USA selected as Country)*

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Form 6

Family History of Preeclampsia

The following questions are about your pregnancy in *mm/yyyy*.

During this pregnancy, did your healthcare provider ask you if you have a family history of preeclampsia? *(single response)*

- Yes
- No
- I'm not sure

During this pregnancy, if you have a family history of preeclampsia, did you let your healthcare provider know? *(single response)*

- Yes *(skip logic)*

- No
- Not Applicable, I do not have a family history of preeclampsia
- I'm not sure

(If Yes) During this pregnancy, were you already aware that your chances of developing preeclampsia were higher, given your family history? *(single response)*

- Yes
- No
- I'm not sure

(If Yes) During this pregnancy, did your healthcare provider share that your chances of developing preeclampsia were higher, given your family history? *(single response)*

- Yes
- No
- I'm not sure

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Form 7

The following questions are about your pregnancy in *mm/yyyy*.

Symptoms

Here is a list of commonly reported symptoms of preeclampsia.

- Headache
- Visual Disturbances
- Swelling
- Abdominal (stomach area) pain
- Indigestion/heartburn
- Chest pain
- Back pain
- Nausea and/or vomiting
- Palpitations
- Vertigo/Dizziness
- Shortness of breath
- Sudden weight gain *(info button:* more than 5 lbs or 2.25kgs in a week)
- Fatigue/tiredness
- Trouble thinking clearly/altered consciousness
- Sleep difficulties
- "Just not feeling right"

Were you aware of the symptoms associated with preeclampsia *before* you were diagnosed with preeclampsia in this pregnancy? *(single response)*

- Yes
- No
- I'm not sure

Did you experience any of these symptoms *before* you were diagnosed with preeclampsia? *(single response)*

- Yes *(skip logic)*

- No
- I'm not sure

(If Yes) What did you do when you experienced any of these symptoms? Check all that apply. *(multiple response)*

- Tried to resolve them on my own (e.g., took pain reliever, laid down, took hot shower)
- Researched on the internet or in books if these symptoms were concerning
- Talked to spouse or partner
- Talked to other family members or friends about my symptoms
- Contacted my healthcare provider
- Went to the hospital, clinic, or doctor's office
- Nothing *(if selected, no other options available)*
- Other (*text box*)
- I'm not sure *(if chosen, no other options available)*

(If Yes) How long did you experience any of these symptoms before reaching out to a healthcare provider? (Select the one best choice) *(single response)*

- I contacted my healthcare provider immediately
- Less than a day
- A day
- A few days (2-5 days)
- A week
- More than a week
- Not Applicable
- Other *(text box)*
- I'm not sure

(If Yes) How long did you experience any of these symptoms before actually speaking with a healthcare provider? (Select the one best choice) (single response)

- I spoke with my healthcare provider immediately
- A few hours
- Less than a day
- A day
- A few days (2-5 days)
- A week
- More than a week
- Not Applicable
- Other (text box)
- I'm not sure

(If Yes) How long did it take for you to see your healthcare provider in person? Select the one best choice.

(single response)

- My healthcare provider sent me straight to the hospital
- My healthcare provider saw me immediately at his/her office
- My healthcare provider saw me that day
- My healthcare provider saw me a few days after I reached out

- I waited until my next prenatal visit to see my healthcare provider
- My healthcare provider did not see me
- Not Applicable
- Other *(text)*

(If Yes) If you had known more about the symptoms of preeclampsia in advance of your diagnosis, would you have done anything differently? *(single response)*

- Yes *(Skip Logic)*
- No
- Not Applicable
- I'm not sure

(If Yes) Which of the following apply? Check all that apply. *(multiple response)*

- I would have recognized my symptoms sooner.
- I would have sought care sooner.
- I would have insisted my symptoms be taken seriously.
- Other *(text)*

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Form 8

The following questions are about your pregnancy in *mm/yyyy*.

Diagnosis

Do you believe you received a timely diagnosis? Select the one best choice. *(single response)*

- Yes
- No, It was missed but eventually diagnosed
- No, It was missed
- I don't know, it was never discussed with me
- Other *(with text box)*

Who first told you that you had preeclampsia? Select the one best choice. *(single response allowed)*

- OB/GYN physician
- High-risk OB physician (Maternal-Fetal Medicine specialist or Perinatologist)
- Nurse in Clinic or Outpatient
- Nurse in Hospital
- Emergency Room Provider
- Primary Care Provider
- Midwife
- Doula
- Nobody, I found out on my own
- Other (*text box)*
- I'm not sure

Where were you first diagnosed? Select the one best choice. (*single response)*

- At my healthcare provider's office
- At a hospital

- At home
- Other (*text box)*
- I'm not sure

When did a healthcare provider first share information with you about preeclampsia? Select the one best choice. *(single response)*

- During or after a previous pregnancy
- During a prenatal visit for this pregnancy
- After I was diagnosed with preeclampsia in this pregnancy
- After delivery in this pregnancy
- At discharge from the hospital
- During a postpartum check-up after this pregnancy
- Sometime later
- Never *(skip logic)*
- Other *(text)*
- I'm not sure

("Never" skips this question) What type of information were you given when you were diagnosed? Check all that apply. *(multiple response)*

- Shared information verbally
- Brochure or pamphlet
- Referred to a website
    - Which website? *(text box)*
- Other (*text box)*
- I'm not sure

("Never" skips this question) Did you feel satisfied with the information that you were given at that time? *(single response)*

(check boxes single response allowed)

- Yes
- No *(skip logic)*
- I'm not sure

(If No) Please specify why you did not feel satisfied with the information you were given at that time. *(text box)*

("Never" skips this question) Did you feel that your healthcare provider conveyed the seriousness of the condition? *(single response)*

- Yes
- No, even though it was serious
- No, it was not serious
- I'm not sure

Did you feel a premonition, apprehension or anxiety prior to your diagnosis?

- Yes
- No
- I'm not sure

(If Yes) In what way(s)? Check all that apply. *(multiple response)*

- "I just knew something wasn't right"
- "I had a very strong sense of foreboding in the days before my diagnosis"
- "I had a dream or vision before my diagnosis"
- "I felt anxious and unsettled in the days before my diagnosis"
- Other *(text box)*
- None of the above *(if selected, do not allow for other responses)*
- I'm not sure *(if selected, do not allow for other responses)*

What degree of mental or emotional impact did **learning of your diagnosis** of preeclampsia have on you? Select the one best choice. *(single response)*

- No Impact
- Minimal Impact
- Some Impact
- Serious Impact

Is there anything else ***about your diagnosis*** that these questions have not covered that you believe is important or that you would like us to know?

[Open text field]

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Form 9

The following questions are about your pregnancy in *mm/yyyy*.

Hospital Care

Did you receive care in more than one hospital or birthing facility, besides where you received prenatal care? *(single response)*

- Yes *(skip logic)*
- No

(If Yes) How many hospitals or facilities did you go to? *(required response)*
Dropdown of numbers (1-9). This will determine how many times the hospital care questions should loop.

Hospital looping begins
Please answer the following questions for the *<first>* hospital or facility you went to. You will have an opportunity to answer questions about the other hospitals, if applicable.

Did you go to this facility before or after diagnosis? *(single response)*

- Before
- After *(skip logic)*
- I'm not sure

(*If After)* How long did it take to be seen at this hospital after your diagnosis? Select the one best choice.
(single response)

- 0 – 12 hours
- 12 – 24 hours
- 1 – 2 days
- More than 2 days
- I'm not sure
- Other (*text box)*

How many weeks and days pregnant were you when you were when you were seen at this hospital?

Dropdown from 45 to 20 weeks, Before 20 weeks, & I Don't Know, *Dropdown from 0-6* Days & I Don't Know *(copy this option from question N3 in general questionnaire)*

Had postpartum preeclampsia *(check box outside dropdowns)*

What happened at this facility? Check all that apply. *(multiple response)*

- I was diagnosed at this hospital
- Regular observations and monitoring of me (e.g.blood pressure, urine evaluation, blood tests, etc.) and/or of my baby (e.g. heart rate monitoring or ultrasound)
- Kept in the hospital for a while, but eventually transferred to another hospital
- Immediately transferred to another hospital
- Given blood pressure medication to lower my blood pressure
    - *(if selected)* Did you experience any side effects?
        - Yes
        - No

          (*If Yes)* What type of side effects? (*multiple response)*
            - Light headed or dizzy
            - Heart racing
            - Nausea/vomiting
            - Fatigue/sleepiness
            - Other *(text)*
- Given Magnesium Sulfate
    - *(if selected)* Did you experience any side effects?
        - Yes
        - No

          (if Yes) What type of side effects? Check all that apply. *(multiple response)*
            - Feeling hot/flushed
            - Cold/clammy
            - Vision changes
            - Nausea/vomiting
            - Fuzzy thinking
            - Other *(text)*
- Given steroids – for baby's lungs
    - *(if selected)* Did you experience any side effects?
        - Yes
        - No.

          (if Yes) What type of side effects? Check all that apply. *(multiple response)*
            - Anxiety
            - Difficulty sleeping

- Change in mood
- Other *(text)*

- Sent home. Check all that apply.
  (If selected, multiple response)
  - With information of symptoms to look out for
  - On bed rest
  - On reduced activity
  - To monitor my own blood pressure
  - Later readmitted to hospital because of preeclampsia.
- Delivered *(single response)*
  - Delivered within 12 hours
  - Delivered between 13 and 48 hours
  - Delivered after 48 hours
- Diagnosed after delivery
- Other *(text box)*
- I'm not sure

Were you given information about what was being done for you? (*single response)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) Was the information adequate? (*single response)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) Why do you feel this information was adequate? Check all that apply. *(multiple response)*

- I was told why something was being done
- I understood what was being communicated
- I was told about the benefits, alternatives, and risks to me
- I was told about the benefits, alternatives, and risks to my baby

(If Yes) Who provided you with information about what was being done for you? Check all that apply. (*multiple responses)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Nurse in Clinic or Outpatient
- Nurse in Hospital
- Emergency Room Provider
- Primary Care Provider
- Midwife
- Doula
- Other (*text box*)
- I'm not sure

How did you get to the hospital? Select the one best choice.(*single response)*

- My spouse/friend/family member drove me
- I drove myself
- I took an ambulance
- I took public transportation (bus, subway, taxi)
- I walked
- Other (*text box*)
- I'm not sure

Where were you sent when you arrived at the hospital? (*single response)*

- Emergency Room
- Labor & Delivery/Maternity
- Other (*text box*)
- I'm not sure

Did your healthcare provider call ahead to the hospital? (*single response)*

- Yes
- No
- I'm not sure

Did your healthcare provider tell you what you could expect when you arrived at the hospital? (*single response)*

- Yes
- No
- Not Applicable
- I'm not sure

Were you seen by a specialist at the hospital? (*single response)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) What type of specialist? Check all that apply. (*multiple response)*

- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Cardiologist (Heart)
- Pulmonologist (Lung)
- Nephrologist (Kidney)
- Hematologist (Blood)
- Neurologist (Brain)
- Other (*text box*)
- I'm not sure

Who greeted you at the hospital when you arrived? Select the one best choice. (*single response)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Nurse in Hospital
- Emergency Room Provider
- Primary Care Provider

- Midwife
- Doula
- Administrative staff
- Other (*text box)*
- I'm not sure

When you arrived at the hospital, did hospital staff give you information about your diagnosis and what to expect? (*single response)*

- Yes *(skip logic)*
- No
- Not applicable, I did not have a diagnosis yet
- I'm not sure

(*If Yes)* What type of information were you given? Check all that apply. (*multiple response)*

- Shared information verbally
- Brochure or pamphlet
- Referred to a website
    - *(if selected)* Which website? (*text field*)
- Other (*text box*)
- I'm not sure

(If Yes) Did you feel satisfied with the information that you were given at that time? (*single response)*

- Yes
- No *(skip logic)*
- I'm not sure

(If No) Please specify why. *(text box)*

Insert looping back for another hospital/transfer here

What were some steps taken to address your mental/emotional well-being **during your hospitalization**? Check all that apply OR Not Applicable. (*multiple responses)*

- Took anti-depressant or anti-anxiety medication
- Spent time with a counselor/therapist/social worker/chaplain
- Sought support from a faith-based community
- Got support via an online community
- Participated in a support group
- Sought support from friends and family
- Got support or information from my healthcare provider
- Nothing, experienced it privately *(If selected, should not be able to select any other options)*
- Other (please specify) *text box*
- Not applicable – I did not have any mental/emotional needs *(If selected, should not be able to select any other options)*

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Form 10

The following questions are about your pregnancy in *mm/yyyy*.

