

What All of Us illuminates about All of Us: The NNLM Experience Engaging **Populations Historically Underrepresented** in Biomedical Research NCNMLG/MLGSCA Joint Meeting 14 June 2019

Amanda J. Wilson

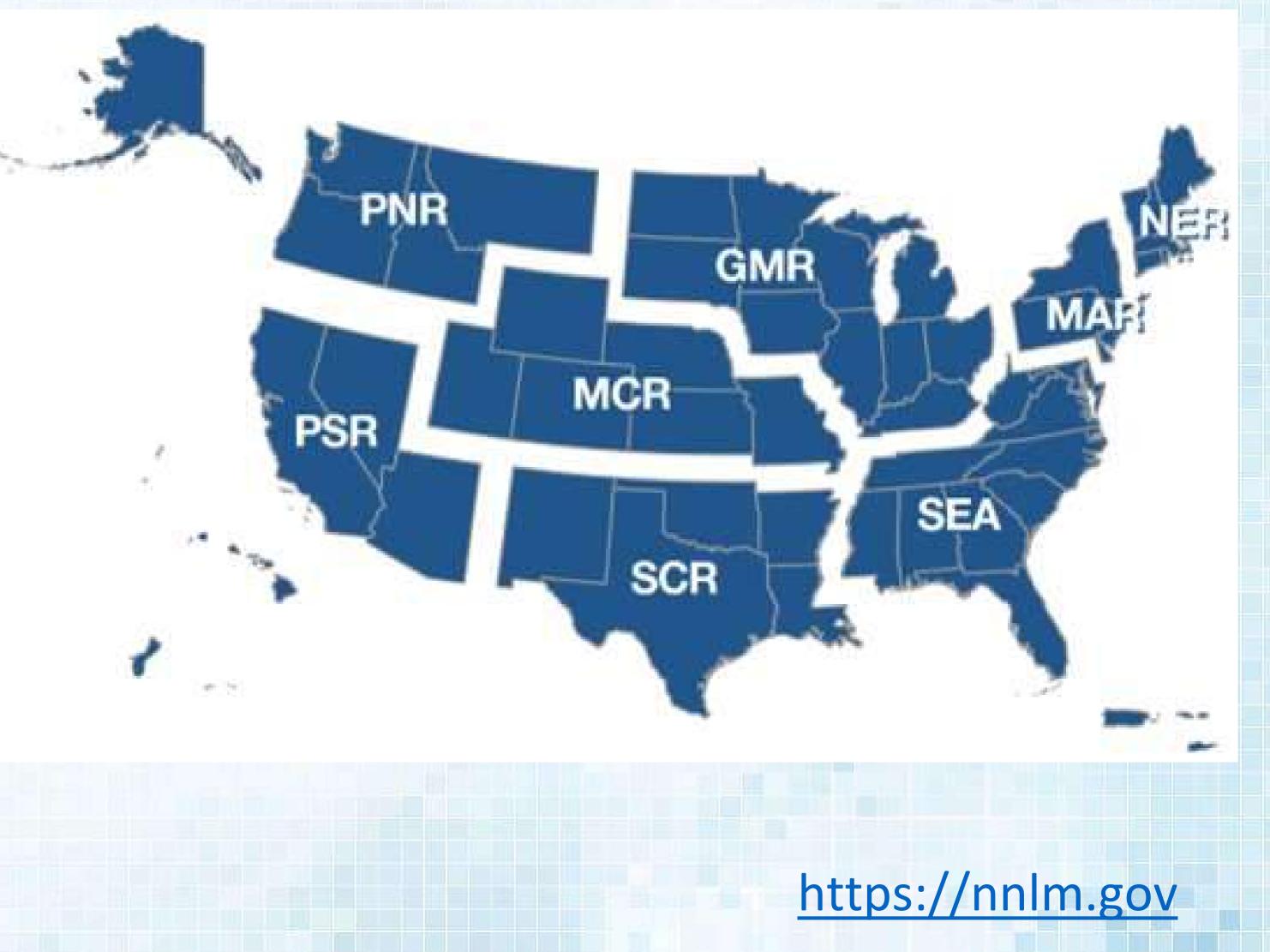
Head, National Network Coordinating Office National Library of Medicine



### National Network of Libraries of Medicine (NNLM)

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	Libraries	
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Greater Midwest Region (GMR)	lowa
Middle Atlantic Region (MAR)	Pitt
MidContinental Region (MCR)	Utah
New England Region (NER)	UMass
Pacific Northwest Region (PNR)	UW
Pacific Southwest Region (PSR)	UCLA
South Central Region (SCR)	UNT
Southeastern/Atlantic Region (SEA)	UMB



#### National Offices (Institution)

**DOCLINE Coordination (UMB)** 

Evaluation (UW)

Public Health Coordination (UMass)

Training (Utah)

Web Services (Pitt)



