

# PregSource<sup>®</sup>:

## Crowdsourcing to Understand Pregnancy

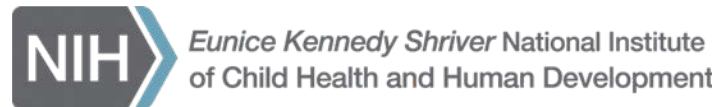
Caroline Signore, MD, MPH

September 13, 2018

NACHHD Update



[pregsource.nih.gov](http://pregsource.nih.gov)





## **PregSource: Crowdsourcing to Understand Pregnancy**

**This online research registry will gather data on a real-time basis directly from adult pregnant women via an interactive online platform using a crowdsourcing approach.**



# Why create an online pregnancy ‘registry’?

Harness the power of crowdsourcing to learn more about the:

- Normative range of physical and emotional experiences, as well as alterations in behavior, that women have during pregnancy and after giving birth
  - Impact of these experiences on women’s lives
  - Detail the natural history – and variations – of human pregnancy
  - Provide information about pregnancy from trusted sources





# Scientific Goals

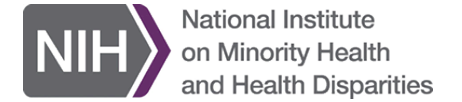
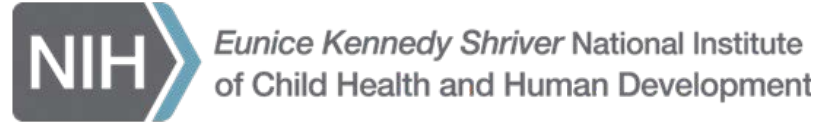
[pregsource.nih.gov](https://pregsource.nih.gov)



- Build a more complete picture of **typical pregnancy** and develop strategies for improving maternal care and pregnancy outcomes
- Gain information on **understudied groups** (e.g., pregnant women with disabilities)
- Build a large **epidemiological dataset** to inform future research; deidentified data will be made available to approved researchers for analysis
- Support research by informing women about **research participation** opportunities



# PregSource Partners





# How Was PregSource Developed?

- **NICHD gathered together trusted partner organizations**
- **Expert partners brainstormed the critical questions to ask participants**
- **Questionnaires were written to meet readability requirements for the general public**
- **Website and database programming done via contract**
- **Built on earlier experience with DS-Connect<sup>®</sup>**

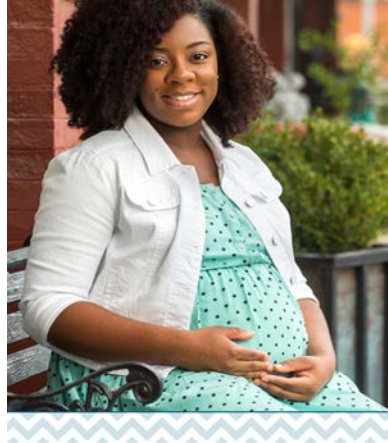


## How Does It Work?

- Inclusion criteria: currently pregnant adults
- Online consent process
- Username and password
- Complete profile and contact preferences
- Enter data through questionnaires and trackers
- Update throughout pregnancy and postpartum



[pregsource.nih.gov](https://pregsource.nih.gov)



## What's in it for me?

- Print trackers and questionnaires to share with healthcare provider
- Compare pregnancy experiences to those of other participants
  - To see whether symptoms are “typical”
- Read extensive, reliable pregnancy information from leading experts
- No advertisements for pregnancy- or baby-related products or services
- Personal information will not be sold or shared





# Focus on Health Research

- Information will be collected only for research purposes
- Deidentified data will be made available to approved researchers for analysis
- Women who express interest in participating in clinical studies will receive information on specific studies for which they might be eligible
- PregSource will not share user information directly with researchers



[pregsource.nih.gov](https://pregsource.nih.gov)



# PregSource Secondary Outcomes

Besides health research outcomes, PregSource has some methodological questions to answer:

- How many participants will join an online registry?
- How many will regularly continue to enter data throughout their pregnancy?
  - For monthly questionnaires
  - For trackers
- Or after pregnancy, when they are busy taking care of their new babies?





## Hello Caroline!

You are in **week 31** of pregnancy: **Pregnancy 1**  
Your last visit to PregSource® was: **August 25, 2018**

# Dashboard

Questionnaires to complete

### Questionnaires

**To Do**

- [During This Pregnancy](#)
- [Weeks 25-28: Tell Us How You Are Doing](#)
- [My Health History: Before This Pregnancy](#)
- [My Health History: Medications Before This Pregnancy](#)
- [Tell Us More About You](#)
- [My Health History: Prior Pregnancies](#)

**Done (Completed)**

- [Due Date and More About This Pregnancy](#)
- [My Latest Updates](#)

### 15 Trackers [Update](#)

[Add My Latest Updates](#)  
[Update My Due Date](#)

Update information in trackers

### Medication and Supplement Tracker [Add](#)

Select "Add" to list a prescription or over-the-counter medicine, vitamin, or herbal supplement. If you stopped taking an item or need to change information about it, select "Edit" next to that item.

