

PregSource[®] :

Crowdsourcing to Understand Pregnancy

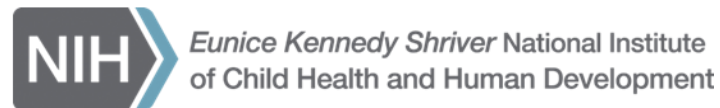
Caroline Signore, MD, MPH

September 27, 2018

PHACS CAB



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:

- Range of physical and emotional experiences, as well as changes 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

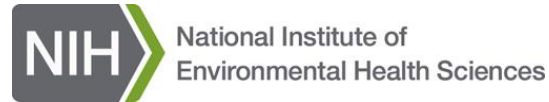
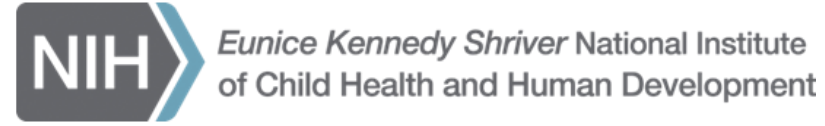
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- Build a more complete picture of **typical pregnancy** and develop strategies for improving maternal care and pregnancy outcomes
- Gain information on **understudied groups** (e.g., pregnant women with disabilities)
- Build a large **epidemiological 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
- Website and database programming done via contract
- Built on earlier experience with DS-Connect[®]
- Tested with a group of pregnant women, then revised

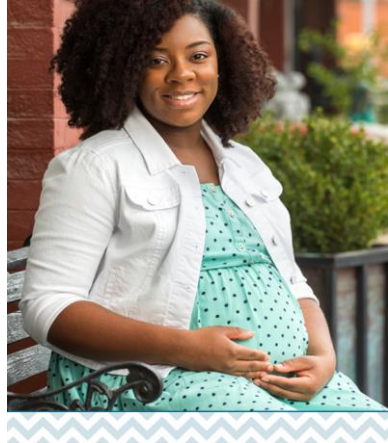


How Does It Work?

- Eligible: 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



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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 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? *