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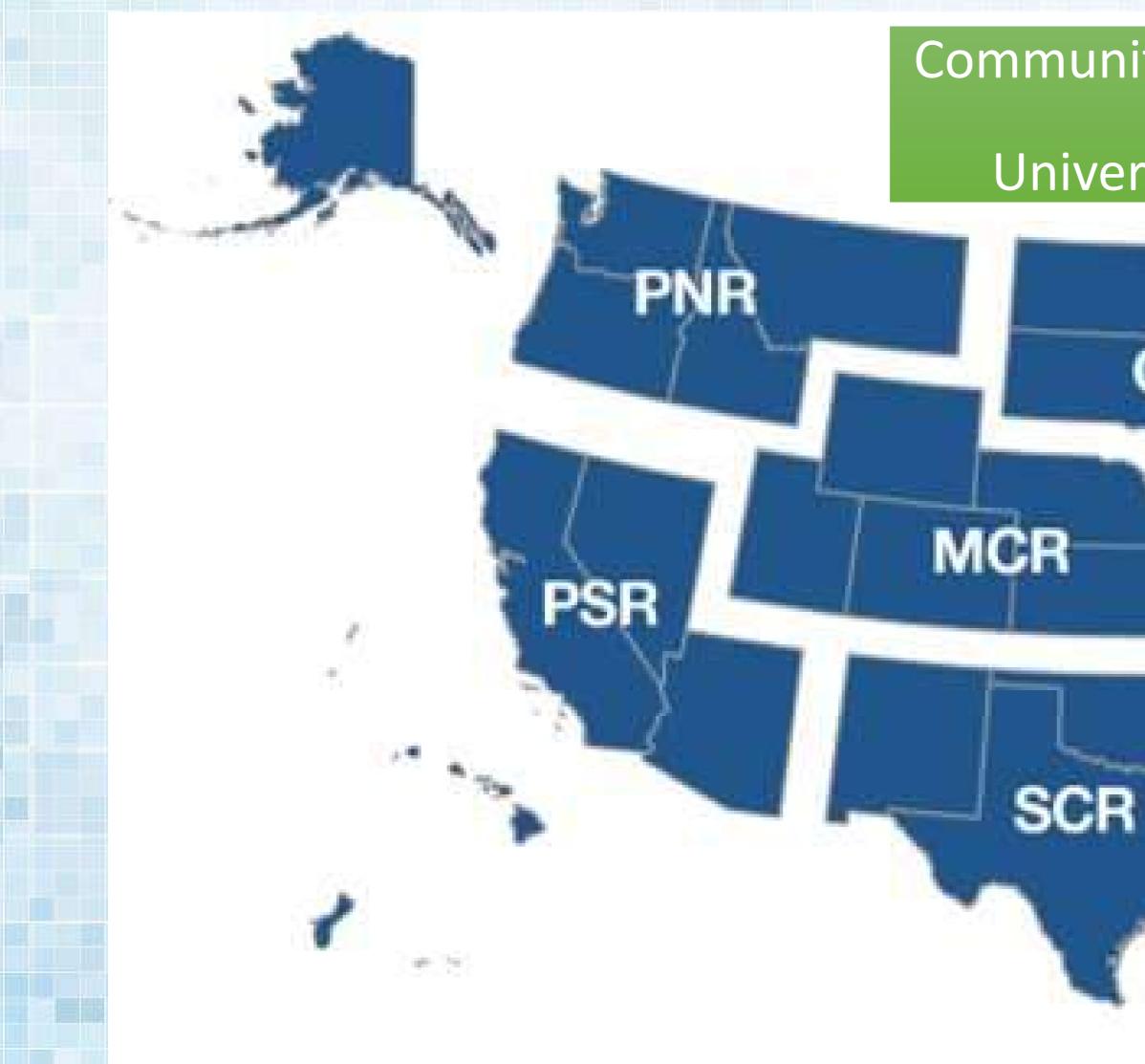


https://joinallofus.org/nlm



### NNLM All of Us National Program Coordinating Centers

GMR



### **Community Engagement** University of Iowa

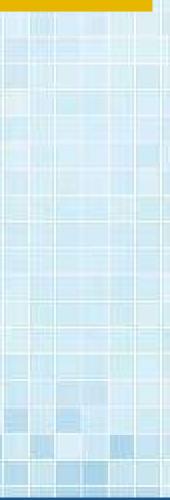
SEA

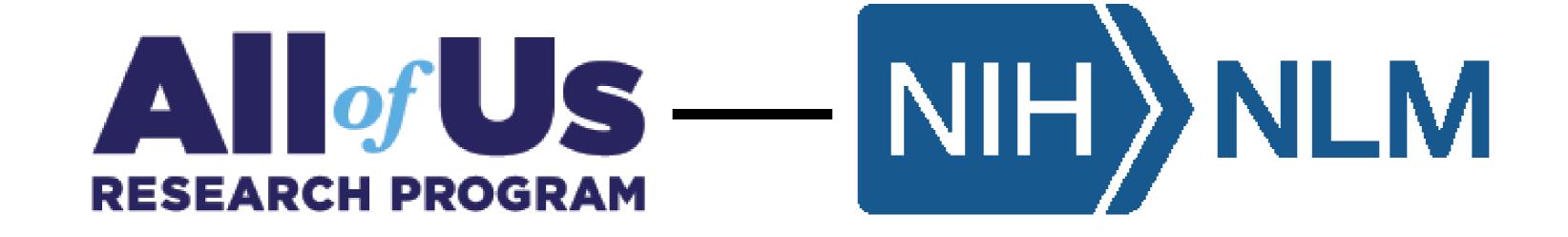
Training and Education at University of Pittsburgh









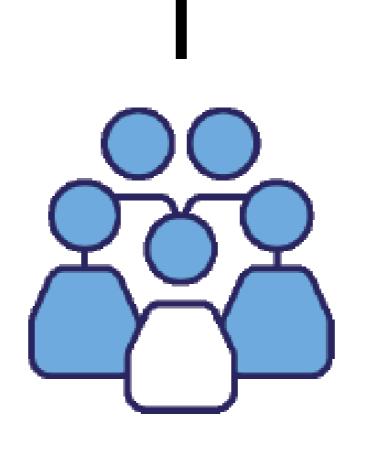




## Education

### Community Engagement

### **AoU Learning** Platform









<b>UBR Population Description</b>	Determination
Race/Ethnicity	Is reported and is His something other than
Age	Under 18 or over 65
Sex	Assigned female or i
Sexual and Gender Minorities (SGM)	Is reported and is no sexual orientation is
Income relative to FPL	Is reported and below
Educational Attainment	Is reported and is les
Geography	Zip code is reported population resides in
Access to Care	Participant needed of but cannot readily us as needed
Disability	Participant has a phy

ispanic, Latino or Spanish; race is reported and identifiin White

intersex at birth

ot Man, or is different than participant-reported sex at birth; reported and is not straight

ow Federal Poverty Level

ess than a high school degree

and is contained in the list of rural zip codes (>50% of n a non-metro county and/or rural Census Tract)

or needs any medical visit in the past 12 months or currently, se the health care system or could not pay for medical care