#### Current Medications and Supplements

### Messages

You have **3** new message(s).

View data

### Data, Facts, & Figures

[Show My Progress Trackers](#)  
[Show Me All PregSource Data](#)  
[Go to my Personalized Article Library](#)

### Change My Pregnancy Info



# Questionnaires

Include:

- Due date
- Health history
- Demographics
- Trackers
- Monthly gestational age-specific questionnaires

## Hello, FirstName

You do not have to complete the survey at one time. You may log out at any time and your answers will be saved. For more detailed instruction, [click here](#).

### Due Date

0%


Due Date

Enter the details about your due date.


What is your due date for this pregnancy? \*

DD/MM/YYYY

Please make your selection from the calendar icon.

24/12/2015 

How was your due date determined? \*

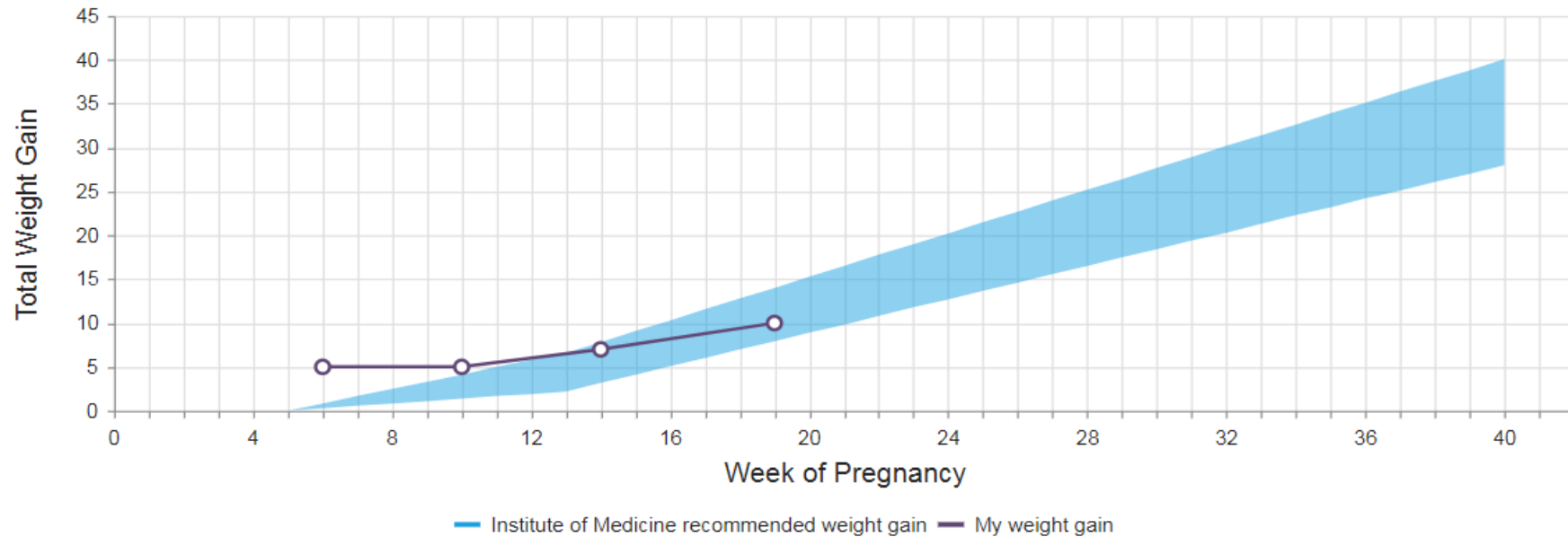
Assisted Reproductive Technolc 



# Track

## My Weight Gain For BMI less than 18.5

This graph shows your weight gain throughout pregnancy compared to the recommended weight gain for your body mass index (BMI)