Delivery & Decision-Making

Please answer the following questions for the hospital where you delivered.

How soon after you were admitted did you deliver? Select the one best choice. *(single response)*

- Delivered within 12 hours
- Delivered between 13 and 48 hours
- Delivered after 48 hours
- Other (*text box*)
- I'm not sure

Did your healthcare provider indicate why delivery was necessary? (*single responses)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) Please specify why delivery was necessary. Check all that apply. *(multiple response)*

- I was in labor
- My baby was in distress or danger
- My baby had died
- I was in immediate danger
- Other (text)
- I'm not sure

Did you feel that you were adequately involved in making decisions about your care? (*single response)*

- Yes
- No *(skip logic)*
- I'm Not Sure

(If No) Please share why. Check all that apply. (*multiple response)*

- I was unconscious or in a coma
- I was "out of it"; or in and out of consciousness
- I did not understand what was happening
- There was no time before delivery
- I did not want to be involved
- My family was involved instead of me
- Inadequate communications from healthcare provider(s)
- Other (please specify) *(text box)*

Which healthcare providers were involved in your healthcare decisions? Check all that apply. (*multiple response)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Nurse in Clinic or Outpatient

- Nurse in Hospital
- Emergency Room Provider
- Primary Care Provider
- Midwife
- Doula
- Other (*text box*)
- I'm not sure

Were others (such as family or friends) involved in your healthcare decisions? (*single response)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) Please specify who else was involved. (*multiple responses)*

- Spouse/Partner
- Family
- Friends
- Legal representative
- Other *(text box)*

Were you aware of the Preeclampsia Foundation during **this** preeclampsia experience, and the educational resources it provides? (*single responses)*

- Yes *(skip logic)*
- No, I don't think it existed at the time
- No, but I found it later
- No
- I'm not sure

(If Yes or "No, but later") How did you become aware of it? Select the one best choice. *(single response)*

- From an online search engine (e.g. Google)
- On a pregnancy website or mobile app
- Through a friend or family member
- In a magazine or print newspaper
- On TV
- On another type of website
- From a brochure or pamphlet
- From my healthcare provider
- Other *(text box)*
- I'm not sure

Did you have postpartum preeclampsia?

Yes, my preeclampsia continued after delivery
Yes, I had new onset preeclampsia after delivery
No
I don't know

Is there anything else about your treatment or delivery that these questions have not covered that you believe is important or you would like us to know? (open text)

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Form 11

Skip this form if Yes, new onset of preeclampsia after delivery
The following questions are about your pregnancy in *mm/yyyy*.

Health Updates After Delivery

The following questions address the communications you had with your healthcare providers, not your perceptions about the quality of care they delivered.

Did you receive updates about how you and/or your baby were doing after delivery? (*single response)*

- Yes *(skip logic)*
- No
- Not applicable
- I'm not sure

(If Yes) How frequently did you receive updates about how you and/or your baby were doing? Select the one best choice.
(single responses)

- Once a day
- A few times a day
- Hourly
- Other (*text box*)
- I'm not sure

(If Yes) Who provided you with these updates? Check all that apply. (*multiple responses)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Neonatologist
- OB Nurse
- NICU Nurse
- Emergency Room Provider
- Primary Care Provider
- Midwife
- Doula
- Other (*text box*)
- I'm not sure (*Only single response if this is selected)*

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Form 12

The following questions are about your pregnancy in *mm/yyyy*.

Going Home

The following questions should be answered based on leaving from your final hospital.

When it was time to go home, who spoke to you about your discharge from the hospital? Check all that apply. (*multiple response)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Nurse in Hospital
- Primary Care Provider
- Midwife
- Doula
- Administrative Staff
- Other (*text box*)
- I'm not sure (*Only single response if this is selected)*

Were you provided with any information about preeclampsia before being sent home? *(single response)*

- Yes
- No
- I'm not sure

If Yes, Please explain: *textbox*

Were you instructed to follow up with your healthcare provider regarding your diagnosis of preeclampsia? (*single response)*

- Yes
- No
- I'm not sure
- Not Applicable

Did anyone speak to you about the potential long-term health consequences as a result of preeclampsia? (*single response)*

- Yes, at discharge *(skip logic)*
- Yes, but at a later appointment *(skip logic)*
- No
- I'm not sure

(If Yes) Who spoke with you about the potential long-term health consequences? Check all that apply. *(multiple response)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Nurse in Clinic or Outpatient
- Nurse in Hospital
- Emergency Room Provider
- Primary Care Provider
- Midwife
- Doula
- I'm not sure *(only single response if selected)*
- Other (*text box*)

(If Yes) What information was relayed to you about the potential long-term health consequences? *Text box*

What degree of mental or emotional impact did this experience have on you? Select the one best choice. *(single response)*

- No Impact
- Minimal Impact
- Some Impact
- Serious Impact

What were some steps taken to address your mental/emotional well-being **after you went home**? Check all that apply OR Not Applicable. *(multiple responses)*

- Took anti-depressant or anti-anxiety medication
- Spent time with a counselor/therapist/social worker/chaplain
- Sought support from a faith-based community
- Got support via an online community
- Participated in a support group
- Sought support from friends and family
- Spent time with a healthcare provider learning about preeclampsia
- Nothing, experienced it privately *(single response if selected)*
- Not applicable – I did not have any mental/emotional needs *(single response if selected)*
- Other (please specify) *text box*

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Form 13

Planning for Future Pregnancies
The following questions are about your pregnancy in *mm/yyyy*.

Did your experience with this pregnancy influence your decision to become pregnant again? *(single response)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) Please specify how. Check all that apply. *(multiple response)*

- I wanted more children but decided not to have another pregnancy
- I am considering (or already pursued) adoption
- I am considering (or already pursued) surrogacy
- I will seek (or already sought) preconception counseling by a high risk pregnancy specialist
- If I get pregnant I will be seen by a specialist at that point
- With time my perspective on this question has changed
- Other *(text)*

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Form 14

Would you like to complete this questionnaire for another pregnancy in which you experienced preeclampsia or other hypertensive disorder of pregnancy (for example preeclampsia, HELLP, eclampsia)? You would **not** need to complete it all at one time.

- Yes *(If yes, go to subsequent pregnancy form)*
- No, I do not have any other affected pregnancies, or I wish to stop. *(If no, go to Form 15)*

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Looping Ends

Form 15

In addition to what you've shared so far, is there anything you would like to add about your experiences with preeclampsia? *(text) (include a view of general TPR question field question S1)*

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Conclusion

Thank you for contributing valuable and important information to The Preeclampsia Registry.

Supplemental Table 1: Univariate associations between patient characteristics and outcomes

A. Heard of preeclampsia before first diagnosis	*OR*	*95% CI*	*p-value*
Maternal age (years)			
<25	0.40	0.25-0.66	<0.001
25-29	ref		
30-34	1.73	1.16-2.57	0.007
≥35	1.48	0.93-2.36	0.098
Year of delivery			
Before 2011	0.25	0.15-0.41	<0.001
2011-2013	0.61	0.36-1.03	0.064
2014-2016	0.66	0.41-1.06	0.088
From 2017 onwards	ref		
Highest level of education completed			
High school or less and technical/vocational school	0.33	0.20-0.55	<0.001
Some college	0.67	0.42-1.06	0.086
College	ref		
Graduate school	2.13	1.42-3.19	<0.001
Multiparity	1.39	0.78-2.67	0.262

B. Serious mental/emotional impact	*OR*	*95% CI*	*p-value*
Maternal age (years)			
<25	0.92	0.58-1.48	0.740
25-29	ref		
30-34	1.09	0.78-1.51	0.620
≥35	1.41	0.95-2.09	0.089
Year of delivery			
Before 2011	0.67	0.45-1.01	0.055
2011-2013	0.49	0.32-0.75	0.001
2014-2016	0.81	0.56-1.17	0.257
From 2017 onwards	ref		
Multiparity	1.10	0.70-1.75	0.677
Perinatal loss	3.97	2.36-6.68	<0.001
Cesarean section	1.09	0.82-1.45	0.565
Maternal ICU-stay	1.60	1.12-2.28	0.009
Baby admitted to the NICU	1.82	1.36-2.43	<0.001
Gestational age at delivery (weeks+days)			
<28+0	3.11	1.91-5.05	<0.001
28+0 - 31+6	1.74	1.13-2.68	0.013
32+0 - 36+6	1.30	0.94-1.80	0.112
≥37+0	ref		
Not involved in making decisions	2.20	1.58-3.07	<0.001
Not aware of preeclampsia before diagnosis	1.52	1.10-2.08	0.010
Not aware of the symptoms of preeclampsia before diagnosis	1.26	0.95-1.67	0.109
Healthcare provider did not convey the seriousness of the condition	1.50	1.11-2.02	0.008

C. Family planning: wanted more children but decided not to have another pregnancy	*OR*	*95% CI*	*p-value*
Maternal age (years)			
<25	0.55	0.29-1.06	0.075
25-29	ref		
30-34	0.97	0.65-1.44	0.868
≥35	1.63	1.05-2.53	0.031
Multiparity	2.14	1.31-3.49	0.002
Gestational age at delivery (weeks+days)			
<28+0	1.08	0.62-1.90	0.784
28+0 - 31+6	1.45	0.88-2.39	0.148
32+0 - 36+6	1.26	0.85-1.86	0.247
≥37+0	ref		
Perinatal loss	0.32	0.15-0.68	0.003
No counseling about the risk of preeclampsia in future pregnancies	1.20	0.85-1.69	0.296
No counseling about later-life health risks	1.27	0.82-1.97	0.286
Maternal ICU-stay	1.24	0.83-1.86	0.293
Baby admitted to the NICU	1.34	0.95-1.90	0.094

Results are from univariate logistic regression analysis. OR=Odds Ratio; 95% CI=95% confidence interval; ICU=intensive care unit; NICU=neonatal intensive care unit

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5-6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5-7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5-7
Bias	9	Describe any efforts to address potential sources of bias	7
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7
		(*b*) Describe any methods used to examine subgroups and interactions	7
		(*c*) Explain how missing data were addressed	7
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	NA
		(*e*) Describe any sensitivity analyses	NA
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	8
		(b) Give reasons for non-participation at each stage	8
		(c) Consider use of a flow diagram	Included
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	8-12
		(b) Indicate number of participants with missing data for each variable of interest	Table 1-3
Outcome data	15*	Report numbers of outcome events or summary measures	8-12
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	8-12
		(*b*) Report category boundaries when continuous variables were categorized	6-7, 8-12
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	11
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	11-12
Discussion			
Key results	18	Summarise key results with reference to study objectives	12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	12-16
Generalisability	21	Discuss the generalisability (external validity) of the study results	12-16
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	17

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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The patient journey during and after a preeclampsia-complicated pregnancy: a cross-sectional patient registry study

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Abstract

Objectives: To gain insight into the patient journey through a preeclampsia-complicated pregnancy

Design: Cross-sectional patient registry study

Setting: Online patient registry initiated by the Preeclampsia Foundation

Participants: Women with a history of preeclampsia enrolled in The Preeclampsia Registry™ (TPR)

Primary and secondary outcome measures: Retrospective patient-reported experience measures concerning awareness of preeclampsia, timing and type of information on preeclampsia received, involvement in decision-making regarding medical care, mental/emotional impact of the preeclampsia-complicated pregnancy, and impact on future pregnancy planning.

Results: Of 3,618 TPR-participants invited to complete the Patient Journey questionnaire, data from 833 (23%) responders were available for analysis. Most responders were white (n=795, 95.4%) and lived in the United States (n=728, 87.4%). Before their preeclampsia diagnosis, 599 (73.9%) responders were aware of the term "preeclampsia", but only 348 (43.7%) were aware of its associated symptoms. Women with a lower level of education were less likely to have heard of preeclampsia (OR 0.36, 95% CI 0.21-0.62). Around the time of diagnosis, 29.2% of responders did not feel involved in the decision-making, which was associated with reporting a serious mental/emotional impact of the preeclampsia experience (OR 2.46, 95% CI 1.58-3.84). Over time, there was an increase in the proportion of women who were aware of the symptoms of preeclampsia (32.2% before 2011 to 52.5% after 2016; p-value <0.001) and in the proportion of responders stating they received counseling about the later-life health risks associated with preeclampsia (14.2% before 2011 to 25.6% after 2016; p-value 0.005).

Conclusions: This study demonstrates that improved patient education regarding preeclampsia is needed, that shared decision-making is of great importance to patients to enhance their healthcare experience, and that healthcare providers should make efforts to routinely incorporate counseling about the later-life health risks associated with preeclampsia.