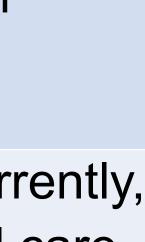
sysical and/or mental disability

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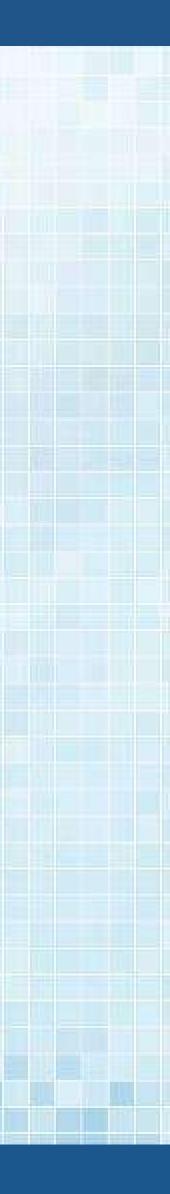
### Community Engagement through NNLM + All of Us

**EDUCATION TOPICS** All of Us Training **Digital Literacy Evaluating Health Information** Genetics **Health Literacy Health Numeracy Researcher Ethics Return of Genomic Results** 

### **ENGAGEMENT ACTIVITIES**

**Book Mobiles/Book Bikes Citizen Science Projects Community Conversations** Health/Science Fairs Health and Wellness Programming **Online Games Summer Reading** 

https://joinallofus.org/nlm



### NNLM + All of Us: Community Engagement Examples

### Types of Activities and Outreach



#### Health/Science Fairs



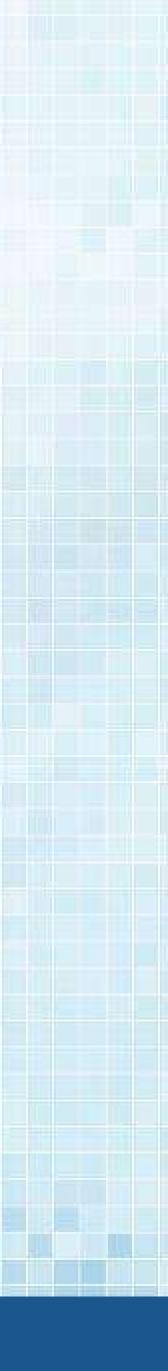
### All of Us Journey Hosting



### Wash and Learn



What have we learned?



### Language from a poster presentation

## What is the All of Us Research Program?

- patient care.

 Establishes cohorts including people with diverse backgrounds normally omitted from research.

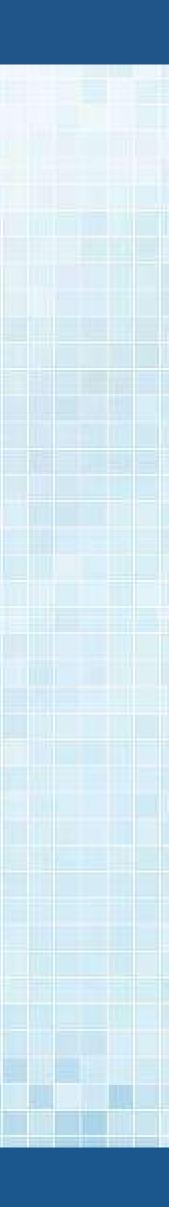
....

 Part of the federal Precision Medicine Initiative. Seizes on advances in research, technology and policies Enables a new era of medicine to develop individualized



### Language from a poster presentation

How does this [All of Us] help library users? The National Library of Medicine intends the library initiative within the All of Us program to reach out to communities of people that tend to be low in health literacy. These are people who for cultural and economic reasons may struggle in communicating with their health care providers or understanding their health care issues. Their local libraries are in an excellent position to supply them with the information they need.



### Conference Proposal

**Program Description** Timid about health programming/outreach to your community? Feel you don't have the requisite skillset? What does health literacy mean today and why does its evolution matter to public librarians? What is the NNLM All of Us Community Engagement Network and how can it help your library advance health literacy initiatives in your community? This learning session includes an interactive poster session by public librarians from across the U.S. sharing how they have actualized a new approach to health literacy programs/services through collaboration with the NNLM All of Us Community Engagement Network. Come learn how your library can benefit! Equity, Diversity, and Inclusion Information People with low health literacy suffer disproportionately from health disparities. We cannot achieve health equity without supporting health literacy - the two are intricately intertwined. This program will illustrate the important role health literacy programs/services play in meeting individuals' health knowledge needs in order to help them attain and maintain better health.