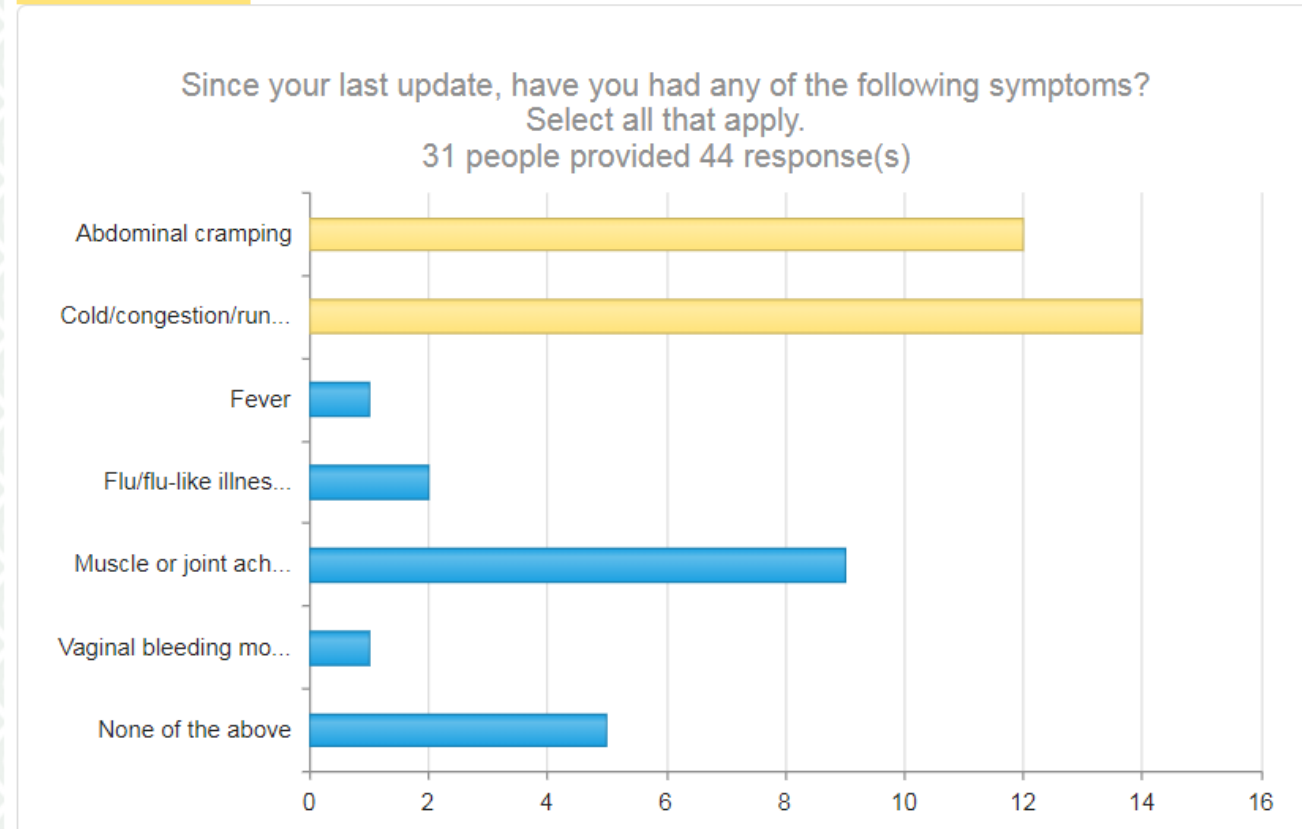
Export as PDF

Export as Image



## WEEKS 17-20: TELL US HOW YOU ARE DOING - MY PREGNANCY CONDITIONS

### Your response



**Deidentified  
data  
feedback:  
Is this  
“normal?”**



# Resource Library: Articles from Trusted Sources

- >450 articles about pregnancy, pregnancy complications, and infant health
- From our Partner organizations

## Resource Library

PregSource™ is pleased to provide this Resource Library with information about different pregnancy topics. All items in the Library come from [PregSource™ Partners](#).

Don't see what you're looking for? You might want to check out the website of one or more of the [PregSource™ Partners](#) for more detailed information.

PregSource™ information does not to the place of advice from a health care provider. If you have specific questions about your pregnancy or your health, please talk to your health care provider.

Search Keyword:





**PregSource**  
Crowdsourcing to Understand Pregnancy

Home About Resource Library Contact Us

**Thank you for joining PregSource®!** Completing your registration involves just a few more steps. The process should only take a few minutes.

First, we need you to "officially" agree or consent to take part in PregSource by reading the information and following the instructions below. Then, we need you to set up your profile – including username and password – and create your unique PregSource ID. Lastly, we need you to type in a special code that helps protect your information and PregSource from spammers and other security threats.

## Informed Consent for PregSource

Please read this electronic consent form carefully. For more information, visit <https://PregSource.nih.gov>. You can also contact the PregSource Support Team, at [PregSource@nih.gov](mailto:PregSource@nih.gov) with any other questions related to PregSource consent text to keep a written statement regarding your consent.

**Note:** Taking part in PregSource is your choice.

**What is PregSource?**  
PregSource is a health research study led by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, which is part of the National Institutes of Health. The study will collect information about their health, from morning sickness and sleep patterns, to how their babies are doing.