Trial registration: https://clinicaltrials.gov/ct2/show/NCT02020174

Strengths and limitations of this study

Strengths

- A structured questionnaire framework was used to assess three important domains along four critical time points during the preeclampsia experience.
- Comprehensive data collection allowed for detailed interpretation of patient responses considering relevant demographic and clinical characteristics.
- Temporal differences in responses were evaluated to reflect changes in patient and provider knowledge and awareness of preeclampsia.

Limitations

- The Preeclampsia Registry™ is enriched for severe disease, thus experiences may not be generalizable to patients with clinically milder forms of preeclampsia.
- There is inadequate racial/ethnic diversity among participants enrolled in the Preeclampsia Registry™, limiting generalizability.

Introduction

Preeclampsia complicates 3-5% of pregnancies, resulting in approximately 150,000 cases per year in the United States alone.[1 2] Preeclampsia often occurs unexpectedly, develops rapidly, and has immediate high acuity impact on both mother and fetus, requiring fast and complex medical decision-making. Patients with preeclampsia often report chronic physical complaints after childbirth (e.g. headache, visual disturbances, tiredness) and are at increased risk for future cardiovascular disease and diabetes.[3-5] Feelings of guilt, shame, lack of control, and symptoms of post-traumatic stress disorder are reported more often by preeclampsia survivors compared to women with uncomplicated pregnancies.[6-8] Preeclampsia survivors also report a poorer health-related quality of life.[9]

Health-related quality of life includes a patient's physical, emotional, and social wellbeing in relation to a medical condition or treatment and is not just a reflection of medical outcomes (e.g. morbidity), but also incorporates the subjective patient experience (e.g. energy level and mood).[10] While patient-centered care focuses on optimizing individual patient-provider communication, even broader impact can be gained by incorporating the patient voice to identify gaps in patient knowledge and patient/provider communication that can be targeted through research and education.[11-13]

By evaluating a patient's journey through a critical health experience, processes worthy of amplifying and areas in need of modifications can be identified so as to improve not only the patient experience, but also the quality of the care provided.[14 15] Recently, a study in which patients completed a questionnaire specific to well-known concerns regarding pregnancy and childbirth prior to a visit with their provider, found that this tool resulted in improved shared decision-making and more personalized care.[16] Given the varied clinical environments in which care for preeclampsia is provided, a comprehensive appraisal of the patient experience is imperative to identify common underlying elements that can be addressed to optimize the immediate and ongoing care of women with this condition. This may allow for a more proactive assessment and addressing of patients' concerns surrounding their preeclampsia diagnosis.

The objective of this study was to ascertain and describe the patient journey in the setting of preeclampsia from the patient's point of view using a structured framework. We hypothesize that a review of patient reported experiences through their journey in a preeclampsia-complicated pregnancy will be instructive to aspects of the care provided before, during, and after this critical obstetric complication. Knowledge regarding baseline awareness of preeclampsia, frequency of provider counseling about preeclampsia before a diagnosis is established, perceived shared-decision making, reproductive planning, long-term implications, and education regarding later-life complications, has the potential to serve as a guide to implement patient-centered care.

Methods

Study population

Participants already enrolled in The Preeclampsia Registry (TPR) (https://clinicaltrials.gov/ct2/show/NCT02020174) who experienced a pregnancy complicated by a hypertensive disorder of pregnancy (HDP) (n=3,618), were invited by email to participate in the Patient Journey Survey to retrospectively assess the patient journey (from before diagnosis, through management and delivery, and to the post-delivery period) of that pregnancy. The questionnaire was first offered January 2016, and data for this study was retrieved up to 24 November 2020. The questionnaire was only available for women who were not currently pregnant since this may initiate reporting bias.

We included participants who self-reported a history of at least one pregnancy complicated by the HDP of: preeclampsia, HELLP (hemolysis, elevated liver enzymes, low platelets) syndrome, eclampsia, or preeclampsia superimposed on chronic hypertension. Previous research using TPR data confirmed self-reported HDP diagnoses in 97.7% after validation with medical records in a random sample of over 200 TPR participants.[17] Although we use the term 'preeclampsia' throughout this manuscript, as this was used in the survey given its familiarity with participants, it is intended to include the four abovementioned HDPs. If a HDP recurred in subsequent pregnancies, only responses

from the first HDP pregnancy were included. We excluded Patient Journey Survey responses from pregnancies with a multifetal gestation and pregnancies with gestational hypertension as the reported HDP (Figure 1).

Ethics Approval

The study protocol regarding the Patient Journey was exempted from IRB approval by Chesapeake IRB (now Advarra Institutional Review Board) (Protocol number Pro00015703). The study protocol regarding TPR was approved by Chesapeake IRB (now Advarra Institutional Review Board) (Pro00008369). All participants provided written informed consent at enrollment with TPR through an online process.

Data collection

Baseline participant characteristics, medical history, and pregnancy and delivery outcomes, including year of delivery, were collected upon initial enrollment in TPR.

The Patient Journey Survey was created to be at a 8th grade reading level using Flesch-Kincaid grade scoring.[18] The survey was chronologically structured to retrospectively query participants about their experience at critical time points along the preeclampsia course to systematically appraise the patient perspective (questionnaire in Supplemental material). The questions included in the questionnaire were chosen by members of TPR's Scientific Advisory Council with the inclusion of two patient representatives. The questionnaire was then tested by members of the Patient Advisory Council and revised based on input such as relevance and clarity of questions. Questions were crafted to assess baseline awareness of preeclampsia, when and what type of information about the diagnosis was provided, counseling around preeclampsia management, with a targeted focus on shared decision-making, post-delivery management, communication, and future reproductive intentions in light of this experience. Participants answered questions organized into three domains: knowledge/awareness, satisfaction, and emotional impact. To capture their experience, we

categorized the data into four distinct and relevant time points: before preeclampsia diagnosis, at the time of diagnosis and subsequent management, the immediate postpartum period, and the long-term postpartum period. To account for possible temporal changes in practice patterns, we evaluated differences in responses over time by year of delivery: prior to 2011, 2011-2013, 2014-2016, and from 2017 onwards. Since the American Heart Association published their guideline with recognition of preeclampsia as a major risk factor for future cardiovascular disease in 2011, 2011 was used as a break point.[19]

Statistical analysis

Baseline characteristics and outcomes were expressed as number (percentage for total of given answers) and median (interquartile range, IQR). Trends over time by year of delivery were visualized in bar charts and evaluated by linear-by-linear association. We performed univariate logistic regression analysis and multivariate logistic regression analysis with backward selection ($p<0.15$) to relate patient characteristics to the probability of the following outcomes: preeclampsia awareness before diagnosis, serious mental/emotional impact of experiencing preeclampsia, and reproductive planning. Guided by the available literature and reasonable assumptions, we selected the following comprehensive list of covariates for inclusion into our analyses: maternal age (<25 years, 25-30 years, 30-35 years, >35 years), year of delivery (<2011, 2011-2013, 2014-2016, ≥2017), educational level (high school or less and/or technical/vocational school, some college, college, graduate school), parity (1, >1), perinatal loss (yes/no), cesarean delivery (yes/no), maternal intensive care unit (ICU) admission (yes/no), neonatal intensive care unit (NICU) admission (yes/no), and gestational age at delivery (<28+0 weeks, 28+0-31+6 weeks, 32+0-36+6 weeks, ≥37+0 weeks). For analyses pertaining to emotional impact and future reproductive planning, we also considered participants' reported involvement in decision-making (yes/no), preeclampsia awareness (yes/no), knowledge of preeclampsia symptoms (yes/no), whether they reported if the healthcare provider conveyed the

seriousness of the condition (yes/no), counseling about preeclampsia recurrence (yes/no), and counseling about long term health risks (yes/no).

Statistical analyses were performed using SPSS 25.0; p-values <0.05 were considered statistically significant. The number of missing values is reported per variable. Unaltered quotes from free text field answers are included as an adjunct to illustrate the results; no thematic analysis was performed.

Patient and public involvement statement

The Preeclampsia Foundation, established in 2000, is a U.S.-based not-for-profit patient advocacy organization with a key goal of catalyzing research. It established TPR in 2013 to build a resource of data and samples intended to support this goal, and key to TPR was governance by a Patient Advisory Council (PAC) in partnership with other stakeholders. Each member of the PAC is a preeclampsia survivor or a family member of a woman who suffered death or disability as the result of preeclampsia and are chosen through an application and screening process that ensures demographic, geographic, and experiential diversity. Individuals are recruited online to TPR through social media, web searches, and emailed invitations. In some instances, healthcare providers direct eligible patients to the registry. Any questionnaire provided to registry participants is reviewed by the Scientific Advisory Council in consultation with PAC, thereby anchoring patient involvement in the design of this study. A patient representative was involved in the rationale and design of this study, helped with interpretation of the results, and co-authored this manuscript (NAK). Results of this study will also be disseminated by the Preeclampsia Foundation to the PAC and all stakeholders, making the results available to all relevant parties.

Results

Of 3,618 TPR participants, 1,154 (32%) initially responded to the Patient Journey Survey. After exclusion of women without self-reported HDP, multiple gestation pregnancies, and incomplete

surveys, questionnaire results were available from 833 (23%) women, from here on referred to in this paper as "responders" (Figure 1). Non-responders were more often younger, non-US residents, non-white , had a lower family income and educational level, and more often delivered before 2011 (Table 1).

Of the responders, median maternal age at delivery was 30 years (IQR 27-33 years), 795 (95.4%) reported being of white race, 728 (87.4%) lived in the United States, and 753 (90.4%) were nulliparous at the time of their preeclampsia pregnancy. Cesarean delivery rates were high (542, 65.6%) and 456 infants required NICU admission (58.6%). Perinatal loss, defined as stillbirth, termination of pregnancy, or neonatal/infant demise, occurred in 87 (10.4%) cases (Table 1). The median interval between delivery and Patient Journey Survey completion was 2.6 years (IQR 1.1-6.2 years).

Patient experience

Before preeclampsia diagnosis

Before diagnosis, 73.9% of responders reported being aware of the term "preeclampsia", however, only 43.7% were aware of associated symptoms. Symptoms were present in 90.9% before diagnosis and 30.6% of these individuals waited more than 6 days before contacting a healthcare provider. If they had known more about the symptoms, 85.4% indicated they would have acted otherwise, of whom 71.5% would have sought care sooner (Table 2A).

"I wish I had known what to look for. Looking back on it now, I was symptomatic for weeks."

[24 years old, delivered at 23 weeks]

At preeclampsia diagnosis and subsequent management

A little over one-half of responders (58.6%) reported that the first time a healthcare professional provided any information about preeclampsia was at the moment they were diagnosed. Of the responders who received information about preeclampsia at any time, 50.2% were dissatisfied with

the information provided. 698 (84.9%) responders reported independently researching additional information about preeclampsia, mostly on the internet. Of all responders, 38.1% felt that their healthcare provider did not convey the seriousness of the condition. Almost a third (29.2%) reported that they did not feel involved in the medical decision-making regarding their care, which they attributed to having a poor understanding of what was happening, lack of time before delivery, and inadequate communication from the healthcare provider (Table 2B).

"I wasn't given any detailed information - perhaps I want more than what is normal, but I felt left out of my care to a degree."

[22 years old, delivered at 37 weeks]

Immediately postpartum

Only 30.7% of the responders indicated that they were provided with information about preeclampsia before being sent home and almost a third of responders (29.7%) reported not being instructed to follow-up with their healthcare provider regarding their diagnosis of preeclampsia.

Almost half of the responders (49.0%) indicated that the experience of having preeclampsia seriously impacted their mental/emotional well-being, with the vast majority reporting a negative impact (70.3%). Additionally, 49.3% reported symptoms of postpartum depression after this pregnancy, and 17.3% reported being diagnosed with postpartum depression (Table 2C).

"I felt robbed of what should have been such an amazing experience."

[39 years old, delivered at 40 weeks]

Long-term postpartum

With respect to long-term management, 36.6% of responders reported not being counseled about preeclampsia recurrence risk and 79.1% indicated that they did not receive any counseling regarding later-life health risks associated with preeclampsia. For 626 (81.3%) responders, the experience of

preeclampsia influenced their future pregnancy planning, with 24.3% deciding not to pursue another pregnancy and 13.1% considering (or had already pursued) adoption and/or surrogacy (Table 2D).

"I will have another child, but I have this fear of dying."