## Taking an active role in your health care.







### Engagement

# What is engagement? Listen Understand Ask questions

## Why is engagement important?Better health and satisfaction



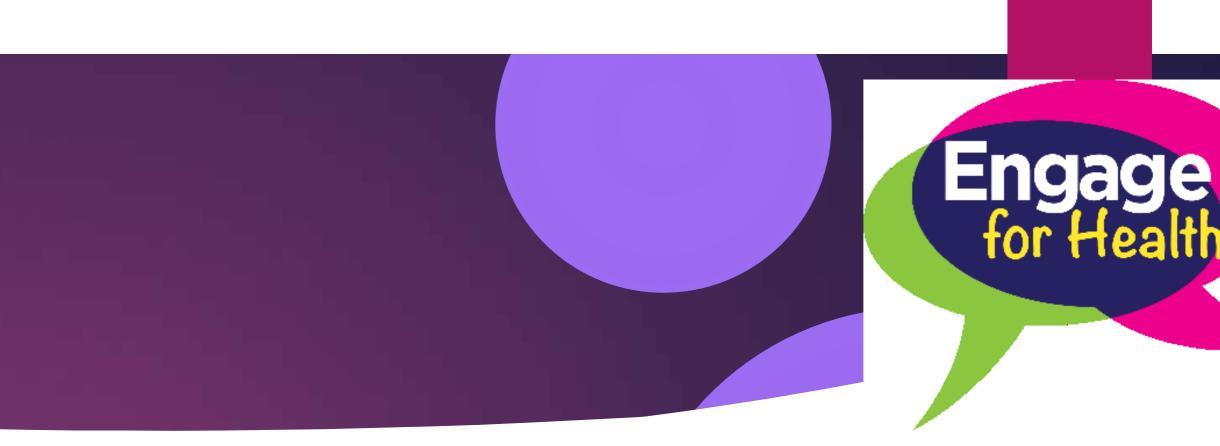
### Tips to Stay Engaged

Take a friend or family member with you Write things down Repeat back what you've heard Ask questions



### Communication

### "The single biggest problem in communication is the illusion that it has occurred."



### -George Bernard Shaw



### **Questions are the Answers**



#### **URL** for AHRQ Waiting Room Video



### **3 Types of Questions**

### What is this test for? What are my choices?

Why do I need this treatment?

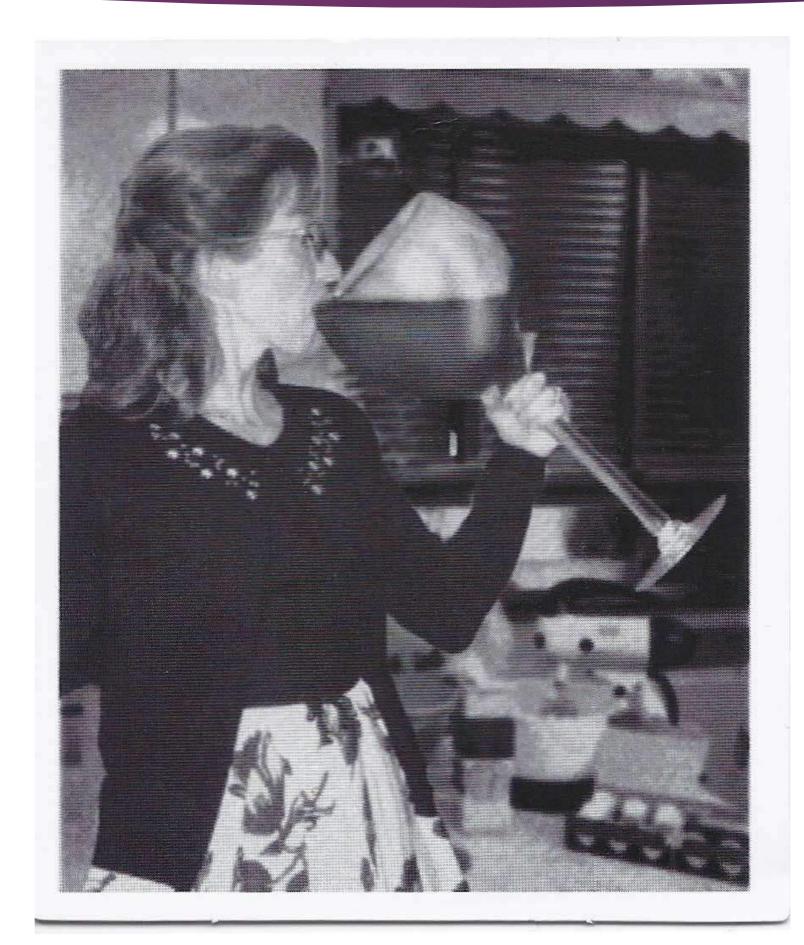
How often do I need to take the medication? How do you spell the name of that drug?