**PregSource has been approved by the NICHD Institutional Review Board.**

For the purposes of the consent form below, "I", "my", "you" and "your" refers to the pregnant woman who is giving consent.

Please type the full name of the person giving consent:

By consenting, I agree to the following:

- I have read the informed consent document. I have had a chance to ask questions and get answers, and I have no other questions at this time.
- I understand the purposes, risks, and benefits of taking part in PregSource<sup>SM</sup>.
- I understand that taking part in PregSource<sup>SM</sup> is entirely my choice.
- If I change my mind and no longer want to take part in PregSource<sup>SM</sup>, I am free to do so and do not have to give any reason.
- I agree to allow PregSource<sup>SM</sup> Coordinators to contact me by email.

I am the participant (pregnant woman) and I am 18 years of age or older. I hereby consent to take part in PregSource<sup>SM</sup>.

# Groundbreaking for NICHD

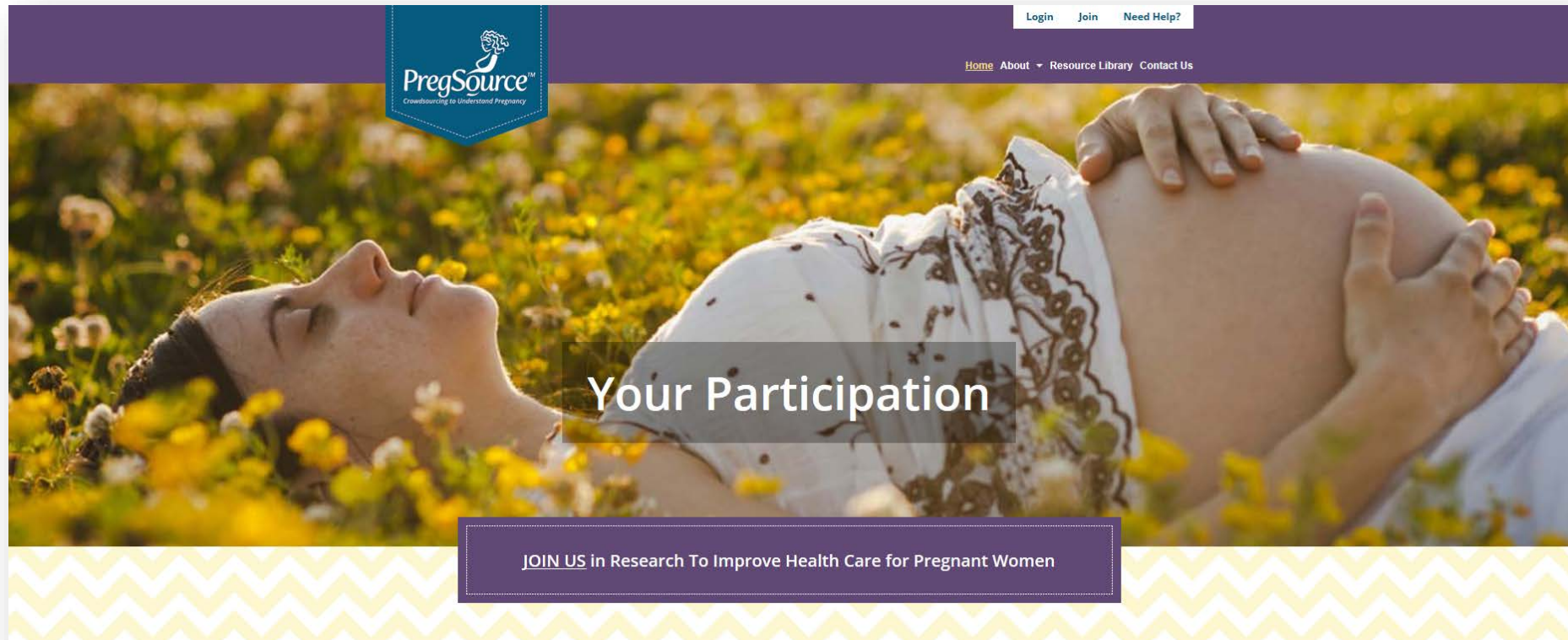
With DS-Connect®,  
earliest substantial  
experiences with  
research conducted  
entirely online





Released: October 2017

[pregsource.nih.gov](http://pregsource.nih.gov)



**PregSource: Your Pregnancy. Your Experience. Your Care.**



# Outreach

We **rely on our partners** to share PregSource information with their members and constituents.



