

October 26-28, 2020

Maternal & Infant Health in the Digital World:

Patient-Centered Care During COVID and Beyond

VIRTUAL CONFERENCE

hmhbga.org/event/beyondcovid2020

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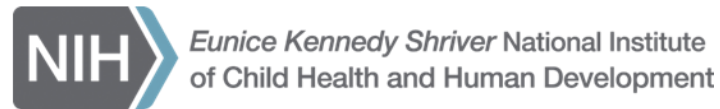
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Crowdsourcing to Understand Pregnancy

Stephanie Archer, M.S and Sujata Bardhan, Ph.D;

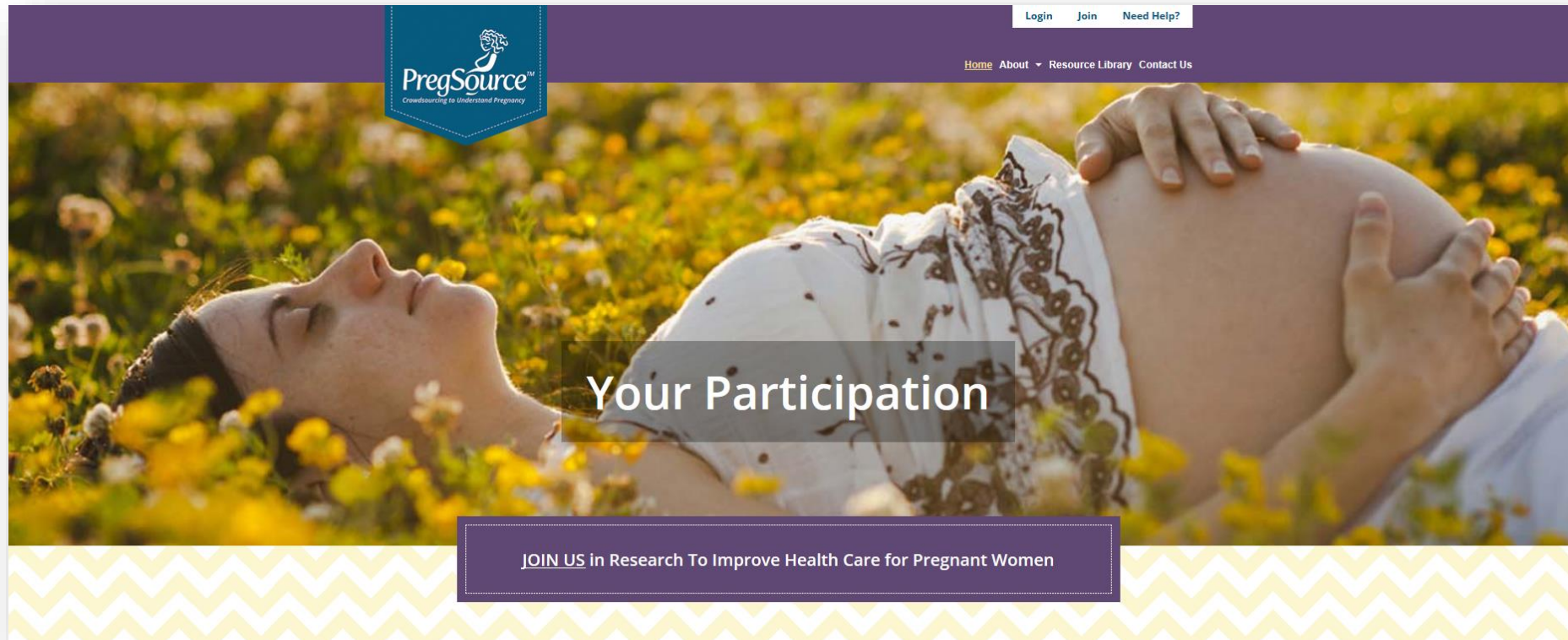


<http://pregsource.nih.gov>



Released: October 2017

pregsource.nih.gov



PregSource: Your Pregnancy. Your Experience. Your Care.



pregsource.nih.gov



Why create an online pregnancy ‘registry’?

With crowdsourcing, we can efficiently establish a large data set and serve our participants:

- Detail the **natural history**—and variations—of human pregnancy
 - Impact of these experiences on women’s lives
- Provide information about pregnancy from trusted sources





How Does It Work?