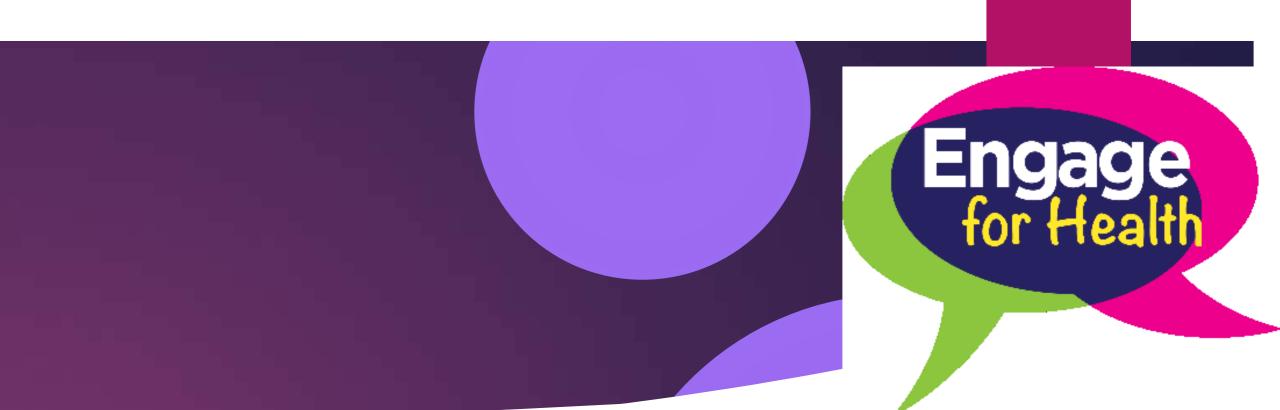


## Why do I need to decrease how much salt I eat?



### What Did You Hear?





### Activity-Role Play





### Questions?

### **Role Play**



#### **Health Topics**

#### **Drugs & Supplements**



#### **Health Topics**

Find information on health, wellness, disorders and conditions



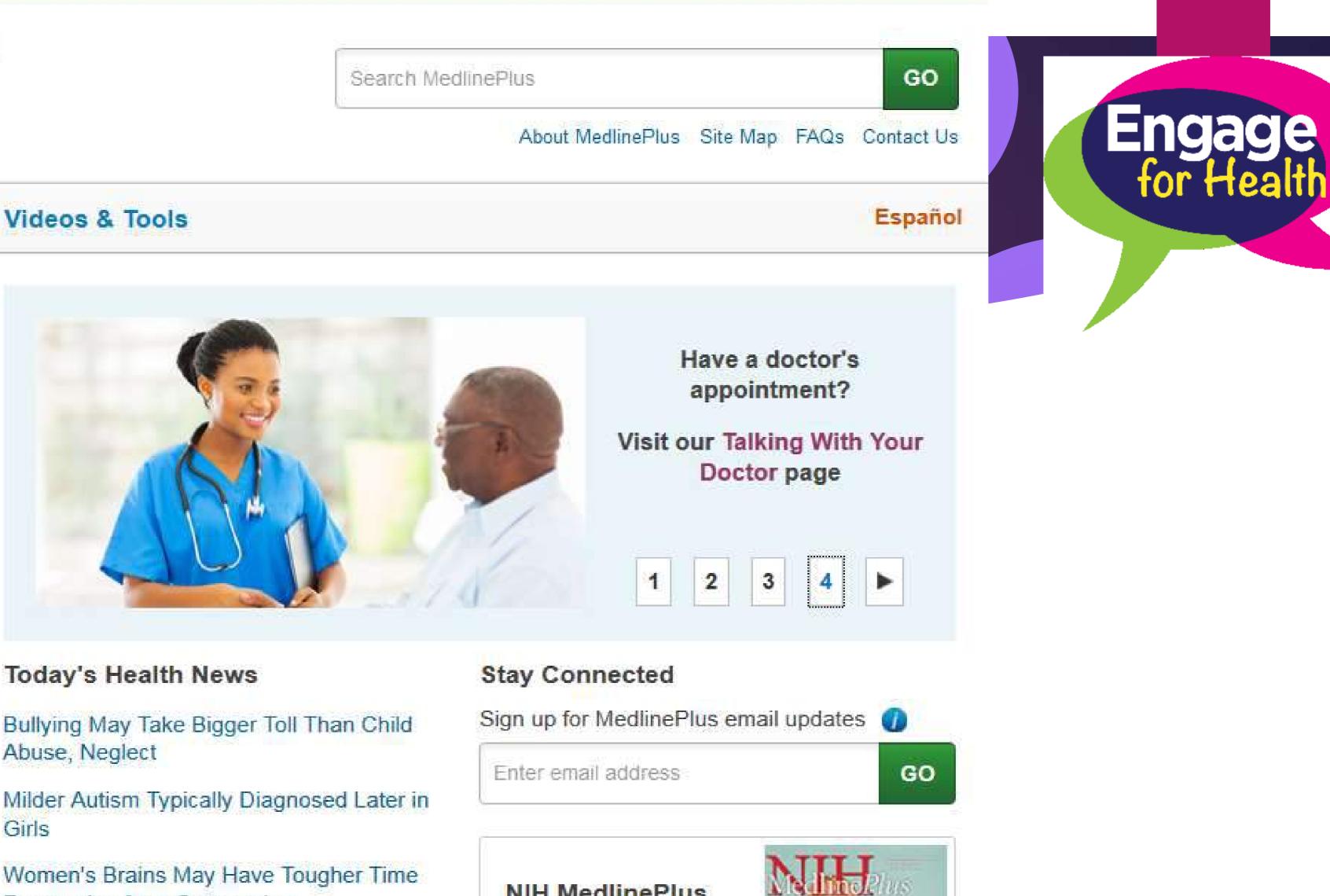
#### **Drugs & Supplements** Learn about prescription drugs, over-the-counter medicines, herbs, and supplements