 **NIH** *Eunice Kennedy Shriver* National Institute of Child Health and Human Development

**PregSource**<sup>®</sup>  
Crowdsourcing to Understand Pregnancy

**Shape the future  
of obstetric care.**

[pregsource.nih.gov](http://pregsource.nih.gov)



# Outreach Plan

## Phase 1

### Soft Launch: ACNM & Lamaze, Fall 2017

- Fine-tuned messages and strategies and ensured site stability
- Press release

## Phase 2

### Full Launch: All partners, 2018

- Provided promotional toolkit to partners for use on their channels
- Ad placement on social media, babycenter.com, other platforms
- In-person outreach at conferences and health fairs (e.g., NBC4 Health & Fitness Expo in DC)
- Guest blogs; social influencers

## Phase 3

### Regroup & Revise: Fall 2018

- Video in production
- Evaluate what has/hasn't worked and revise tactics and strategies to capitalize on successes, adjust messages and materials, and plan for additional phases



## NEWS RELEASES

Wednesday, November 1, 2017

# NIH launches PregSource, a crowdsourcing project to better understand pregnancy

*Pregnant women can track their experiences through a secure and confidential website.*



The National Institutes of Health has launched [PregSource](#), a research project that aims to improve knowledge of pregnancy experiences and information directly from pregnant women. The project focuses on physical and emotional aspects of pregnancy, labor and delivery, and distinct challenges faced by subgroups of women, including those with disabilities. By offering a more comprehensive and personalized experience — from normal pregnancies to those with other factors — PregSource promises to improve the quality of maternal care in the United States.

“PregSource benefits everyone—the participants, the researchers, and the research community,” said Diana W.



Home > Newsroom > News

> Podcast: NICHD launches PregSource to learn more about pregnancy

## Podcast: NICHD launches PregSource to learn more about pregnancy

Wednesday, February 7, 2018



**NICHD News & Info** @NICHD\_NIH · Aug 24

What is a typical pregnancy? #PregSource, an #NICHD-led research project, aims to find out. @kingWTOP speaks with NICHD’s Dr. Caroline Signore. [bit.ly/2GMZyiv](https://bit.ly/2GMZyiv)



[pregsource.nih.gov](https://pregsource.nih.gov)



## Patient Education: Crowdsourcing Comes to Pregnancy with PregSource™

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) has been working with ACOG and several other women's health organizations to develop a new website and app called PregSource™ to help women track their pregnancy experiences. The data collected through this resource can help improve care for pregnant women by allowing them to record and compare their pregnancy and post-pregnancy experiences.



## Crowdsourcing to Understand Pregnancy

The National Institutes of Health has launched PregSource, a research project that aims to improve knowledge of pregnancy by collecting information directly from pregnant women. Women who sign up for PregSource use online surveys to share what they are experiencing, and they can compare these experiences with those of other participants. Over the course of their pregnancies, women can chart changes to their weight, sleep, mood, morning sickness, and physical activity. In addition, they can access informational resources developed by experts on pregnancy, childbirth, and child



development. PregSource also enables women to track their experiences after childbirth to help determine if any outcomes, such as heart disease, can be linked to events during pregnancy. Find the website here: <https://pregsource.nih.gov>.

June 2018

[https://nwhjournal.org/article/S1751-4851\(18\)30109-0/pdf](https://nwhjournal.org/article/S1751-4851(18)30109-0/pdf)

## Lamaze Partners with PregSource™ in Support of Study and You Can Help



NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development



### Shape the future of obstetric care.

Encourage your patients to **join the PregSource™** research project today.

[pregsource.nih.gov](https://pregsource.nih.gov)

FEATURE

## NIH goes straight to pregnant women in new research project

**Publish date:** December 2, 2017

By [Christine Kilgore](#); Ob.Gyn. News



Research on pregnancy is now being crowdsourced, with pregnant women being asked in a new federal research project to "tell researchers and health care providers what

[Home](#) » [Health & Fitness News](#) » What is a typical...

## What is a typical pregnancy? Research project aims to be resource



By [Kristi King](#) | [@KingWTOP](#)  
February 28, 2018 4:23 am





UT Southwestern  
Medical Center

Your Pregnancy Matters

## Crowdsourcing: Can it help get women through pregnancy?

February 27, 2018



Robyn Horsager-Boehrer, M.D.

## Support PregSource™: A Research Project to Shape the Future of Obstetric Care

The American College of Nurse-Midwives is proud to partner with the Eunice Kennedy Shriver National Institute of Child Health and Human Development to support a research project that allows pregnant women to share their experiences on a confidential website. The PregSource data will help



What are the patterns of weight gain during pregnancy, and how do they affect maternal, fetal, and infant health?

se—change over the course of the pregnancy?

abilities or chronic diseases, experience

chart participants' weight, sleep, mood, morning

### Our Moment of Truth

Discover Midwife Care & Women's Health



### Let's talk about pregnancy!

Share and compare your experiences with other pregnant women. Join the PregSource™ research project to make a difference in pregnancy care.

[pregsource.nih.gov](http://pregsource.nih.gov)

From May 2019 Birth Club

## PregSource - Help with research once you are pregnant!



MoussenSquirrel

Posted 07/13/2018

Hi everyone, I'm just posting this here in case anyone else is a science nerd like me!