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



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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 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 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](#)


 **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\(s\).](#)

 **Data, Facts, & Figures**

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

 **Change My Pregnancy Info**

Questionnaires to complete

Update information in trackers

View data



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 



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?

bactracillin g

bactracillin g benzathine

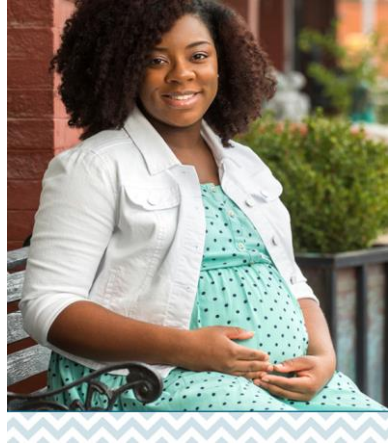
bactrim

bactroban

Systemic Formulas Bio Command 3 Bactrex

Systemic Formulas T3 Bactrex Tincture

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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



PregSource will *never* sell your data!

The Washington Post

April 10, 2019

Technology

Is your pregnancy app sharing your intimate data with your boss?

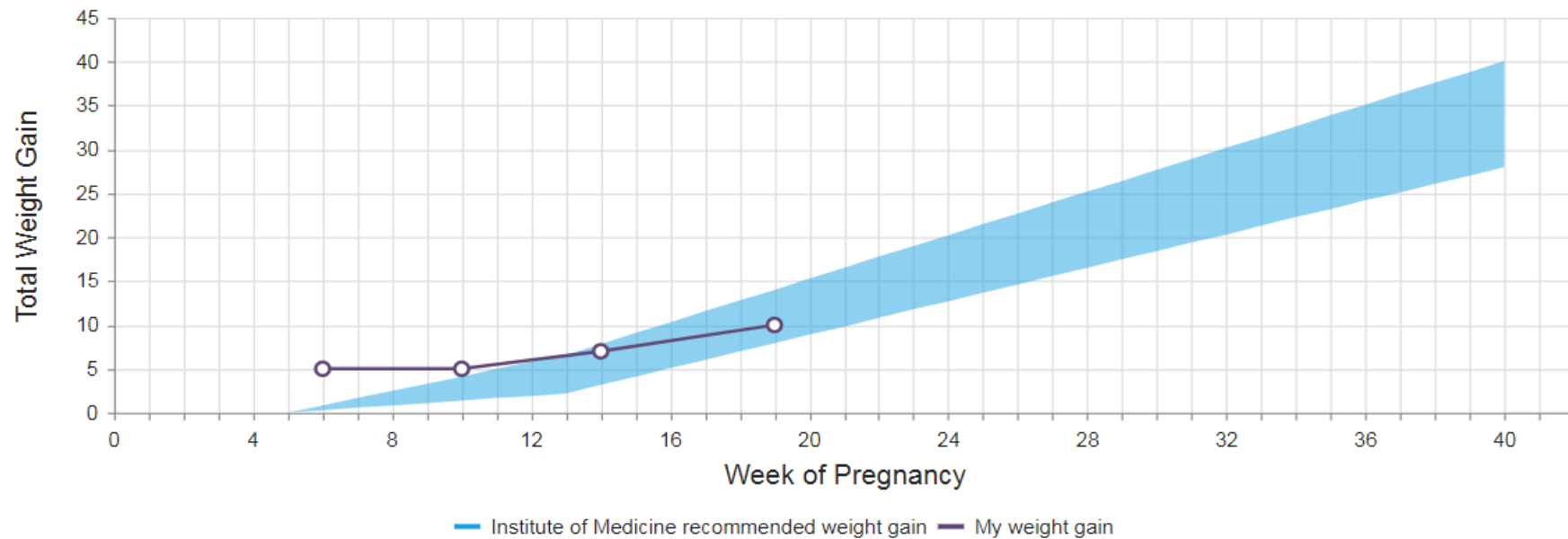
As apps to help moms monitor their health proliferate, employers and insurers pay to keep tabs on the vast and valuable data



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)