#### Videos & Tools

Discover tutorials, health and surgery videos, games, and quizzes

#### Medical Encyclopedia

Articles and images for diseases, symptoms, tests, treatments



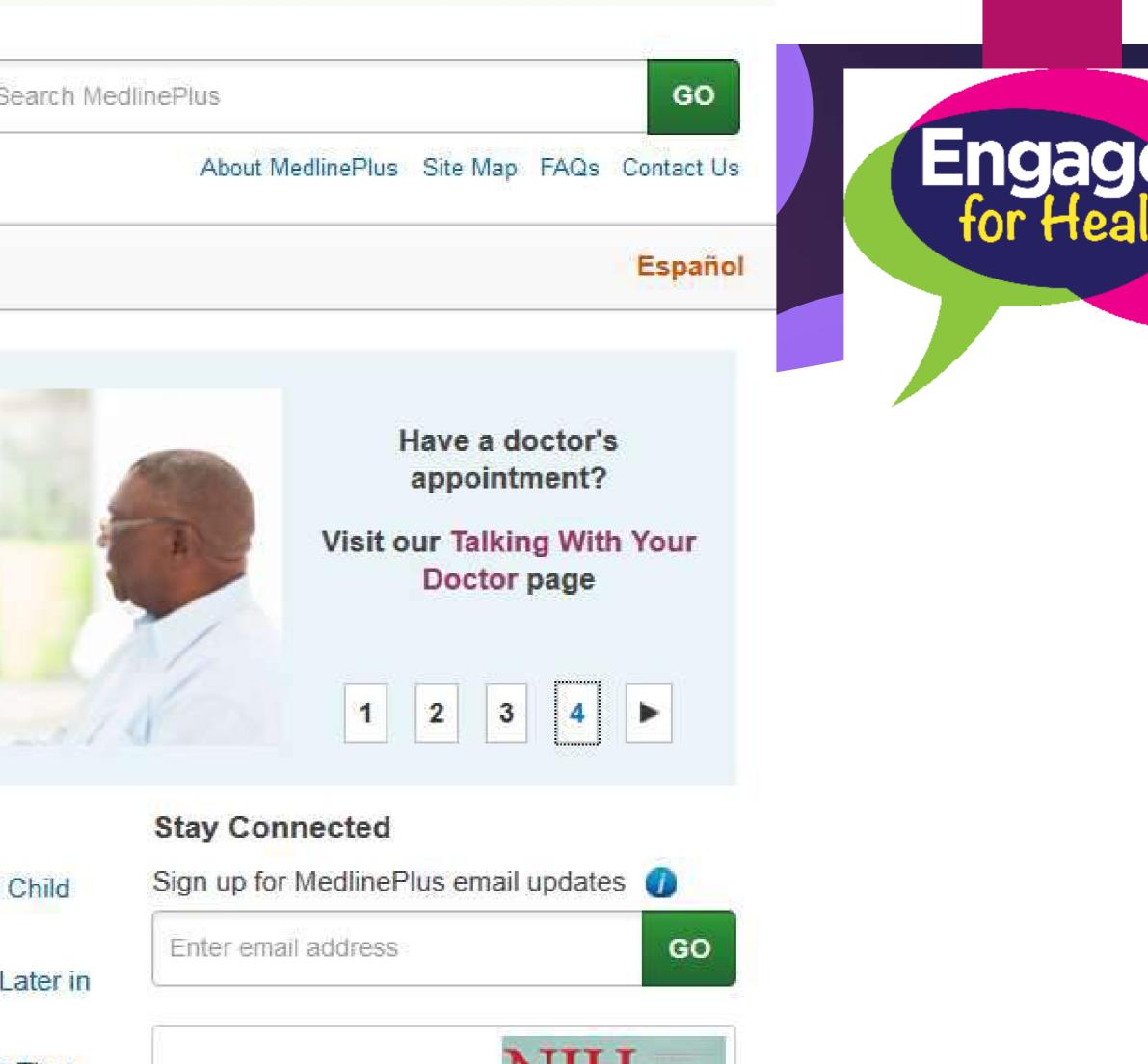
#### **Today's Health News**

Abuse, Neglect

Girls

Women's Brains May Have Tougher Time Recovering from Concussion

More health news



Magazine

NIH MedlinePlus

Read the

#### **URL for MedlinePlus**





#### Videos & Tools **Health Topics** Drugs & Supplements

Home → Health Topics → Talking With Your Doctor

#### **Talking With Your Doctor**

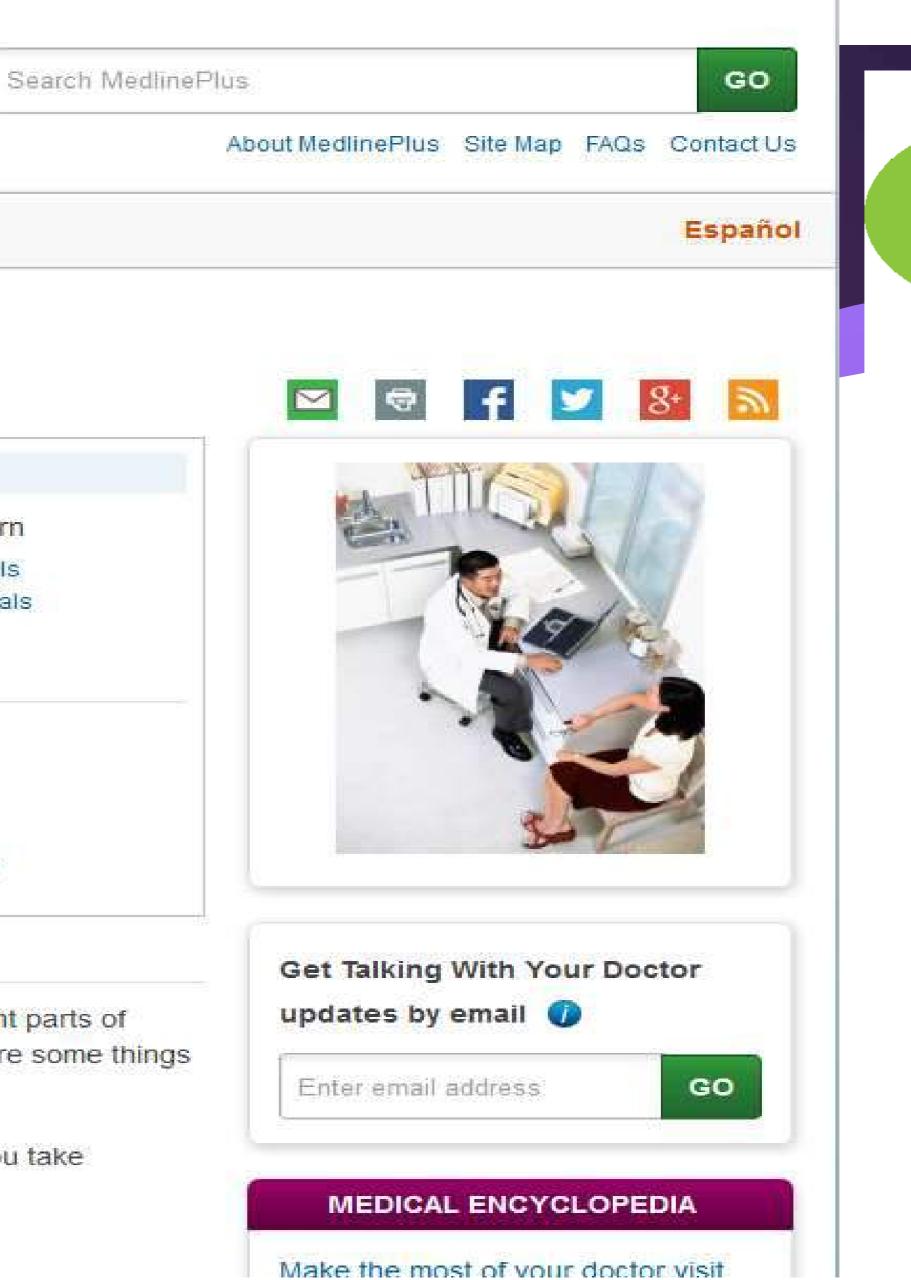
On this page		
Basics	Learn More	See, Play and Learn
Summary	Related Issues	Health Check Tools
Start Here		Videos and Tutorials
Latest News		
Treatments and Therap	ies	
Research	Resources	For You
Clinical Trials	Reference Desk	Children
<ul> <li>Journal Articles</li> </ul>		Teenagers
		Seniors
		Patient Handouts