[31 years old, delivered at 38 weeks]

Differences in responses over time

A sequential increase in the proportion of positive responses over time was observed across critical parameters (Figure 2A-D). Of responders who delivered before 2011, only 32.2% reported being aware of the symptoms of preeclampsia before diagnosis, which increased to 52.5% in those who delivered after 2016 (Figure 2A, p<0.001). Of the responders who delivered before 2011, 60.5% felt involved in the decision-making about their care, which increased to 77.1% after 2016 (Figure 2B, p<0.001). Also, an increase was seen in the percentage who reported receiving instructions to follow up with their healthcare provider regarding their diagnosis of preeclampsia: from 52.1% in the period before 2011 to 85.0% after 2016 (Figure 2C, p<0.001). A small, but still significant, increase was observed in the proportion of responders indicating that they were counseled about the later-life health risks associated with preeclampsia (14.2% before 2011 to 25.6% after 2016) (Figure 2D, p=0.005). No significant interaction was observed between year of delivery and the interval between delivery and survey completion.

Associations between patient characteristics and outcomes

Results of univariate logistic regression analysis are reported in Supplemental Table 1 and the results of the multivariate analysis are reported in Table 3. Responders who delivered before 2011 and those with only high school or vocational training were less likely to have been aware of preeclampsia before their diagnosis compared to responders who delivered after 2016 (OR 0.28, 95% CI 0.17-0.47) and those with college level education (OR 0.36, 95% CI 0.21-0.62), respectively. Graduate level education

was associated with a higher likelihood of being aware of preeclampsia (OR 2.05, 95% C 1.35-3.11) (Table 3A).

Perinatal loss (OR 8.26, 95% CI 3.06-22.38), NICU admission (OR 1.81, 95% CI 1.19-2.76), and not feeling involved in the decision-making about their care (OR 2.46, 95% CI 1.58-3.84) were all independently associated with the preeclampsia experience having a serious impact on the responders' mental/emotional well-being (Table 3B).

Responders over the age of 35 years at delivery (OR 1.72, 95% CI 1.02-2.89; reference group 25-30 years) and who were multiparous (OR 1.80, 95% CI 1.02-3.18) were more likely to decide not to pursue another pregnancy. Conversely, responders who experienced perinatal loss were less likely to avoid future pregnancies (OR 0.20, 95% CI 0.06-0.64) (Table 3C).

Discussion

Main findings

In this study of women with a history of preeclampsia, we describe the patient journey before, during and after diagnosis. In our study population, knowledge about preeclampsia improved over time, but still more than half of the responders were unaware of the associated symptoms before diagnosis. Experiencing preeclampsia had a notable mental/emotional impact and women who did not feel involved in medical decision-making were twice as likely to report a serious negative impact. Moreover, a quarter of the responders desired more children, but elected not to pursue another pregnancy due to the preeclampsia experience. Most responders were instructed to follow up with their healthcare provider regarding preeclampsia after discharge, however, counseling about related future health risks was reported in only a quarter of the population, despite the evidence supporting an increase in risk for cardiovascular disease in women with prior preeclampsia.[4 20] Although several assessed parameters had more positive responses with more recent deliveries, results from this study demonstrate concrete areas for improved patient-provider communication.

Comparison with literature

The perceived lack of knowledge regarding the symptoms associated with preeclampsia is in accordance with other, smaller studies.[21 22] Approximately 85% of responders in our study indicated that they would have acted differently and, for example, sought medical care earlier, had they known more about preeclampsia, highlighting the importance of better patient education. We also found that patient-specific characteristics, such as education level, influenced the likelihood of having heard of preeclampsia and its symptoms. Given that easily-accessible and reliable tools to predict preeclampsia, especially in nulliparous women, remain elusive[23], education regarding preeclampsia should be provided to all obstetric patients and the development of education tools should take these patient level factors into consideration.

Our finding of a significant association between not feeling involved in the medical decision-making and experiencing a more serious mental/emotional impact from the preeclampsia-complicated pregnancy is in line with the principles of patient-centered health care.[11] Indeed, patient reported outcomes are substantively important in judging the quality of care, along with purely medical outcomes. As new preeclampsia diagnosis may require urgent action and, therefore, comprehensive involvement of the patient in shared-decision making may not always be feasible. This potential constraint, however, underscores the need for rigorous and effective communication. Importantly, inadequate communication was one of the most commonly mentioned reasons for not feeling involved in obstetrical care (40.6%). This lack of effective communication during a stressful event may contribute to feelings of being unprepared, adding to a lingering dissatisfaction conveyed by the women included in our study, even several years after the HDP pregnancy. Shared decision-making is positively associated with patient-satisfaction[24], and our results suggest that effective communication by the health care team can crucially augment the patient experience with a preeclampsia pregnancy.

In 2011, the American Heart Association (AHA) recognized preeclampsia as a major risk factor for future cardiovascular disease, recommending an annual cardio-metabolic assessment.[19 25 26] Despite these recommendations, only 25.6% of women in our study who delivered after 2011 were counseled about these long-term risks. A German study from 2013 found that, although the majority of obstetricians were aware of the higher risk of cardiovascular disease after preeclampsia, knowledge of current guidelines among these physicians was low, suggesting that improved evidence-based counseling is needed in geographically diverse locations.[27] Previous research showed that, even when obstetricians are aware of the long term effects of preeclampsia, they often do not take action on management to reduce risk.[28] Most women in our cohort were instructed to follow up with their healthcare provider regarding their HDP diagnosis, suggesting that most providers are aware of the possibility for postpartum complications, but they may not have appropriate guidance regarding who is responsible for the long-term counseling and the optimal timing to inform women of these specific risks. To meet these needs, individual healthcare systems should develop evidence-based care pathways and processes for transition of care that are in line with the local health care landscape.

Strengths and limitations

We used a large patient cohort with structured and comprehensive data collection, allowing for detailed interpretation of patient responses in light of relevant demographic and clinical characteristics. Our ability to incorporate temporal differences in responses is also important given the rapidly changing landscape of preeclampsia research and awareness. Importantly, patient involvement at the time of study design allowed for appropriate centering of the core concepts of the survey and for them to be in line with relevant metrics. Self-report of the diagnosis of preeclampsia was proven to be very accurate, since prior work through TPR has confirmed excellent concordance between patient-reported diagnoses and those confirmed by medical record review.[17] Since TPR is an initiative by the Preeclampsia Foundation, patient involvement in TPR design and data use is the basis of TPR and this paper.

Our study is not without limitations. First, given the relatively low response rate, selection bias and lack of representation are a concern as almost all women in our study were non-Hispanic white and highly educated. At 18.5%, Hispanic individuals make up the largest minority in the United States, but only 6% of responders self-identified as Hispanic in our study.[29] TPR and the Patient Journey Survey are not available in Spanish, possibly contributing to this lack of representation. Significant differences between responders and non-responders (i.e. age, country of residence, racial background, family income, and educational level) were observed, thus limiting incorporation of experiences across populations. Further evaluation of the specific experience of adolescent women (under 20 years of age) was not feasible in our cohort, since only 11.7% of responders were under 25 years of age and, of those, only 12 (1.4%) were under the age of 20 years. Other patient characteristics, such as living in a rural area, living under financial stress or experiencing intimate partner violence, may also impact the patient journey during and after preeclampsia. These factors should be addressed in future studies evaluating the social context of experiencing pregnancy complications. Also, whether a family history of preeclampsia impacts the patient experience, remains to be explored. The relatively low response rate that may have impacted the lack of representation of all population groups, could be due to the degree of literacy that is necessary to fill out the survey. For further research on this topic, the survey should be evaluated, and potentially re-phrased, at a lower level of literacy. Additionally, TPR is notably enriched for severe disease, as indicated by 12.2% of responders who delivered before 28 weeks gestation and 10.4% of responders who experienced perinatal loss. Thus, the experiences of included participants may not be generalizable to patients with clinically milder forms of preeclampsia.

Second, recall bias may have influenced results given the interval from delivery to survey completion (median 2.6 years). As such, for virtually all questions, 'I don't know' or 'I'm not sure' were included as answer options. Literature, however, suggests that emotionally stirring life events are unlikely to be forgotten and that the memory of these events is accurate.[30 31]

Conclusion and future perspectives

By providing a comprehensive insight into the patient journey before, during, and after a preeclampsia pregnancy, this study adds to a growing body of literature establishing the importance of a patient-centered approach to healthcare. In our study population of women with a prior preeclampsia pregnancy, a large proportion reported being unaware of this condition and its associated symptoms prior to diagnosis and many indicated not feeling involved in the decision-making regarding their care. In turn, they noted that their preeclampsia experience had a serious negative impact on their mental/emotional wellbeing and influenced their future pregnancy planning. Counseling regarding the long-term health risks associated with preeclampsia was reported to occur infrequently. This systematic assessment of the patient perspective through a preeclampsia-complicated pregnancy provides invaluable insights to catalyze enhanced education, communication and counseling for this common obstetric complication associated with significant morbidity. Also, our results emphasize the importance of addressing mental health in women who experience preeclampsia. Future research should be replicated in a more diverse population. Such knowledge can help develop targeted tools for improving the experienced patient journey and augmenting preeclampsia knowledge based on community level characteristics. Counseling regarding postpartum complications and follow-up clearly needs to be initiated by obstetric providers. Mechanisms to support ongoing counseling and management of this population at risk for long-term morbidity are best established at the local level, however, blueprints from successful programs in current practice can be leveraged and tailored to regional needs.[32-35]

Author contribution statement

RS, EZT, MPHK and EWS designed this study. AB collected the data. Analysis and interpretation of the data was performed by RCB, SB, RS, MPHK and EWS. RCB, SB and RS wrote the first draft of the manuscript. Critical feedback was provided by AB, NAK, EZT, MPHK and EWS. All authors contributed to reviewing and editing the manuscript.

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Competing interests statement

None declared.

Data sharing statement

Data that support the findings of this work are available upon reasonable request from the corresponding author.

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Table 1. Baseline characteristics responders and non-responders

Individual characteristics	Responders (833) *Median (IQR) / N (%)*	Non-responders (2,161) *Median (IQR) / N (%)*	p-value
Maternal age (years)	30 (27; 33)	29 (26; 33)	<0.001
<25	97 (11.7%)	393 (18.3%)	
25-29	265 (31.9%)	700 (32.6%)	
30-34	305 (36.7%)	744 (34.6%)	
≥35	163 (19.6%)	312 (14.6%)	
	Missing: 3	*Missing: 12*	
Country of residence			0.012
United States	728 (87.4%)	1,796 (83.1%)	
Other	105 (12.6%)	365 (16.9%)	
	Missing: 0	*Missing: 0*	
Race			0.001
White	795 (95.4%)	1,990 (92.1%)	
Non-white	38 (4.6%)	171 (7.9%)	
	Missing: 0	*Missing: 0*	
Ethnicity			0.281
Non-Hispanic	781 (94.0%)	1,967 (92.9%)	
Hispanic	50 (6.0%)	151 (7.1%)	
	Missing: 2	*Missing: 43*	
Totally family income per year (USD)			0.020
Less than 25.000	66 (13.2%)	264 (18.1%)	
25.000-99.999	259 (51.9%)	745 (51.2%)	
100.000-249.999	149 (29.9%)	401 (27.6%)	
250.000 or more	25 (5.0%)	45 (3.1%)	
	Missing: 334	*Missing: 706*	
Highest level of education completed			<0.001
High school or less and technical/vocational school	74 (9.0%)	277 (13%)	
Some college	117 (14.2%)	368 (17.3%)	
College	341 (41.4%)	885 (41.7%)	
Graduate school	292 (35.4%)	593 (27.9%)	
	Missing: 9	*Missing: 38*	
Marital Status			0.978
Married or in a relationship	795 (95.8%)	2,056 (95.8%)	
Divorced/single	35 (4.2%)	90 (4.2%)	
	Missing: 3	*Missing: 15*	

(Continues on next page)

Pregnancy details	*Median (IQR) / N (%)*	*Median (IQR) / N (%)*	p-value
Parity			0.622
1	753 (90.4%)	1,966 (91.0%)	
>1	80 (9.6%)	195 (9.0%)	
	Missing: 0	*Missing: 0*	
Mode of delivery			0.731
Vaginal birth	284 (34.4%)	747 (35.1%)	
Cesarean section	542 (65.6%)	1,384 (64.9%)	
	Missing: 7	*Missing: 30*	
Gestational age at delivery (weeks+days)	35+2 (32+1; 38+3)	34+5 (31+1; 37+3)	0.566
<28+0	99 (12.2%)	266 (12.6%)	
28+0 - 31+6	117 (14.4%)	334 (15.8%)	
32+0 - 36+6	306 (37.6%)	815 (38.5%)	
≥37+0	291 (35.8%)	704 (33.2%)	
	Missing: 20	*Missing: 42*	
Year of delivery			<0.001
Before 2011	187 (22.4%)	623 (28.8%)	
2011-2013	174 (20.9%)	456 (21.1%)	
2014-2016	286 (34.3%)	507 (23.5%)	
From 2017 onwards	186 (22.3%)	574 (26.6%)	
	Missing: 0	*Missing: 1*	
Pregnancy outcome			0.238
Living child	746 (89.6%)	1,931 (89.4%)	
Live birth with subsequent infant death	52 (6.2%)	119 (5.5%)	
Stillbirth(s)	33 (4.0%)	88 (4.1%)	
Miscarriage	0 (0%)	1 (0%)	
Induced pregnancy termination	2 (0.2%)	22 (1%)	
	Missing: 0	*Missing: 0*	
Birthweight child (grams)	2,359 (1,452; 3,039)	2,268 (1,406; 3,036)	0.188
	Missing=14	*Missing: 56*	
Maternal ICU-admittance	156 (19.6%)	413 (20.2%)	0.730
	Missing: 37	*Missing: 114*	
Baby admitted to the NICU	456 (58.6%)	1,208 (60.6%)	0.334
	Missing: 55	*Missing: 168*	