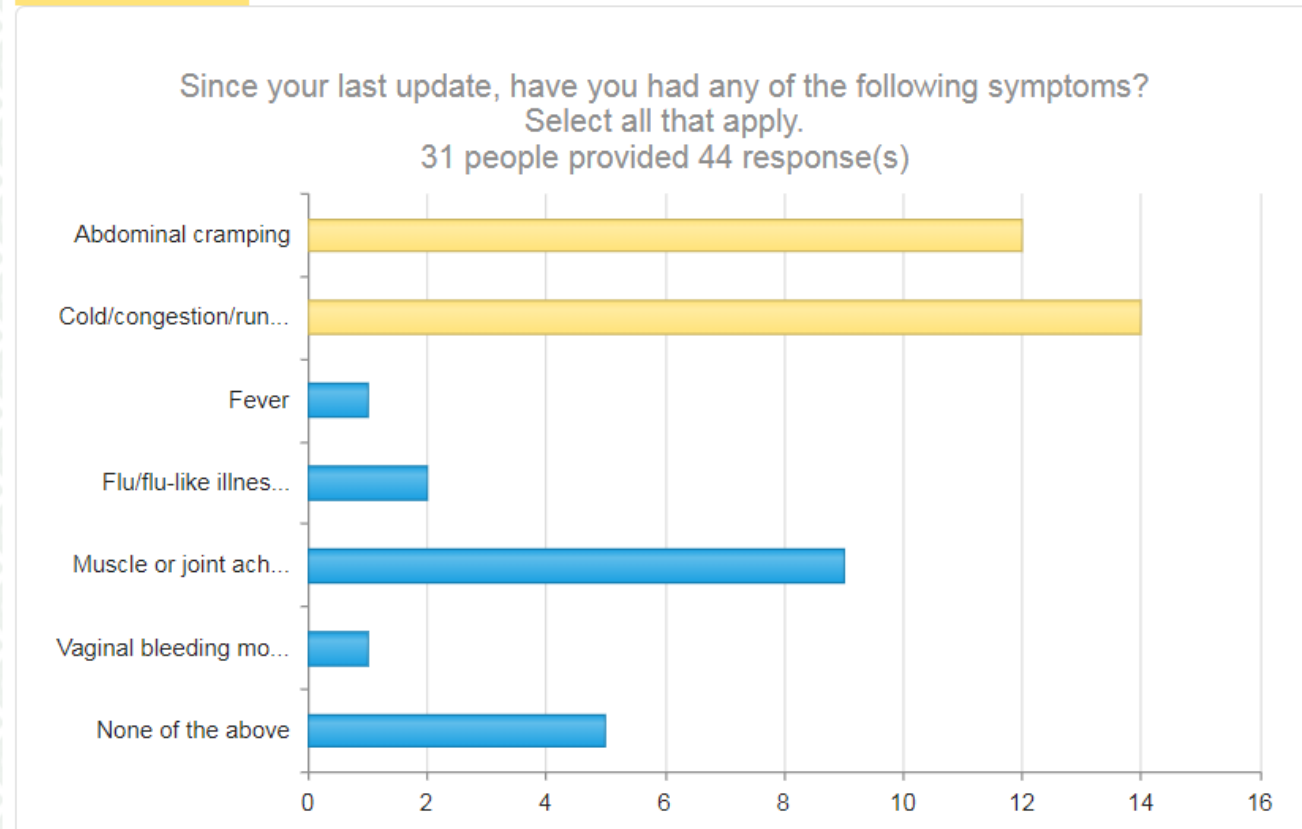
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[Export as Image](#)



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:



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What's Coming Up?

- Outreach
- Mobile app
- 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



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



Pregnant women:

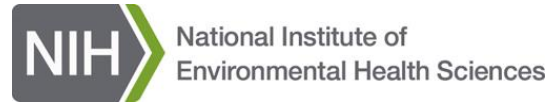
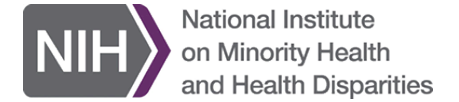
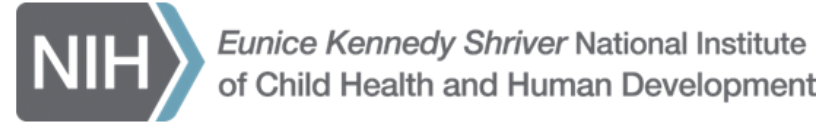
Share and compare your experiences in the PregSource® research project.

