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

• 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
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®
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
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
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

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

Trackers

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 messages.

Data, Facts, & Figures

Show My Progress Triggers
Show Me All PregSource Data
Go to my Personalized Article Library

View data

Change My Pregnancy Info
Questionnaires

Include:

- Due date
- Health history
- Demographics
- Trackers
- Monthly gestational age-specific questionnaires
This graph shows your weight gain throughout pregnancy compared to the recommended weight gain for your body mass index (BMI).
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)

- Abdominal cramping
- Cold/congestion/run...
- Fever
- Flurfflu-like illness...
- Muscle or joint achi...
- Vaginal bleeding mo...
- None of the above

Deidentified data feedback: Is this “normal?”

pregsource.nih.gov
Resource Library:
Articles from Trusted Sources

• >450 articles about pregnancy, pregnancy complications, and infant health
• From our Partner organizations
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℠.
- I understand that taking part in PregSource℠ is entirely my choice.
- If I change my mind and no longer want to take part in PregSource℠, I am free to do so and do not have to give any reason.
- I agree to allow PregSource℠ 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℠.
Released: October 2017

Outreach

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

Shape the future of obstetric care.
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 the physical, informational and emotional aspects of pregnancy, labor and delivery, and the distinct challenges faced by subgroups of women, including those with disabilities. By offering a more comprehensive and personal experience — from normal pregnancies to high-risk pregnancies and other factors — PregSource promises to inform maternal care in the United States.

"PregSource benefits everyone—the participants and the research community," said Diana Waked, Ph.D., director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

Source: NIH

pregsource.nih.gov
What is a typical pregnancy? Research project aims to be resource

By Kristi King | @KingWTOP
February 28, 2018 4:23 am
Crowdsourcing: Can it help get women through pregnancy?

February 27, 2018
Robyn Herrsager-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 Cenius Foundation, Obgyn National Institute of Child Health and Human Development, and Pregsource to bring you the PregSource website. The site is designed to gather data from women across the United States.

The PregSource data will help shape the future of obstetric care.

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

PregSource provides a platform where pregnant women can contribute to research by tracking their pregnancy journey—change over the course of the pregnancy.

Pregnant participants can track their pregnancy journey, smart participants' weight, sleep, mood, morning sickness, and more.

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 preg-sources information directly from pregnant women. The physical and emotional aspects of pregnancy, and the identification of distinct challenges faced by subgroups of women.
Recruitment

579 Participants Enrolled

pregsource.nih.gov
## Participant Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>PregSource</th>
<th>US Pop*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age &lt;35y</td>
<td>62%</td>
<td>87%</td>
</tr>
<tr>
<td>Hispanic, Latina, or Spanish Origin</td>
<td>6%</td>
<td>23%</td>
</tr>
<tr>
<td>White Race</td>
<td>92%</td>
<td>75%</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>89%</td>
<td>50%</td>
</tr>
<tr>
<td>Master’s Degree or higher</td>
<td>63%</td>
<td>12%</td>
</tr>
<tr>
<td>Employed</td>
<td>78%</td>
<td>--</td>
</tr>
<tr>
<td>1st Trimester at Enrollment</td>
<td>29%</td>
<td>--</td>
</tr>
<tr>
<td>Nulliparous</td>
<td>40%</td>
<td>30%</td>
</tr>
<tr>
<td>Overweight or Obese</td>
<td>41%</td>
<td>52%</td>
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</tbody>
</table>

*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

Users: 177, increase 14.2% vs last 7 days
Sessions: 322, increase 43.8%
Bounce Rate: 31.37%
Session Duration: 14m 33s, increase 87.5%

% Exit: 7.09%

New Visitor: 61.4%
Returning Visitor: 38.6%
“Leverage established and support new infrastructures/collaborations to perform research in pregnant women and lactating women”
This shows how the search feature will help you find the correct drug even if you don't know the full name.

The tracker is indexed to the National Library of Medicine database, RxNorm.

Dashboard Addition

**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?

<table>
<thead>
<tr>
<th>bactr</th>
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<tbody>
<tr>
<td>bactracillin g</td>
</tr>
<tr>
<td>bactracillin g benzathine</td>
</tr>
<tr>
<td>bactrim</td>
</tr>
<tr>
<td>bactroban</td>
</tr>
<tr>
<td>Systemic Formulas Bio Command 3 Bactrex</td>
</tr>
<tr>
<td>Systemic Formulas T3 Bactrex Tincture</td>
</tr>
</tbody>
</table>
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.
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

* The fields with the red asterisk are required.
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
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)
Stephanie Archer
Sujata Bardhan
Lisa Kaeser
Melissa Parisi
Caroline Signore
Christina Stile
Paul Williams
Tonse Raju
Debowanna Blackshear
Debbie Jae
PregSource Partners

Thank you