IQR=interquartile range; USD=United States dollars; ICU=intensive care unit; NICU=neonatal intensive care unit

Table 2. Patient Journey *(N=833)*

A. Before preeclampsia diagnosis	N(%)
Heard of preeclampsia	599 (73.9%)
Missing: 22	
Aware of the symptoms associated with preeclampsia	348 (43.7%)
Missing: 36	
Experienced any symptoms	746 (90.9%)
Missing: 12	
Symptoms length before reaching out to a healthcare provider	
<1 day	244 (37.7%)
2-5 days	206 (31.8%)
≥6 days	198 (30.6%)
Missing: 185	
Would have done anything differently if had more knowledge about symptoms	536 (85.4%)
Missing: 205	
Would have sought care sooner	383 (71.5%)

(Continues on next page)

B. At preeclampsia diagnosis and subsequent management	N(%)
Healthcare provider asked for a family history of preeclampsia	248 (39.6%)
Missing: 207	
Moment at which a healthcare provider first shared information about preeclampsia	
During or after a previous pregnancy	15 (2.0%)
During a prenatal visit for this pregnancy	258 (33.9%)
After I was diagnosed with preeclampsia in this pregnancy	356 (46.8%)
After delivery in this pregnancy	64 (8.4%)
At discharge from the hospital	3 (0.4%)
During a postpartum check-up after this pregnancy	12 (1.6%)
Sometime later	11 (1.4%)
Never	42 (5.5%)
Missing: 72	
Satisfied with the provided information	325 (49.8%)
Missing: 180	
Researched preeclampsia by themselves	698 (84.9%)
Missing: 11	
Healthcare provider conveyed the seriousness of the condition	
Yes	460 (61.9%)
No, even though it was serious	283 (38.1%)
Missing: 90	
Degree of mental or emotional impact of preeclampsia diagnosis	
No Impact	26 (3.1%)
Minimal Impact	96 (11.6%)
Some Impact	321 (38.8%)
Serious Impact	385 (46.5%)
Missing: 5	
Healthcare provider indicated why delivery was necessary	751 (93.1%)
Missing: 26	
Did not feel involved in making decisions	212 (29.2%)
Missing: 107	
Reasons why women felt not involved *(Multiple answers possible)*	
I was unconscious or in a coma	10 (4.7%)
I was "out of it''	65 (30.7%)
I did not understand what was happening	86 (40.6%)
There was no time before delivery	62 (29.2%)
I did not want to be involved	0
My family was involved instead of me	20 (9.4%)
Inadequate communications from healthcare provider(s)	86 (40.6%)
Other	28 (13.2%)

(Continues on next page)

C. Immediately postpartum	N(%)
Provided with information about preeclampsia before being sent home	220 (30.7%)
Missing: 116	
Instructed to follow up with a healthcare provider regarding preeclampsia	543 (70.3%)
Missing: 61	
Degree of mental or emotional impact	
No Impact	38 (4.6%)
Minimal Impact	76 (9.2%)
Some Impact	308 (37.2%)
Serious Impact	406 (49.0%)
Missing: 5	
Pregnancy negatively affected the emotional/psychological wellbeing	565 (70.3%)
Missing: 29	
Believed they had postpartum depression	382 (49.3%)
Missing: 58	
Officially diagnosed with postpartum depression	131 (17.3%)
Missing: 74	

D. Long-term postpartum	N(%)
Counseled about the risk of having preeclampsia in future pregnancies	505 (63.4%)
Missing: 36	
Counseled about later-life health risks associated with preeclampsia	165 (20.9%)
Missing: 43	
Preeclampsia affected relationship with family or friends	392 (54.2%)
Missing: 110	
How did preeclampsia affect the relationship with your partner?	
For the better	163 (41.6%)
For the worse	97 (24.7%)
Both for the better and worse	132 (33.7%)
Missing: 0	
Influenced decision to become pregnant again	
My decision to become pregnant again has not been influenced	144 (18.7%)
My decision to become pregnant again has been influenced	626 (81.3%)
I wanted more children but decided not to have another pregnancy	187 (24.3%)
I am considering (or already pursued) adoption and/or surrogacy	101 (13.1%)
I will seek (or already sought) preconception counseling by a high risk pregnancy specialist	246 (31.9%)
If I get pregnant I will be seen by a specialist at that point	217 (28.2%)
With time my perspective on this question has changed	150 (19.5%)
Other	143 (18.6%)
Missing: 63	

**Indentations: this question only applies when a specific answer was given to the previous question; percentages are provided for total of given answers*

Table 3. Associations between patient characteristics and outcomes

A. Heard of preeclampsia before first diagnosis	*OR*	*95% CI*	*p-value*
Year of delivery			
<2011	0.28	0.17-0.47	<0.001
2011-2013	0.64	0.37-1.11	0.111
2014-2016	0.66	0.40-1.09	0.106
≥2017	ref		
Highest level of education completed			
High school or less and technical/vocational school	0.36	0.21-0.62	<0.001
Some college	0.72	0.45-1.16	0.182
College	ref		
Graduate school	2.05	1.35-3.11	0.001
Multiparity	1.65	0.88-3.08	0.118

Covariates removed by backward selection: maternal age

B. Serious mental/emotional impact	*OR*	*95% CI*	*p-value*
Year of delivery			
<2011	0.89	0.49-1.64	0.718
2011-2013	0.54	0.29-1.02	0.056
2014-2016	1.20	0.70-2.05	0.508
≥2017	ref		
Perinatal loss	8.26	3.06-22.28	<0.001
Cesarean section	0.7	0.45-1.09	0.112
Baby admitted to the NICU	1.81	1.19-2.76	0.006
Not involved in making decisions	2.46	1.58-3.84	<0.001

Covariates removed by backward selection: gestational age, parity, maternal age, maternal intensive care admittance, healthcare provider conveyed the seriousness of the condition, aware of preeclampsia symptoms before diagnosis, heard of preeclampsia before diagnosis

C. Family planning: wanted more children but decided not to pursue another pregnancy	*OR*	*95% CI*	*p-value*
Maternal age (years)			
<25	0.57	0.27-1.19	0.134
25-29	ref		
30-34	1.07	0.68-1.68	0.773
≥35	1.72	1.02-2.89	0.040
Multiparity	1.80	1.02-3.18	0.041
Gestational age at delivery (weeks+days)			
<28+0	2.00	0.94-4.26	0.072
28+0 - 31+6	1.72	0.98-3.01	0.057
32+0 - 36+6	1.11	0.72-1.72	0.632
≥37+0	ref		
Perinatal loss	0.20	0.06-0.64	0.007

Covariates removed by backward selection: child admitted to neonatal intensive care unit, counseled about risk of experiencing preeclampsia in future pregnancies, maternal intensive care admittance

Results are from multivariate logistic regression analysis. OR=Odds Ratio; 95% CI=95% confidence interval; NICU=neonatal intensive care unit

Figures

Figure 1: Flowchart of responders Patient Journey questionnaire in the Preeclampsia Registry™.

Abbreviations: TPR=The Preeclampsia Registry; HDP=Hypertensive disorder of pregnancy, defined as preeclampsia, HELLP (hemolysis, elevated liver enzymes, low platelets) syndrome, eclampsia, or preeclampsia superimposed on chronic hypertension.

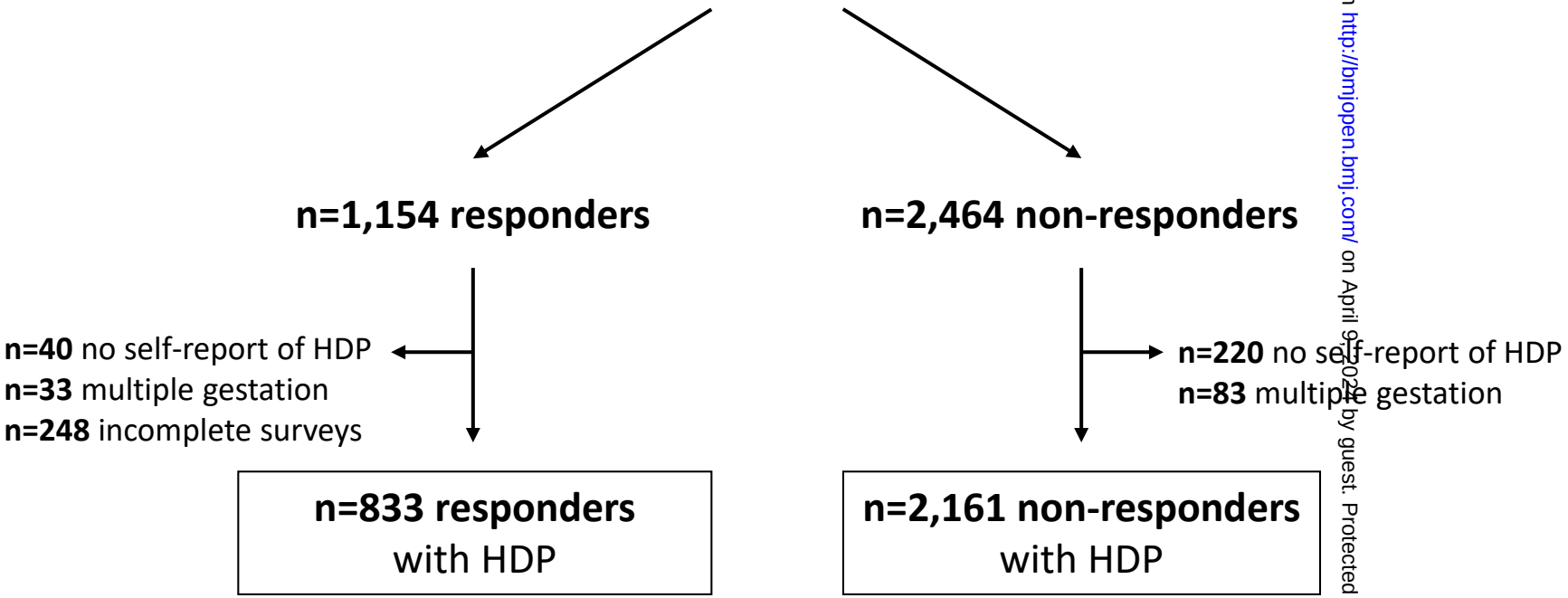
Figure 2: Differences in responses over time

A: Were you aware of the symptoms associated with preeclampsia before you were diagnosed with preeclampsia in this pregnancy?

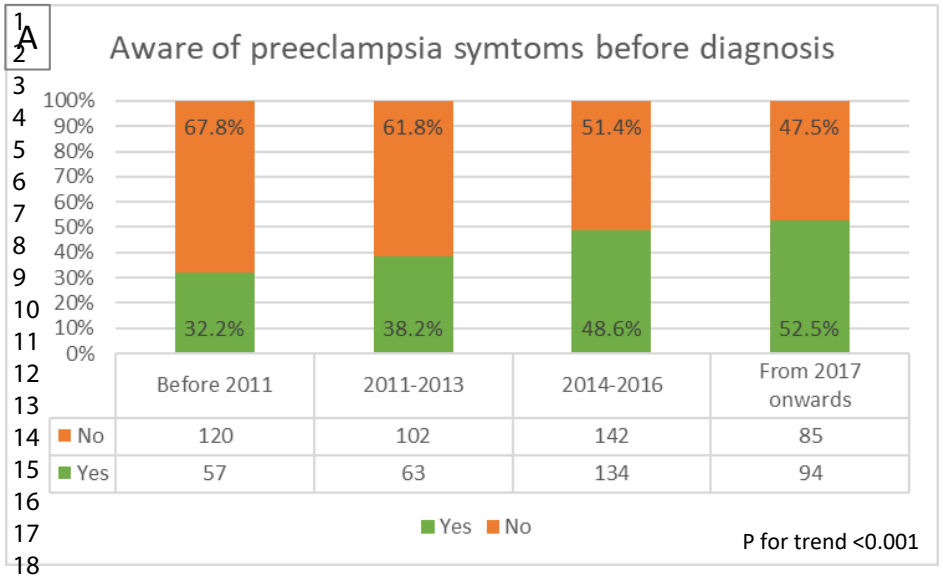
B: Did you feel that you were adequately involved in making decisions about your care?