#### Summary

How well you and your doctor communicate with each other is one of the most important parts of getting good health care. Being prepared can help make the most of your visit. Here are some things you can bring.

- Lists of your concerns, any allergies and all the medicines, herbs, or vitamins you take
- A description of symptoms when they started, what makes them better
- A trusted friend or family member
- A way to take notes during your appointment

#### <u>URL</u> for Talking With Your Doctor (MedlinePlus)





### **TeensHealth**

#### from Nemours

Search here...

#### **Teens Home**

Body

Mind

**Sexual Health** 

Food & Fitness

**Diseases &** Conditions

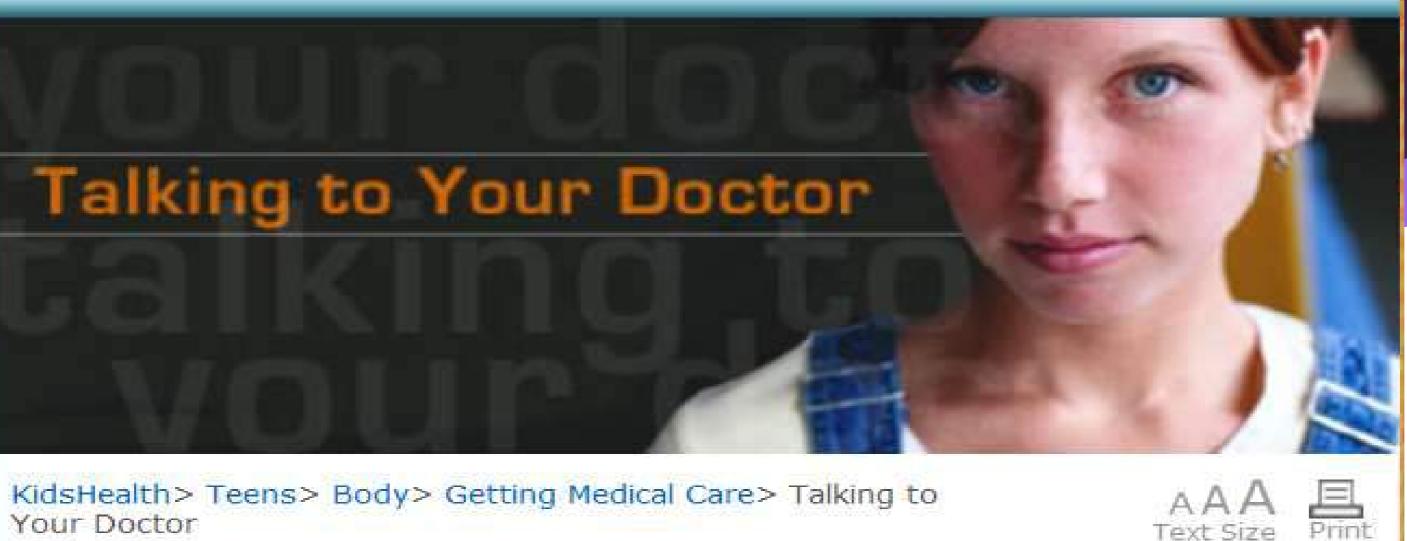
Infections

Q&A

School & Jobs

Drugs & Alcohol

**Staying Safe** 



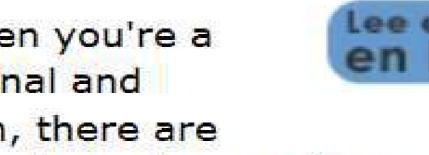
What's in this article?

#### Listen ()

Life gets way more complex when you're a en Español teen. On top of all of the emotional and physical changes you go through, there are more choices and decisions to make and more stresses from school, sports, jobs, family, and even friends.