I read this [Washington Post article](#) about pregnancy forums today.

It mentioned an NIH sponsored research website that pregnant women can contribute to. The point of the site is to collect real data on things like nausea, changes in weight and sleep in pregnant ladies and then provide that information to OB/GYNs everywhere. I'm sure we've all noticed how none of our doctors seem to



## NIH Launches PregSource, A Crowdsourcing Project to Better Understand Pregnancy

November 2, 2017

The National Institutes of Health has launched PregSource, a research project that aims to improve knowledge of pregnancy information directly from pregnant women. The physical and emotional aspects of pregnancy, labor and delivery, and identify distinct challenges faced by subgroups of pregnant women.

[Quick Read](#)



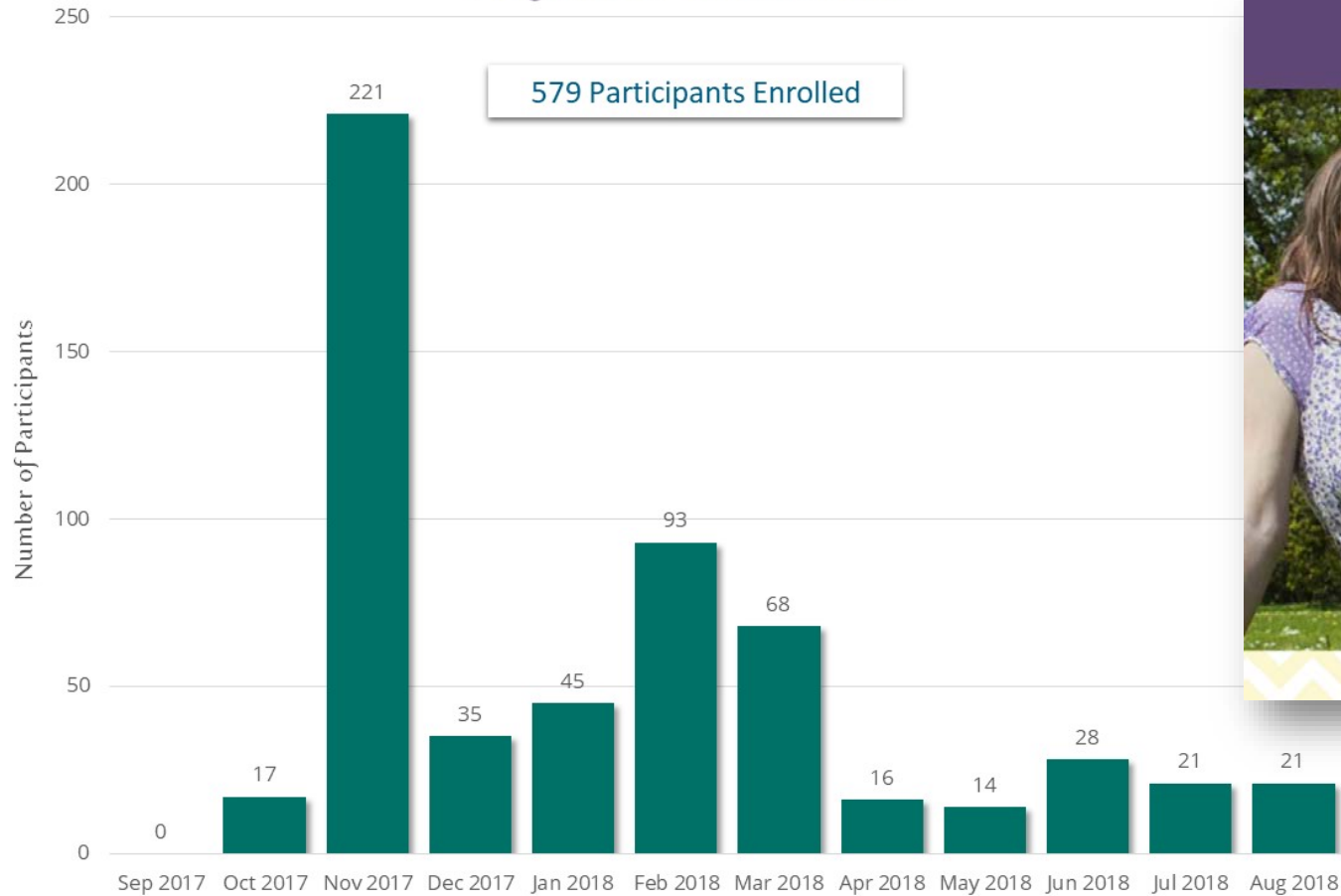
BERMAN INSTITUTE  
BIOETHICS BULLETIN

[pregsource.nih.gov](http://pregsource.nih.gov)