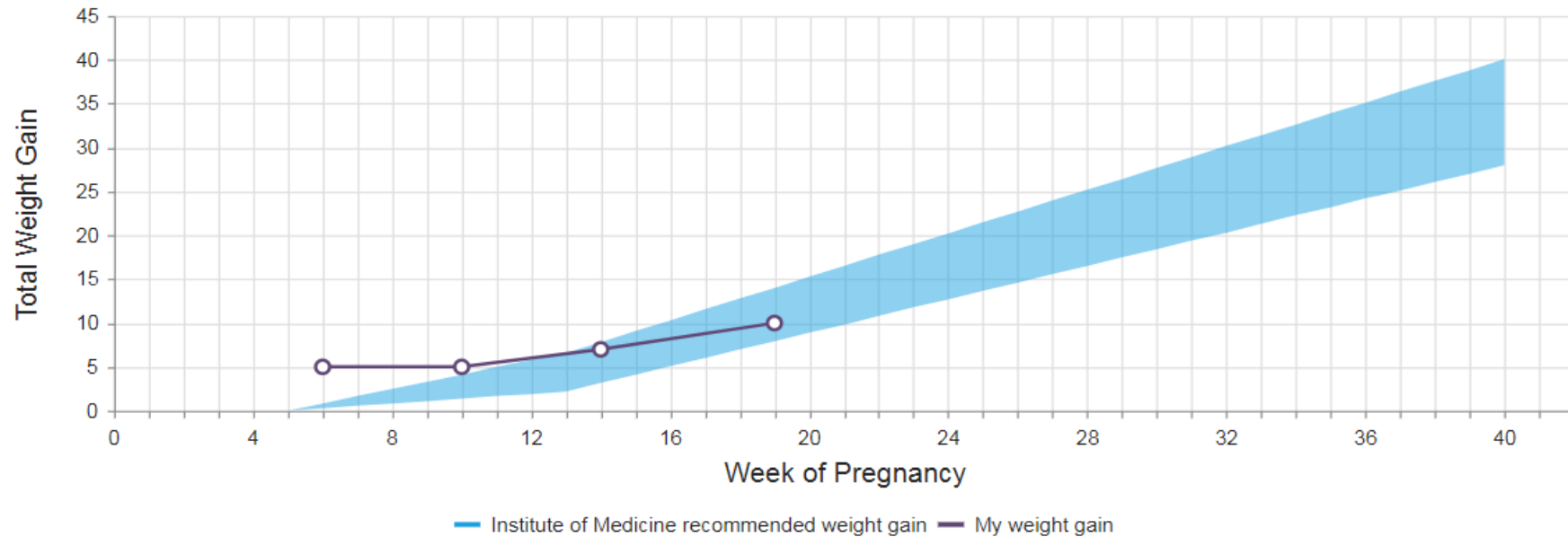
Assisted Reproductive Technolc 



Trackers

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

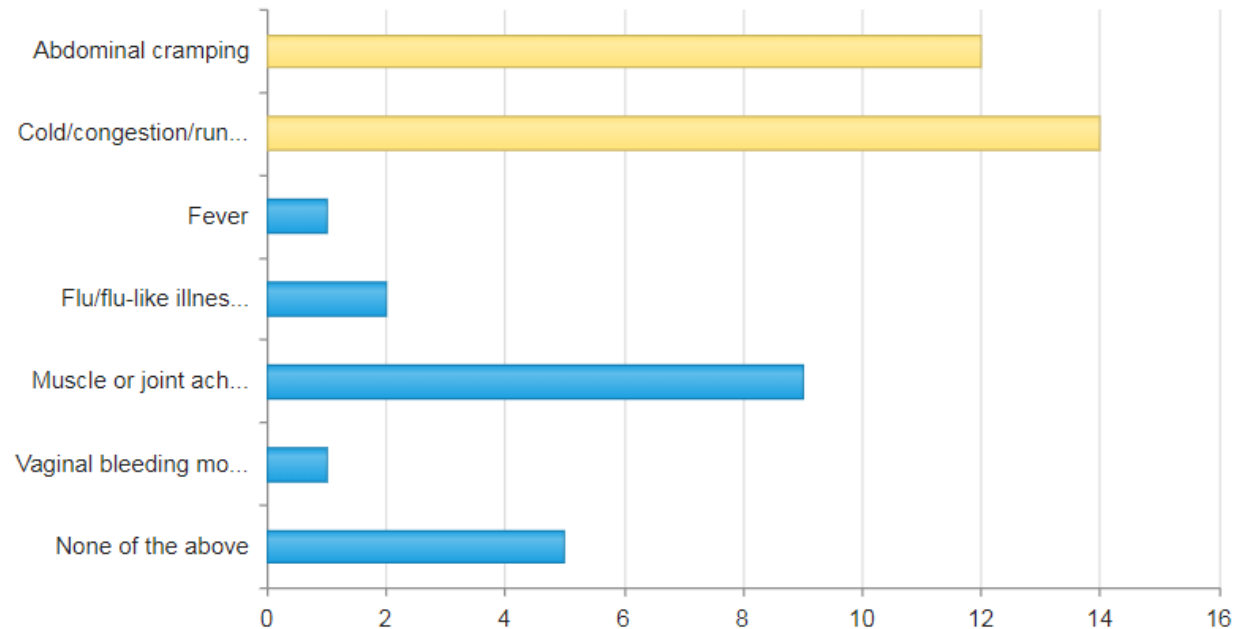


WEEKS 17-20: TELL US HOW YOU ARE DOING - MY PREGNANCY CONDITIONS

Your response

Since your last update, have you had any of the following symptoms?
Select all that apply.

31 people provided 44 response(s)



**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:





Released: October 2017

pregsource.nih.gov

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PregSource™
Crowdsourcing to Understand Pregnancy

Your Participation

[JOIN US](#) in Research To Improve Health Care for Pregnant Women

PregSource: Your Pregnancy. Your Experience. Your Care.



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 maternal care in the United States.

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



pregsource.nih.gov

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





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 experi



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

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 pregnancy is really like.”

[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 data collected will help researchers understand what are the patterns of weight gain during pregnancy, and how do they affect maternal, fetal, and infant health?



PregSource data will help

Our Moment of Truth

Discover Midwife Care & Women's Health



Eunice Kennedy Shriver National Institute of Child Health and Human Development



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

...se—change over the course of the pregnancy?

...abilities or chronic diseases, experience

...chart participants' weight, sleep, mood, morning

From May 2019 Birth Club

PregSource - Help with research once you are pregnant!



MousenSquirrel

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 project focuses on the physical and emotional aspects of pregnancy, and aims to identify distinct challenges faced by subgroups of pregnant women.