C: Were you instructed to follow up with your healthcare provider regarding your diagnosis of preeclampsia?

D: Did anyone speak to you about the potential long-term health consequences as a result of preeclampsia?



A



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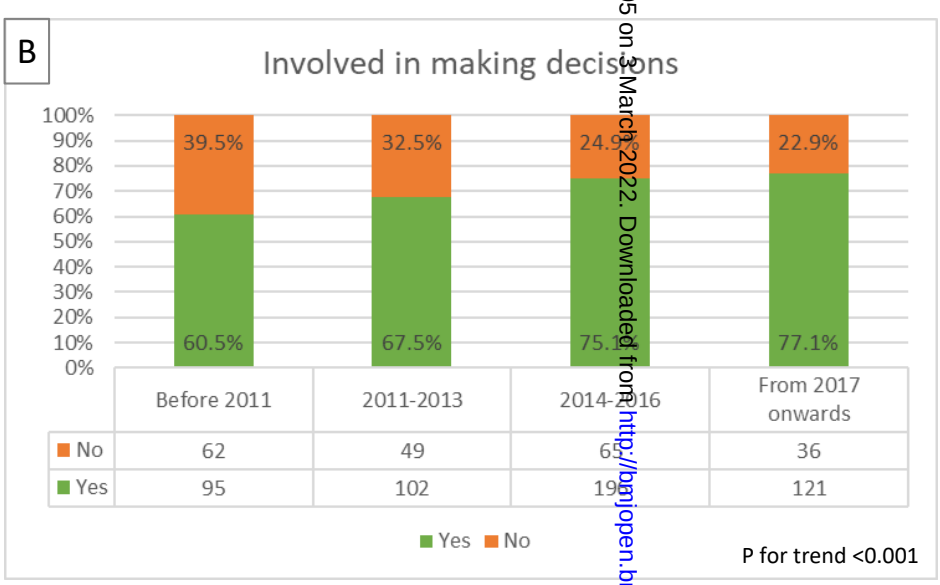

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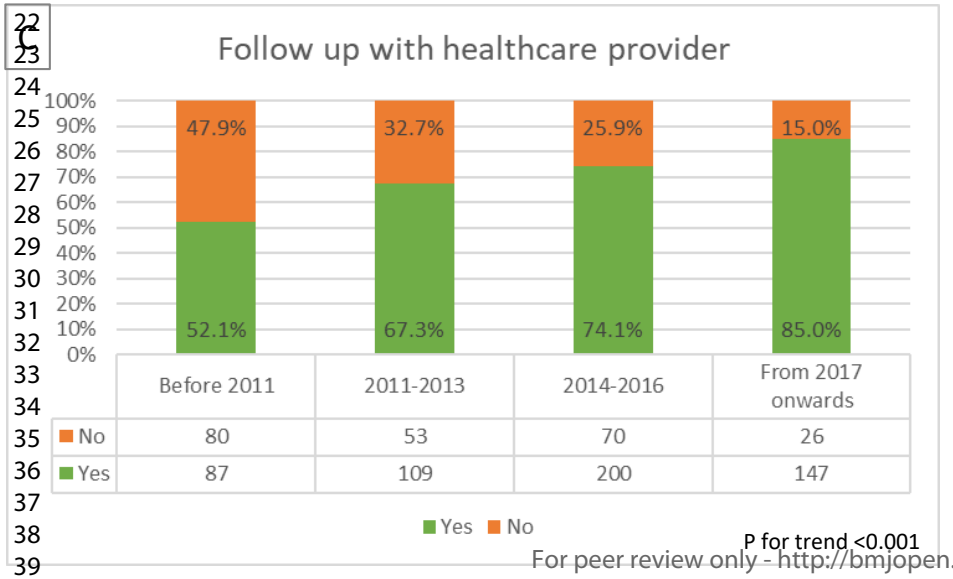

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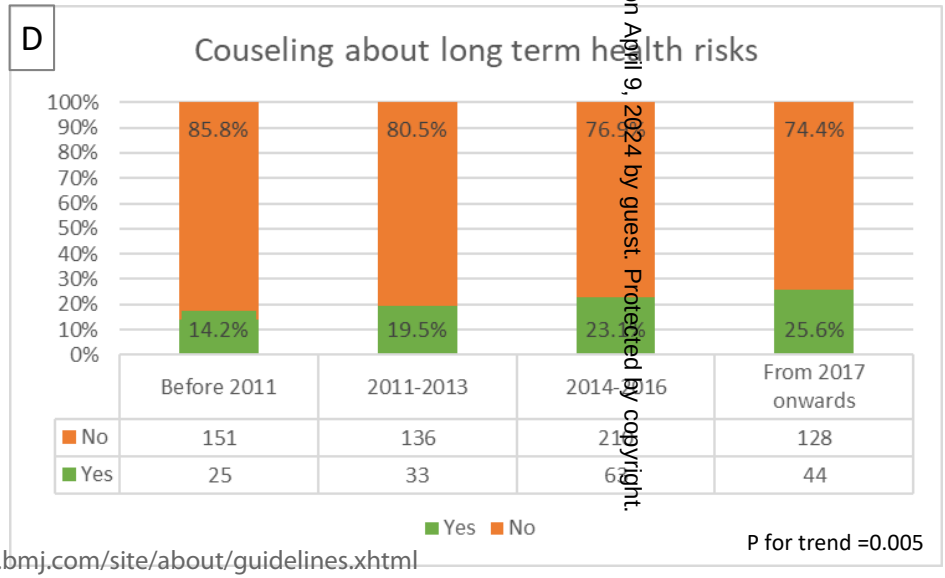

Patient Journey Survey

The following survey has been added to The Preeclampsia Registry to better understand the patient journey including diagnosis, management, treatment, and delivery. This research is being conducted by the Preeclampsia Foundation, in collaboration with rEVO Biologics, a biotechnology company that is developing therapies to treat uncommon conditions, including early onset preeclampsia, and under the supervision of Dr. Ellen Seely (Brigham & Women's Hospital, Harvard University) and Drs. Hilary Gammill and Swati Shree (University of Washington). The information collected in this survey will be de-identified and then used by rEVO Biologics to more effectively address the needs of women with preeclampsia and their healthcare providers. In addition, it will be used by the Preeclampsia Foundation to improve patient education and support, and advocate for better healthcare practices. Other investigators may also use this information for additional research studies. You do not have to answer these questions in order to continue your participation in The Preeclampsia Registry.

You can learn more about rEVO Biologics at their website www.revobiologics.com and more about the Preeclampsia Foundation at their website www.preeclampsia.org.

The information you provide in the survey will be de-identified. The Preeclampsia Registry will *not* give anybody your name, contact information, or any information that can identify you.

This survey will take approximately 30 minutes to complete. Some of these questions relate to how you felt about your experience and some relate to the sequence of events. You do **not** need to complete it all at one time. If you are not comfortable answering any question, please skip ahead to the next question. If you don't know the answer to a question, you may select "I'm not sure".

If you have any questions or concerns, you may contact The Preeclampsia Registry Research Coordinator at (800) 665-9341 or by email at Registry@preeclampsia.org.

Thank you.

"Start Survey"

Form 2

We will be asking about your pregnancies that were complicated by preeclampsia. This includes postpartum preeclampsia that continued after pregnancy or new onset shortly after pregnancy.**

****Throughout this questionnaire, the term "preeclampsia" will be used as an overall description of all Hypertensive Disorders of Pregnancy, such as preeclampsia (sometimes referred to as toxemia or PIH), HELLP syndrome, gestational hypertension, preeclampsia superimposed on chronic hypertension. We are aware these are different complications of pregnancy.**

Information and Awareness

Had you heard of preeclampsia before your first diagnosis?
(check boxes single response)

- Yes
- No
- I'm not sure

If Yes, What did you know about preeclampsia before you were first diagnosed with the condition? *(text box)*

Have you ever done any research on preeclampsia on your own?
(check boxes single response)

- Yes *(skip logic)*
- No *(skip logic)*
- I'm not sure

(If No) Why? Check all that apply. *(multiple response)*

- No access to internet or library
- I was too scared to learn more
- I was content with what I knew
- Other (*text box*)
- I'm not sure

(If Yes) When did you do this research? Check all that apply. *(multiple response)*

- Before conception
- During pregnancy *if checked (multiple response)*
  Check all that apply.
  - Before I was diagnosed
  - When I experienced symptoms
  - After I was diagnosed
- Immediately after delivery (within 48 hours or during hospitalization) *if checked (multiple response)*
  Check all that apply.
  - Before I was diagnosed
  - When I experienced symptoms
  - After I was diagnosed
- Later after delivery (up to 6 weeks later) *if checked (multiple response)*
  Check all that apply
  - Before I was diagnosed
  - When I experienced symptoms
  - After I was diagnosed
- Much later after delivery (more than 6 weeks)
- Other *(text box)*
- I'm not sure

(If Yes) What sources of information did you use? Check all that apply.

(multiple response)

- Website
  - Which website? *(text field)*
- Mobile app
  - Which mobile app? *(text field)*
- Pregnancy Books
- Pamphlets/handouts from the hospital
- Family member/spouse/friend
- Social Media
- Chat rooms/Message boards
- Nurse or other hospital staff
- Additional medical opinions (i.e., “second opinions”)
- Other *(text box)*
- I’m not sure *(single response if selected)*

(If Yes) How satisfied were you with the information that you found? Select the one best choice.

(single response)

- Not satisfied
- A little satisfied
- Very satisfied
- Completely satisfied

(If Yes) How did the information make you feel? *(text box)*

(If Yes) What is your primary mode of electronic research? Select the one best choice.*(single response)*

- Mobile phone
- Tablet
- Laptop computer
- Desktop computer
- Other (*text box*)
- I’m not sure

Based on your experience, what information would be most useful to women with preeclampsia that was not available to you? *(text box)*

What word(s) would you use to describe the emotion(s) you felt *during* your first experience with preeclampsia? *(short text box & limit characters to 117)*

What word(s) would you use to describe the emotion(s) you felt *after* your first experience with preeclampsia? *(short text box & limit characters to 117)*

Did preeclampsia affect your relationship with your family or friends? *(single response)*

- Yes
- No
- I’m not sure

(If Yes) How were your relationships affected? (Check all that apply) *(multiple response)*

- Changed my relationship with my partner for the worse
- Changed my relationship with my partner for the better
- Distanced me from some or all family members
- Brought me closer to some or all family members
- Ended friendships
- Brought me closer to friends
- Other (please specify)

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Form 3

Long-term Health

What NEW lingering effects do you believe preeclampsia had on you? That is, issues you did not have (or were not diagnosed with) before pregnancy. Check all that apply *(multiple responses)*

- Fatigue, beyond "new mother" sleeplessness
- Pain
- Emotional/psychological (e.g. anxiety, depression, intense feeling of loss)
- Kidney disease
- Liver disease
- Multiple hospitalizations resulting from condition(s) associated with pregnancy
- Heart conditions or heart disease
- Stroke
- High blood pressure
- Clotting disorders
- Autoimmune disorders (e.g. lupus, arthritis, etc.)
- Thyroid problems
- Diabetes
- None
- Other *(text)*

(Asked once if any of the above are checked except for "None") Did or do you receive medical care for this problem(s)?*(single response)*

- Yes
- No
- I'm not sure

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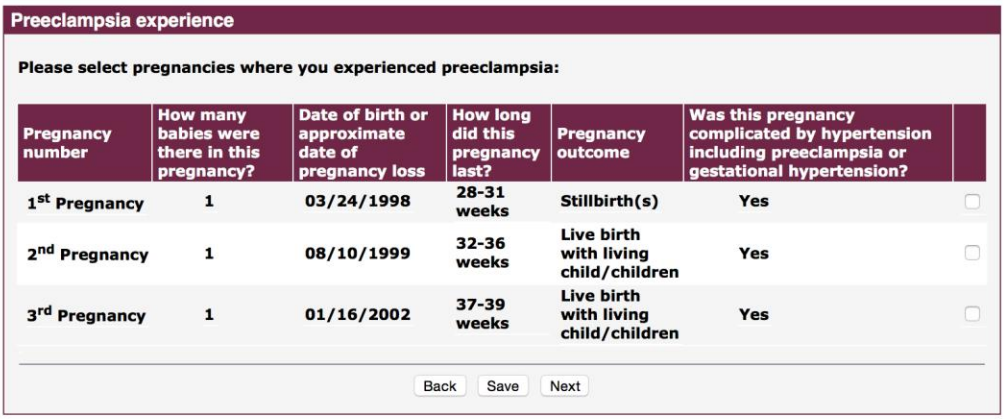
Form 4

This is the pregnancy history we have on file for you. You will be given the option to provide details about each of the pregnancies in which you experienced preeclampsia. If there are any mistakes in this information please contact registry@preeclampsia.org.