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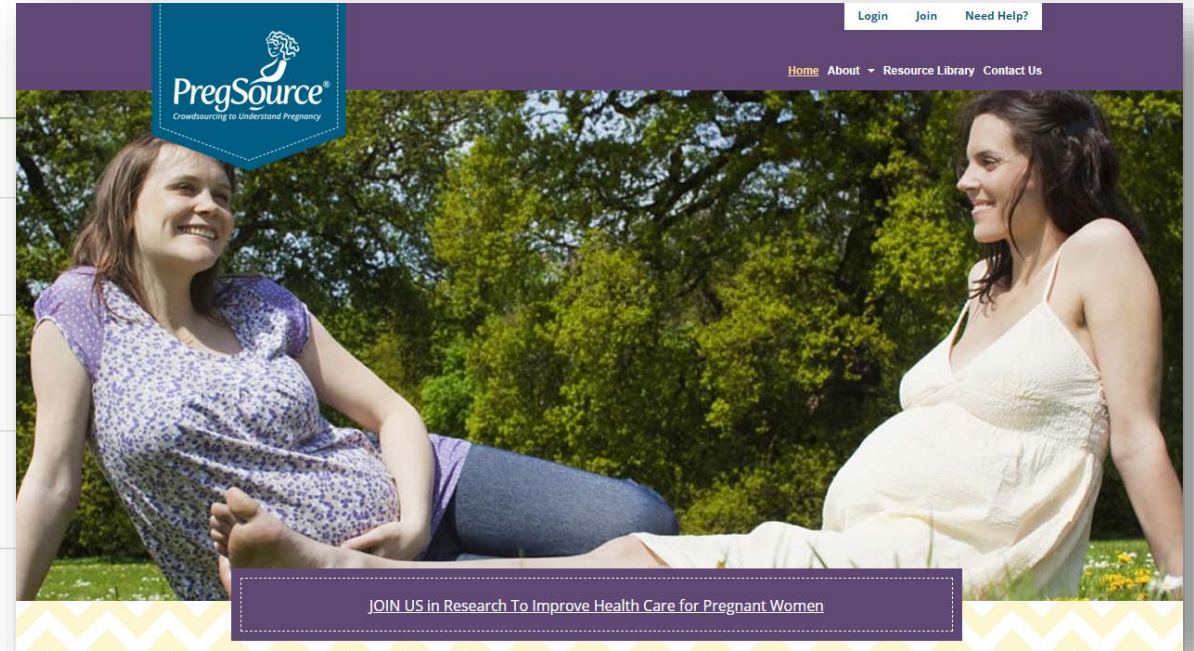
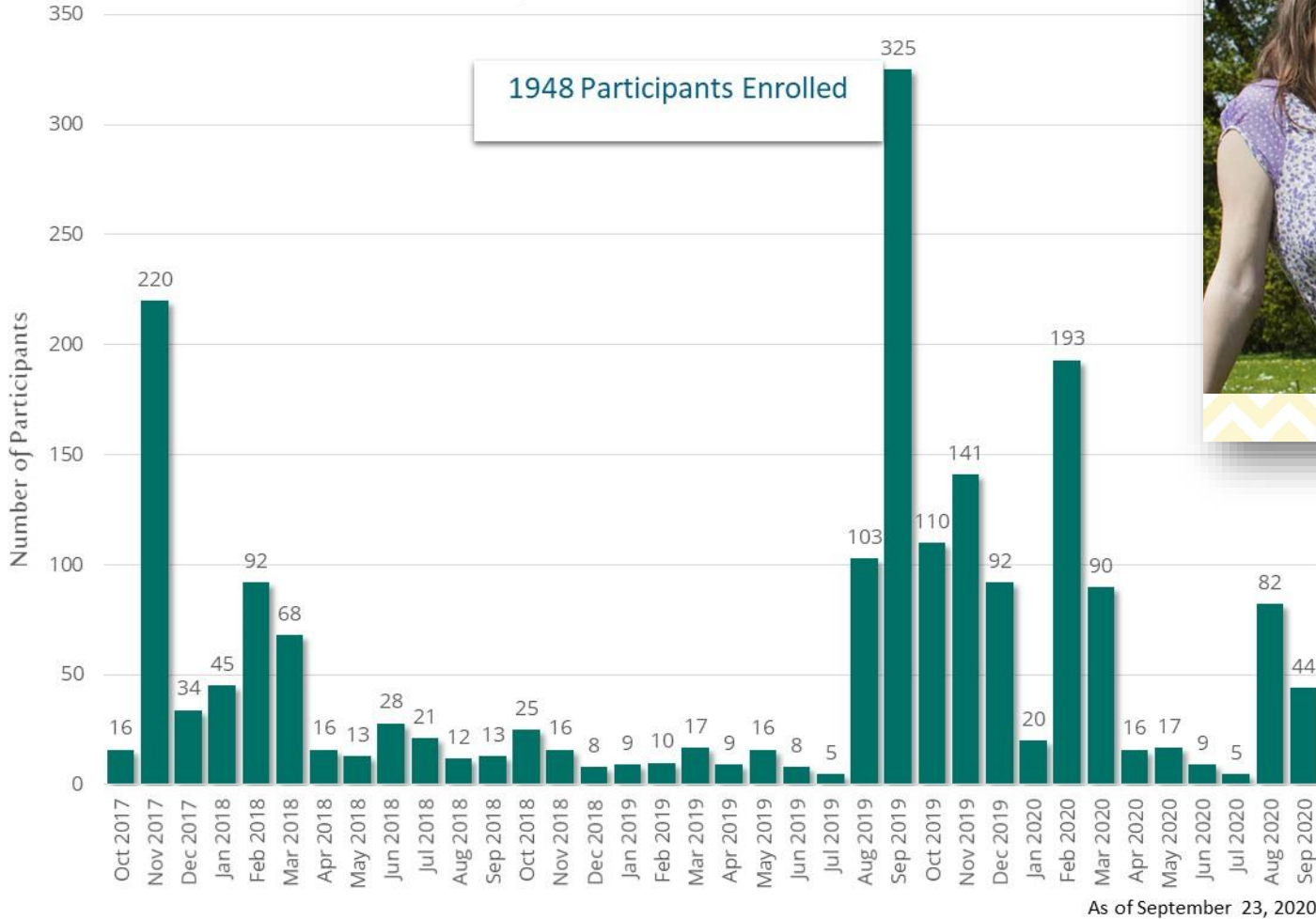
PregSource Partners