# Recruitment

PregSource® Recruitment



As of August 31, 2018



[pregsource.nih.gov](http://pregsource.nih.gov)



# Participant Characteristics

	PregSource	US Pop*
Age <35y	62%	87%
Hispanic, Latina, or Spanish Origin	6%	23%
White Race	92%	75%
Private Insurance	89%	50%
Master's Degree or higher	63%	12%
Employed	78%	--
1 <sup>st</sup> Trimester at Enrollment	29%	--
Nulliparous	40%	30%
Overweight or Obese	41%	52%



[pregsource.nih.gov](https://pregsource.nih.gov)

\*NVSS, Births 2016,  
[https://www.cdc.gov/nchs/data\\_access/vitalstatsonline.htm](https://www.cdc.gov/nchs/data_access/vitalstatsonline.htm)

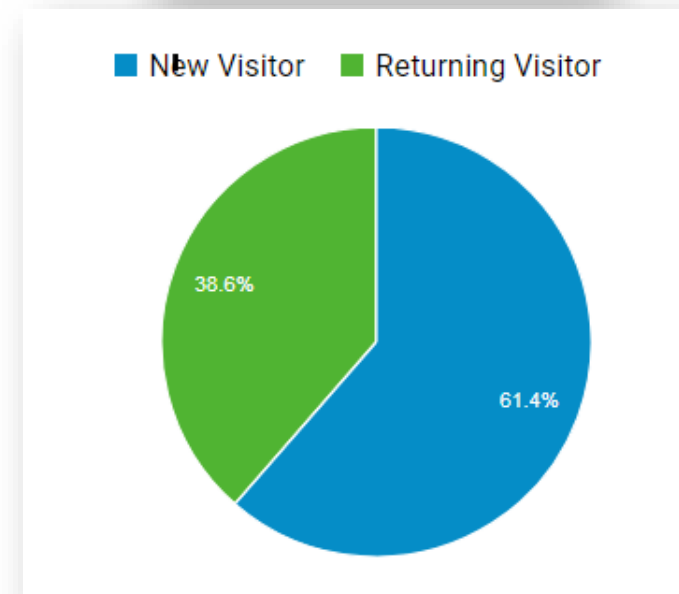
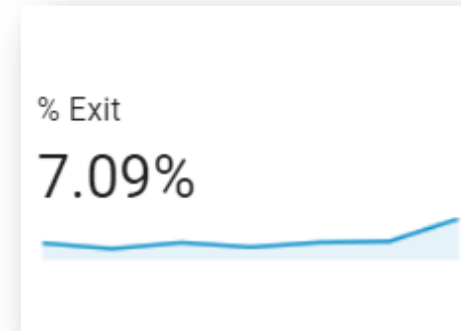
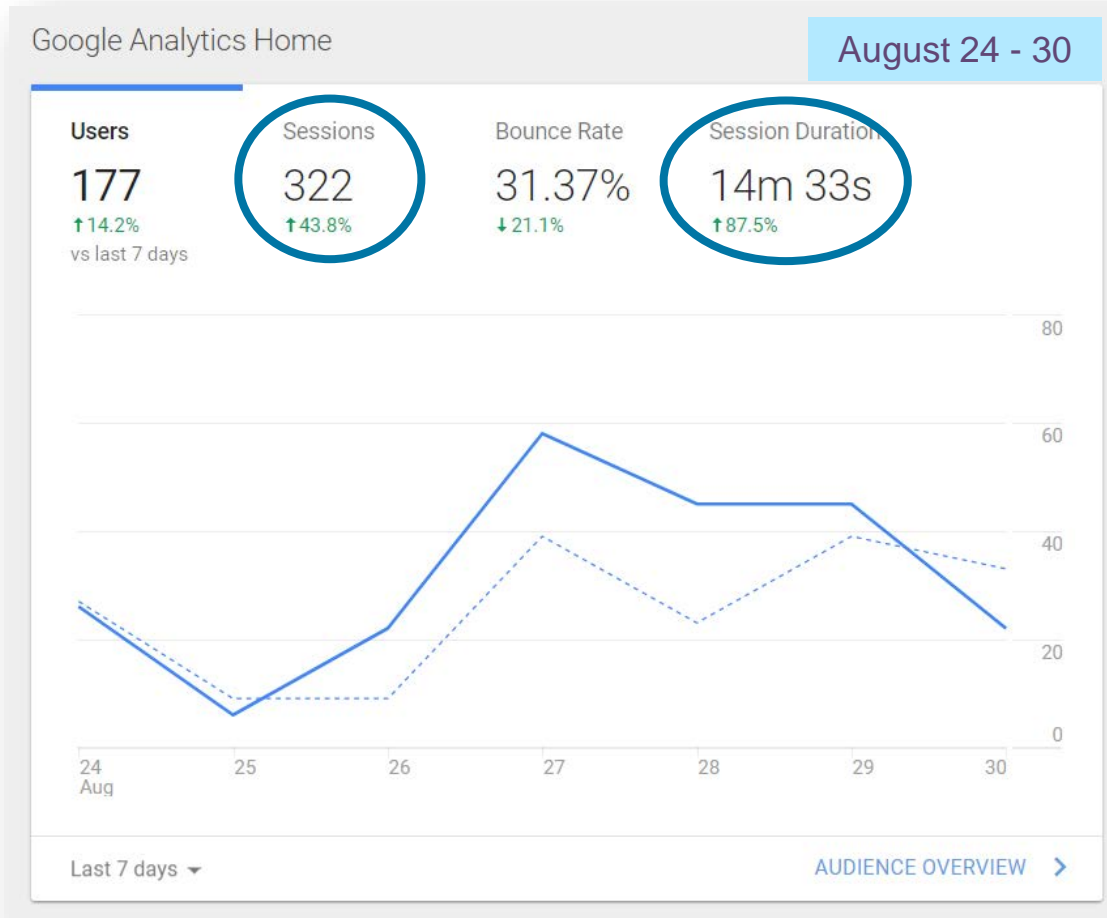
As of July 31, 2018