This will determine how many times this questionnaire can loop and for what pregnancies.



Preeclampsia experience

Please select pregnancies where you experienced preeclampsia:

Pregnancy number	How many babies were there in this pregnancy?	Date of birth or approximate date of pregnancy loss	How long did this pregnancy last?	Pregnancy outcome	Was this pregnancy complicated by hypertension including preeclampsia or gestational hypertension?	
1st Pregnancy	1	03/24/1998	28-31 weeks	Stillbirth(s)	Yes	☐
2nd Pregnancy	1	08/10/1999	32-36 weeks	Live birth with living child/children	Yes	☐
3rd Pregnancy	1	01/16/2002	37-39 weeks	Live birth with living child/children	Yes	☐

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Looping begins here:

Begin looping with oldest pregnancy checked

Form 5

Demographics

The following questions are about your pregnancy in *mm/yyyy*.

Because you are enrolled in The Preeclampsia Registry, we already have most of the basic information we need about you and your pregnancy(s).

1. Where did you live during this pregnancy with preeclampsia?
   City: *(text)* Country: *(dropdown countries)* State/Province: *(Dropdown US States if USA selected as Country)*

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Form 6

Family History of Preeclampsia

The following questions are about your pregnancy in *mm/yyyy*.

During this pregnancy, did your healthcare provider ask you if you have a family history of preeclampsia? *(single response)*

- Yes
- No
- I'm not sure

During this pregnancy, if you have a family history of preeclampsia, did you let your healthcare provider know? *(single response)*

- Yes *(skip logic)*

- No
- Not Applicable, I do not have a family history of preeclampsia
- I'm not sure

(If Yes) During this pregnancy, were you already aware that your chances of developing preeclampsia were higher, given your family history? *(single response)*

- Yes
- No
- I'm not sure

(If Yes) During this pregnancy, did your healthcare provider share that your chances of developing preeclampsia were higher, given your family history? *(single response)*

- Yes
- No
- I'm not sure

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Form 7

The following questions are about your pregnancy in *mm/yyyy*.

Symptoms

Here is a list of commonly reported symptoms of preeclampsia.

- Headache
- Visual Disturbances
- Swelling
- Abdominal (stomach area) pain
- Indigestion/heartburn
- Chest pain
- Back pain
- Nausea and/or vomiting
- Palpitations
- Vertigo/Dizziness
- Shortness of breath
- Sudden weight gain *(info button:* more than 5 lbs or 2.25kgs in a week)
- Fatigue/tiredness
- Trouble thinking clearly/altered consciousness
- Sleep difficulties
- "Just not feeling right"

Were you aware of the symptoms associated with preeclampsia *before* you were diagnosed with preeclampsia in this pregnancy? *(single response)*

- Yes
- No
- I'm not sure

Did you experience any of these symptoms *before* you were diagnosed with preeclampsia? *(single response)*

- Yes *(skip logic)*

- No
- I'm not sure

(If Yes) What did you do when you experienced any of these symptoms? Check all that apply. *(multiple response)*

- Tried to resolve them on my own (e.g., took pain reliever, laid down, took hot shower)
- Researched on the internet or in books if these symptoms were concerning
- Talked to spouse or partner
- Talked to other family members or friends about my symptoms
- Contacted my healthcare provider
- Went to the hospital, clinic, or doctor's office
- Nothing *(if selected, no other options available)*
- Other (*text box*)
- I'm not sure *(if chosen, no other options available)*

(If Yes) How long did you experience any of these symptoms before reaching out to a healthcare provider? (Select the one best choice) *(single response)*

- I contacted my healthcare provider immediately
- Less than a day
- A day
- A few days (2-5 days)
- A week
- More than a week
- Not Applicable
- Other *(text box)*
- I'm not sure

(If Yes) How long did you experience any of these symptoms before actually speaking with a healthcare provider? (Select the one best choice) (single response)

- I spoke with my healthcare provider immediately
- A few hours
- Less than a day
- A day
- A few days (2-5 days)
- A week
- More than a week
- Not Applicable
- Other (text box)
- I'm not sure

(If Yes) How long did it take for you to see your healthcare provider in person? Select the one best choice.

(single response)

- My healthcare provider sent me straight to the hospital
- My healthcare provider saw me immediately at his/her office
- My healthcare provider saw me that day
- My healthcare provider saw me a few days after I reached out

- I waited until my next prenatal visit to see my healthcare provider
- My healthcare provider did not see me
- Not Applicable
- Other *(text)*

(If Yes) If you had known more about the symptoms of preeclampsia in advance of your diagnosis, would you have done anything differently? *(single response)*

- Yes *(Skip Logic)*
- No
- Not Applicable
- I'm not sure

(If Yes) Which of the following apply? Check all that apply. *(multiple response)*

- I would have recognized my symptoms sooner.
- I would have sought care sooner.
- I would have insisted my symptoms be taken seriously.
- Other *(text)*

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Form 8

The following questions are about your pregnancy in *mm/yyyy*.

Diagnosis

Do you believe you received a timely diagnosis? Select the one best choice. *(single response)*

- Yes
- No, It was missed but eventually diagnosed
- No, It was missed
- I don't know, it was never discussed with me
- Other *(with text box)*

Who first told you that you had preeclampsia? Select the one best choice. *(single response allowed)*

- OB/GYN physician
- High-risk OB physician (Maternal-Fetal Medicine specialist or Perinatologist)
- Nurse in Clinic or Outpatient
- Nurse in Hospital
- Emergency Room Provider
- Primary Care Provider
- Midwife
- Doula
- Nobody, I found out on my own
- Other (*text box)*
- I'm not sure

Where were you first diagnosed? Select the one best choice. (*single response)*

- At my healthcare provider's office
- At a hospital

- At home
- Other (*text box)*
- I'm not sure

When did a healthcare provider first share information with you about preeclampsia? Select the one best choice. *(single response)*

- During or after a previous pregnancy
- During a prenatal visit for this pregnancy
- After I was diagnosed with preeclampsia in this pregnancy
- After delivery in this pregnancy
- At discharge from the hospital
- During a postpartum check-up after this pregnancy
- Sometime later
- Never *(skip logic)*
- Other *(text)*
- I'm not sure

("Never" skips this question) What type of information were you given when you were diagnosed? Check all that apply. *(multiple response)*

- Shared information verbally
- Brochure or pamphlet
- Referred to a website
    - Which website? *(text box)*
- Other (*text box)*
- I'm not sure

("Never" skips this question) Did you feel satisfied with the information that you were given at that time? *(single response)*

(check boxes single response allowed)

- Yes
- No *(skip logic)*
- I'm not sure

(If No) Please specify why you did not feel satisfied with the information you were given at that time. *(text box)*

("Never" skips this question) Did you feel that your healthcare provider conveyed the seriousness of the condition? *(single response)*

- Yes
- No, even though it was serious
- No, it was not serious
- I'm not sure

Did you feel a premonition, apprehension or anxiety prior to your diagnosis?

- Yes
- No
- I'm not sure

(If Yes) In what way(s)? Check all that apply. *(multiple response)*

- "I just knew something wasn't right"
- "I had a very strong sense of foreboding in the days before my diagnosis"
- "I had a dream or vision before my diagnosis"
- "I felt anxious and unsettled in the days before my diagnosis"
- Other *(text box)*
- None of the above *(if selected, do not allow for other responses)*
- I'm not sure *(if selected, do not allow for other responses)*

What degree of mental or emotional impact did **learning of your diagnosis** of preeclampsia have on you? Select the one best choice. *(single response)*

- No Impact
- Minimal Impact
- Some Impact
- Serious Impact

Is there anything else ***about your diagnosis*** that these questions have not covered that you believe is important or that you would like us to know?

[Open text field]

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Form 9

The following questions are about your pregnancy in *mm/yyyy*.

Hospital Care

Did you receive care in more than one hospital or birthing facility, besides where you received prenatal care? *(single response)*

- Yes *(skip logic)*
- No

(If Yes) How many hospitals or facilities did you go to? *(required response)*
Dropdown of numbers (1-9). This will determine how many times the hospital care questions should loop.

Hospital looping begins
Please answer the following questions for the *<first>* hospital or facility you went to. You will have an opportunity to answer questions about the other hospitals, if applicable.

Did you go to this facility before or after diagnosis? *(single response)*

- Before
- After *(skip logic)*
- I'm not sure

(*If After)* How long did it take to be seen at this hospital after your diagnosis? Select the one best choice.
(single response)

- 0 – 12 hours
- 12 – 24 hours
- 1 – 2 days
- More than 2 days
- I'm not sure
- Other (*text box)*

How many weeks and days pregnant were you when you were when you were seen at this hospital?

Dropdown from 45 to 20 weeks, Before 20 weeks, & I Don't Know, *Dropdown from 0-6* Days & I Don't Know *(copy this option from question N3 in general questionnaire)*

Had postpartum preeclampsia *(check box outside dropdowns)*

What happened at this facility? Check all that apply. *(multiple response)*

- I was diagnosed at this hospital
- Regular observations and monitoring of me (e.g.blood pressure, urine evaluation, blood tests, etc.) and/or of my baby (e.g. heart rate monitoring or ultrasound)
- Kept in the hospital for a while, but eventually transferred to another hospital
- Immediately transferred to another hospital
- Given blood pressure medication to lower my blood pressure
    - *(if selected)* Did you experience any side effects?
        - Yes
        - No

          (*If Yes)* What type of side effects? (*multiple response)*
            - Light headed or dizzy
            - Heart racing
            - Nausea/vomiting
            - Fatigue/sleepiness
            - Other *(text)*
- Given Magnesium Sulfate
    - *(if selected)* Did you experience any side effects?
        - Yes
        - No

          (if Yes) What type of side effects? Check all that apply. *(multiple response)*
            - Feeling hot/flushed
            - Cold/clammy
            - Vision changes
            - Nausea/vomiting
            - Fuzzy thinking
            - Other *(text)*
- Given steroids – for baby's lungs
    - *(if selected)* Did you experience any side effects?
        - Yes
        - No.

          (if Yes) What type of side effects? Check all that apply. *(multiple response)*
            - Anxiety
            - Difficulty sleeping

- Change in mood
- Other *(text)*

- Sent home. Check all that apply.
  (If selected, multiple response)
  - With information of symptoms to look out for
  - On bed rest
  - On reduced activity
  - To monitor my own blood pressure
  - Later readmitted to hospital because of preeclampsia.
- Delivered *(single response)*
  - Delivered within 12 hours
  - Delivered between 13 and 48 hours
  - Delivered after 48 hours
- Diagnosed after delivery
- Other *(text box)*
- I'm not sure

Were you given information about what was being done for you? (*single response)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) Was the information adequate? (*single response)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) Why do you feel this information was adequate? Check all that apply. *(multiple response)*

- I was told why something was being done
- I understood what was being communicated
- I was told about the benefits, alternatives, and risks to me
- I was told about the benefits, alternatives, and risks to my baby

(If Yes) Who provided you with information about what was being done for you? Check all that apply. (*multiple responses)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Nurse in Clinic or Outpatient
- Nurse in Hospital
- Emergency Room Provider
- Primary Care Provider
- Midwife
- Doula
- Other (*text box*)
- I'm not sure

How did you get to the hospital? Select the one best choice.(*single response)*

- My spouse/friend/family member drove me
- I drove myself
- I took an ambulance
- I took public transportation (bus, subway, taxi)
- I walked
- Other (*text box*)
- I'm not sure

Where were you sent when you arrived at the hospital? (*single response)*

- Emergency Room
- Labor & Delivery/Maternity
- Other (*text box*)
- I'm not sure

Did your healthcare provider call ahead to the hospital? (*single response)*

- Yes
- No
- I'm not sure

Did your healthcare provider tell you what you could expect when you arrived at the hospital? (*single response)*

- Yes
- No
- Not Applicable
- I'm not sure

Were you seen by a specialist at the hospital? (*single response)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) What type of specialist? Check all that apply. (*multiple response)*

- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Cardiologist (Heart)
- Pulmonologist (Lung)
- Nephrologist (Kidney)
- Hematologist (Blood)
- Neurologist (Brain)
- Other (*text box*)
- I'm not sure

Who greeted you at the hospital when you arrived? Select the one best choice. (*single response)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Nurse in Hospital
- Emergency Room Provider
- Primary Care Provider

- Midwife
- Doula
- Administrative staff
- Other (*text box)*
- I'm not sure

When you arrived at the hospital, did hospital staff give you information about your diagnosis and what to expect? (*single response)*

- Yes *(skip logic)*
- No
- Not applicable, I did not have a diagnosis yet
- I'm not sure

(*If Yes)* What type of information were you given? Check all that apply. (*multiple response)*

- Shared information verbally
- Brochure or pamphlet
- Referred to a website
    - *(if selected)* Which website? (*text field*)
- Other (*text box*)
- I'm not sure

(If Yes) Did you feel satisfied with the information that you were given at that time? (*single response)*

- Yes
- No *(skip logic)*
- I'm not sure

(If No) Please specify why. *(text box)*

Insert looping back for another hospital/transfer here

What were some steps taken to address your mental/emotional well-being **during your hospitalization**? Check all that apply OR Not Applicable. (*multiple responses)*

- Took anti-depressant or anti-anxiety medication
- Spent time with a counselor/therapist/social worker/chaplain
- Sought support from a faith-based community
- Got support via an online community
- Participated in a support group
- Sought support from friends and family
- Got support or information from my healthcare provider
- Nothing, experienced it privately *(If selected, should not be able to select any other options)*
- Other (please specify) *text box*
- Not applicable – I did not have any mental/emotional needs *(If selected, should not be able to select any other options)*

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Form 10

The following questions are about your pregnancy in *mm/yyyy*.