[Quick Read](#)

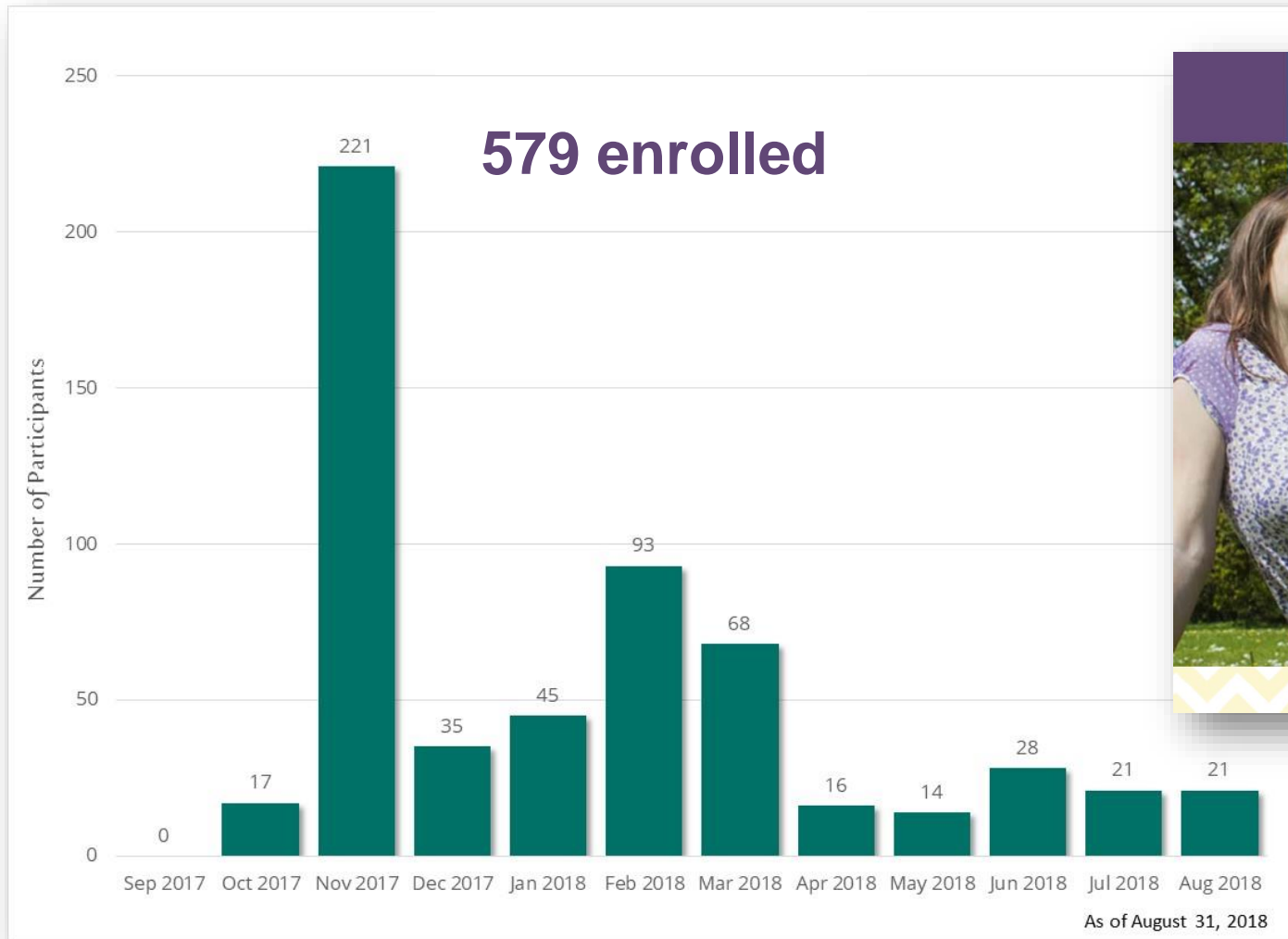


BERMAN INSTITUTE
BIOETHICS BULLETIN

pregsource.nih.gov



Recruitment



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](#)

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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



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



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

pregsource.nih.gov



Professional Portal

- Modeled after DS-Connect[®]
- 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)





Higher Level Access



Level 2

- Custom searches
- Propose new survey modules
- Request a letter of support
- Download deidentified data

Level 3

- Enables investigator to recruit subjects for a study through PregSource

Both Level 2 and 3 access require approval by Registry Coordinator and/or Research Review Committee



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

Thank you