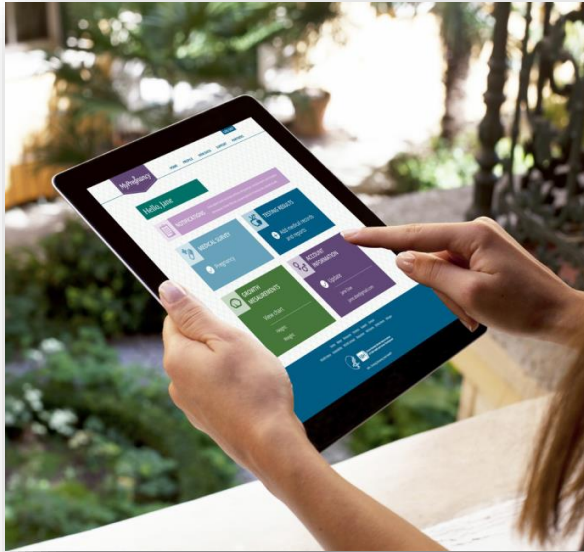
Recruitment

PregSource® Recruitment





Participant Characteristics



	PregSource	US Population*
Age at Registration <35y	32%	87%
Hispanic, Latina, or Spanish Origin	7%	23%
Black, African American, or Negro	4%	12%
White	92%	75%
Private Insurance	88%	50%
Master's Degree or higher	57%	12%
Employed	85%	--
1st Trimester at Enrollment	34%	--
2nd Trimester at Enrollment	40%	--
3rd Trimester at Enrollment	26%	--
Nulliparous	38%	30%
Overweight or Obese	48%	52%
Married	92%	--

*NVSS, Births 2016, https://www.cdc.gov/nchs/data_access/vitalstatsonline.htm



Here's what we need:

You should check out PregSource!





Thank you



Pregnant women:

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pregsource.nih.gov

Questions?