Delivery & Decision-Making

Please answer the following questions for the hospital where you delivered.

How soon after you were admitted did you deliver? Select the one best choice. *(single response)*

- Delivered within 12 hours
- Delivered between 13 and 48 hours
- Delivered after 48 hours
- Other (*text box*)
- I'm not sure

Did your healthcare provider indicate why delivery was necessary? (*single responses)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) Please specify why delivery was necessary. Check all that apply. *(multiple response)*

- I was in labor
- My baby was in distress or danger
- My baby had died
- I was in immediate danger
- Other (text)
- I'm not sure

Did you feel that you were adequately involved in making decisions about your care? (*single response)*

- Yes
- No *(skip logic)*
- I'm Not Sure

(If No) Please share why. Check all that apply. (*multiple response)*

- I was unconscious or in a coma
- I was "out of it"; or in and out of consciousness
- I did not understand what was happening
- There was no time before delivery
- I did not want to be involved
- My family was involved instead of me
- Inadequate communications from healthcare provider(s)
- Other (please specify) *(text box)*

Which healthcare providers were involved in your healthcare decisions? Check all that apply. (*multiple response)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Nurse in Clinic or Outpatient

- Nurse in Hospital
- Emergency Room Provider
- Primary Care Provider
- Midwife
- Doula
- Other (*text box*)
- I'm not sure

Were others (such as family or friends) involved in your healthcare decisions? (*single response)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) Please specify who else was involved. (*multiple responses)*

- Spouse/Partner
- Family
- Friends
- Legal representative
- Other *(text box)*

Were you aware of the Preeclampsia Foundation during **this** preeclampsia experience, and the educational resources it provides? (*single responses)*

- Yes *(skip logic)*
- No, I don't think it existed at the time
- No, but I found it later
- No
- I'm not sure

(If Yes or "No, but later") How did you become aware of it? Select the one best choice. *(single response)*

- From an online search engine (e.g. Google)
- On a pregnancy website or mobile app
- Through a friend or family member
- In a magazine or print newspaper
- On TV
- On another type of website
- From a brochure or pamphlet
- From my healthcare provider
- Other *(text box)*
- I'm not sure

Did you have postpartum preeclampsia?

Yes, my preeclampsia continued after delivery
Yes, I had new onset preeclampsia after delivery
No
I don't know

Is there anything else about your treatment or delivery that these questions have not covered that you believe is important or you would like us to know? (open text)

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Form 11

Skip this form if Yes, new onset of preeclampsia after delivery
The following questions are about your pregnancy in *mm/yyyy*.

Health Updates After Delivery

The following questions address the communications you had with your healthcare providers, not your perceptions about the quality of care they delivered.

Did you receive updates about how you and/or your baby were doing after delivery? (*single response)*

- Yes *(skip logic)*
- No
- Not applicable
- I'm not sure

(If Yes) How frequently did you receive updates about how you and/or your baby were doing? Select the one best choice.
(single responses)

- Once a day
- A few times a day
- Hourly
- Other (*text box*)
- I'm not sure

(If Yes) Who provided you with these updates? Check all that apply. (*multiple responses)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Neonatologist
- OB Nurse
- NICU Nurse
- Emergency Room Provider
- Primary Care Provider
- Midwife
- Doula
- Other (*text box*)
- I'm not sure (*Only single response if this is selected)*

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Form 12

The following questions are about your pregnancy in *mm/yyyy*.

Going Home

The following questions should be answered based on leaving from your final hospital.

When it was time to go home, who spoke to you about your discharge from the hospital? Check all that apply. (*multiple response)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Nurse in Hospital
- Primary Care Provider
- Midwife
- Doula
- Administrative Staff
- Other (*text box*)
- I'm not sure (*Only single response if this is selected)*

Were you provided with any information about preeclampsia before being sent home? *(single response)*

- Yes
- No
- I'm not sure

If Yes, Please explain: *textbox*

Were you instructed to follow up with your healthcare provider regarding your diagnosis of preeclampsia? (*single response)*

- Yes
- No
- I'm not sure
- Not Applicable

Did anyone speak to you about the potential long-term health consequences as a result of preeclampsia? (*single response)*

- Yes, at discharge *(skip logic)*
- Yes, but at a later appointment *(skip logic)*
- No
- I'm not sure

(If Yes) Who spoke with you about the potential long-term health consequences? Check all that apply. *(multiple response)*

- OB/GYN physician
- High-risk OB physician (Maternal Fetal Medicine specialist or Perinatologist)
- Nurse in Clinic or Outpatient
- Nurse in Hospital
- Emergency Room Provider
- Primary Care Provider
- Midwife
- Doula
- I'm not sure *(only single response if selected)*
- Other (*text box*)

(If Yes) What information was relayed to you about the potential long-term health consequences? *Text box*

What degree of mental or emotional impact did this experience have on you? Select the one best choice. *(single response)*

- No Impact
- Minimal Impact
- Some Impact
- Serious Impact

What were some steps taken to address your mental/emotional well-being **after you went home**? Check all that apply OR Not Applicable. *(multiple responses)*

- Took anti-depressant or anti-anxiety medication
- Spent time with a counselor/therapist/social worker/chaplain
- Sought support from a faith-based community
- Got support via an online community
- Participated in a support group
- Sought support from friends and family
- Spent time with a healthcare provider learning about preeclampsia
- Nothing, experienced it privately *(single response if selected)*
- Not applicable – I did not have any mental/emotional needs *(single response if selected)*
- Other (please specify) *text box*

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Form 13

Planning for Future Pregnancies
The following questions are about your pregnancy in *mm/yyyy*.

Did your experience with this pregnancy influence your decision to become pregnant again? *(single response)*

- Yes *(skip logic)*
- No
- I'm not sure

(If Yes) Please specify how. Check all that apply. *(multiple response)*

- I wanted more children but decided not to have another pregnancy
- I am considering (or already pursued) adoption
- I am considering (or already pursued) surrogacy
- I will seek (or already sought) preconception counseling by a high risk pregnancy specialist
- If I get pregnant I will be seen by a specialist at that point
- With time my perspective on this question has changed
- Other *(text)*

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Form 14

Would you like to complete this questionnaire for another pregnancy in which you experienced preeclampsia or other hypertensive disorder of pregnancy (for example preeclampsia, HELLP, eclampsia)? You would **not** need to complete it all at one time.

- Yes *(If yes, go to subsequent pregnancy form)*
- No, I do not have any other affected pregnancies, or I wish to stop. *(If no, go to Form 15)*

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Looping Ends

Form 15

In addition to what you've shared so far, is there anything you would like to add about your experiences with preeclampsia? *(text) (include a view of general TPR question field question S1)*

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Conclusion

Thank you for contributing valuable and important information to The Preeclampsia Registry.

Supplemental Table 1: Univariate associations between patient characteristics and outcomes

A. Heard of preeclampsia before first diagnosis	*OR*	*95% CI*	*p-value*
Maternal age (years)			
<25	0.40	0.25-0.66	<0.001
25-29	ref		
30-34	1.73	1.16-2.57	0.007
≥35	1.48	0.93-2.36	0.098
Year of delivery			
Before 2011	0.25	0.15-0.41	<0.001
2011-2013	0.61	0.36-1.03	0.064
2014-2016	0.66	0.41-1.06	0.088
From 2017 onwards	ref		
Highest level of education completed			
High school or less and technical/vocational school	0.33	0.20-0.55	<0.001
Some college	0.67	0.42-1.06	0.086
College	ref		
Graduate school	2.13	1.42-3.19	<0.001
Multiparity	1.39	0.78-2.67	0.262

B. Serious mental/emotional impact	*OR*	*95% CI*	*p-value*
Maternal age (years)			
<25	0.92	0.58-1.48	0.740
25-29	ref		
30-34	1.09	0.78-1.51	0.620
≥35	1.41	0.95-2.09	0.089
Year of delivery			
Before 2011	0.67	0.45-1.01	0.055
2011-2013	0.49	0.32-0.75	0.001
2014-2016	0.81	0.56-1.17	0.257
From 2017 onwards	ref		
Multiparity	1.10	0.70-1.75	0.677
Perinatal loss	3.97	2.36-6.68	<0.001
Cesarean section	1.09	0.82-1.45	0.565
Maternal ICU-stay	1.60	1.12-2.28	0.009
Baby admitted to the NICU	1.82	1.36-2.43	<0.001
Gestational age at delivery (weeks+days)			
<28+0	3.11	1.91-5.05	<0.001
28+0 - 31+6	1.74	1.13-2.68	0.013
32+0 - 36+6	1.30	0.94-1.80	0.112
≥37+0	ref		
Not involved in making decisions	2.20	1.58-3.07	<0.001
Not aware of preeclampsia before diagnosis	1.52	1.10-2.08	0.010
Not aware of the symptoms of preeclampsia before diagnosis	1.26	0.95-1.67	0.109
Healthcare provider did not convey the seriousness of the condition	1.50	1.11-2.02	0.008

C. Family planning: wanted more children but decided not to have another pregnancy	*OR*	*95% CI*	*p-value*
Maternal age (years)			
<25	0.55	0.29-1.06	0.075
25-29	ref		
30-34	0.97	0.65-1.44	0.868
≥35	1.63	1.05-2.53	0.031
Multiparity	2.14	1.31-3.49	0.002
Gestational age at delivery (weeks+days)			
<28+0	1.08	0.62-1.90	0.784
28+0 - 31+6	1.45	0.88-2.39	0.148
32+0 - 36+6	1.26	0.85-1.86	0.247
≥37+0	ref		
Perinatal loss	0.32	0.15-0.68	0.003
No counseling about the risk of preeclampsia in future pregnancies	1.20	0.85-1.69	0.296
No counseling about later-life health risks	1.27	0.82-1.97	0.286
Maternal ICU-stay	1.24	0.83-1.86	0.293
Baby admitted to the NICU	1.34	0.95-1.90	0.094

Results are from univariate logistic regression analysis. OR=Odds Ratio; 95% CI=95% confidence interval; ICU=intensive care unit; NICU=neonatal intensive care unit

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5-6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5-7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5-7
Bias	9	Describe any efforts to address potential sources of bias	7
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7
		(*b*) Describe any methods used to examine subgroups and interactions	7
		(*c*) Explain how missing data were addressed	7
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	NA
		(*e*) Describe any sensitivity analyses	NA
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	8
		(b) Give reasons for non-participation at each stage	8
		(c) Consider use of a flow diagram	Included
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	8-12
		(b) Indicate number of participants with missing data for each variable of interest	Table 1-3
Outcome data	15*	Report numbers of outcome events or summary measures	8-12
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	8-12
		(*b*) Report category boundaries when continuous variables were categorized	6-7, 8-12
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	11
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	11-12
Discussion			
Key results	18	Summarise key results with reference to study objectives	12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	12-16
Generalisability	21	Discuss the generalisability (external validity) of the study results	12-16
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	17

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.