# Selected Google Analytics data

pregsource.nih.gov





## Task Force on Research Specific to Pregnant Women and Lactating Women (PRGLAC)



The 21st Century Cures Act established PRGLAC to advise the Secretary of Health and Human Services (HHS) regarding gaps in knowledge and research on safe and effective therapies for pregnant women and lactating women. PRGLAC is tasked with identifying these gaps and will report its findings back to

the Secretary.

**“Leverage established and support new infrastructures/collaborations to perform research in pregnant women and lactating women”**



# Dashboard Addition



## Medication and Supplement Tracker

[Add](#)

[Drug list](#)

Select "Add" to list a prescription or over-the-counter medicine, vitamin, or herbal supplement. If you stopped taking an item or need to change information about it, select "Edit" next to that item.

### Current Medications and Supplements

## Add Medication or Supplement

Type the name of a medication, vitamin, or herbal supplement in the search field to add that item to your list.

What are you taking?

bactr

Search

bactracillin g

bactracillin g benzathine

bactrim

bactroban

Systemic Formulas Bio Command 3 Bactrex

Systemic Formulas T3 Bactrex Tincture



**Why are you taking this? \***

- Healthcare provider prescribed or recommended it
- I decided to take it on my own to treat a symptom (for example, a headache)
- I think it is good for me and/or my baby
- Unsure
- Prefer not to answer
- Other

**When did you first start taking this? \***

/  /  

**How do you take this medication? \***

**How many do you take at one time? \***

**How often do you take it? \***

**Are you breastfeeding while taking this? \***

- Yes  No  Unsure  Prefer not to answer

**Are you currently taking this item? \***

- Yes, I am currently taking this.  No, I am no longer taking this.

**Submit**

*\* The fields with the red asterisk are required.*

[pregsource.nih.gov](https://pregsource.nih.gov)



When did you stop taking this item? \*

/  /

Why did you stop taking this? \*

- Change in health insurance coverage
- Course of treatment ended
- Did not seem to work
- Healthcare provider's advice
- Felt better
- Personal decision
- Side effects too severe or too many
- Switched to another medication
- Too expensive
- Worried it might affect my baby through my breastmilk
- Worried that it might affect my pregnancy
- Unsure
- Prefer not to answer
- Other

**Submit**

\* The fields with the red asterisk are required.



[pregsource.nih.gov](https://pregsource.nih.gov)



# What's Coming Up?

- Spanish language version
- New questionnaires:
  - Post-partum and infant health up to 36 months
  - Special populations/topics (e.g., women with physical disabilities)
- Professional portal for approved researchers to access de-identified data
- Dedicated Twitter feed



NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development



## Pregnant women:

Share and compare your experiences in the PregSource® research project.

[pregsource.nih.gov](http://pregsource.nih.gov)

[pregsource.nih.gov](http://pregsource.nih.gov)



# Professional Portal

- Modeled after DS-Connect<sup>®</sup>
- Investigators register for “Level 1 Access” at first
- Registrants are asked to indicate their intended use of the data
- Allows viewing questionnaires and browsing through combined de-identified data
- Includes some simple tabulations (e.g., filtered frequency data)





- Stephanie Archer
- Sujata Bardhan
- Lisa Kaeser
- Melissa Parisi
- Caroline Signore
- Christina Stile
- Paul Williams
- Tonse Raju
- Debowanna Blackshear
- Debbie Jae
- PregSource Partners

**Thank you**