#### For Parents For Kids For Teens

see more [+]





#### <u>URL</u> for Talking to Your Doctor (TeensHealth)

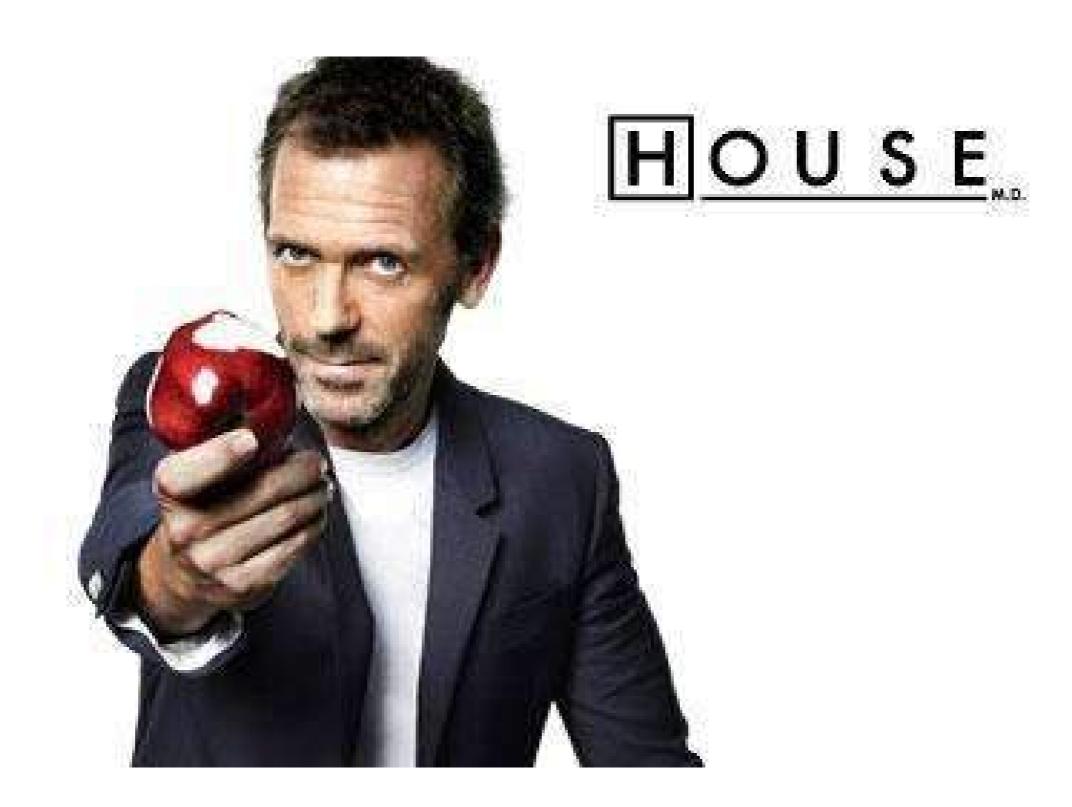




## Questions?



### **Communication is Key!**



#### **URL** for House MD Video



Image from Fox

### For More Information Contact:

### National Network of Libraries of Medicine, Middle Atlantic Region http://nnlm.gov/mar/ nnlmmar@pitt.edu 412.648.2065



This presentation was adapted from the 'Engage for Health': Tools for Health Literacy Community Education from The Hospital & Healthsystem Association of Pennsylvania.

This project is funded by the National Library of Medicine, National Institutes of Health, Department of Health and Human Services, under Cooperative Agreement Number UG4LM012342 with the University of Pittsburgh, Health Sciences Library System.

#### **U.S. National Library of Medicine**

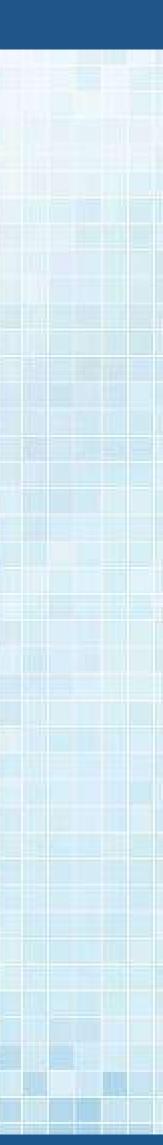
National Network of Libraries of Medicine



### One response to NNLM All of Us presentations to tribal library audiences

and mistreatment."

### "...maybe NNLM and the other All of Us program members may just have to work with more mainstream communities that don't have a long history of exploitation



#### **Jational Poison Prevention Week**

neck out the Household Products atabase (householdproducts.nlm.nih.gov) r information on safety and handling of mmon products!



#### March is Women's **History Month!**

Visit MedlinePlus (medlineplus.gov) for resources on women's health, including pregnancy, menopause, breast cancer, and bone density screenings.

NIH U.S. National Library of Medicine



U.S. National Library of Medicine

#### **National Poison Prevention Week**

Visit MedlinePlus (medlineplus.gov) for resources on carbon monoxide, toxic household products, pesticides, and other substances.



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Discover the ways that women have influenced medicine through the Changing the Face of Medicine online exhibit (cfmedicine.nlm.nih.gov)



**U.S. National Library of Medicine** 

#### **National Poison Prevention Week**

Connect with the Poison Help line at 1-800-222-1222 for support from nurses, pharmacists, doctors, and poison experts 24 hours a day, 365 days a year.





#### March is National **Nutrition Month!**

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nal Network of Libraries of Medicine

Visit MedlinePlus (medlineplus.gov) for information on diets, food labeling, nutrition for series, and more!

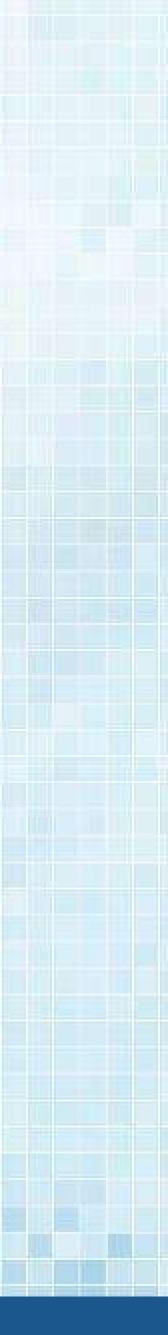




### **Original Materials**







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U.S. National Library of Medicine



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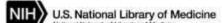
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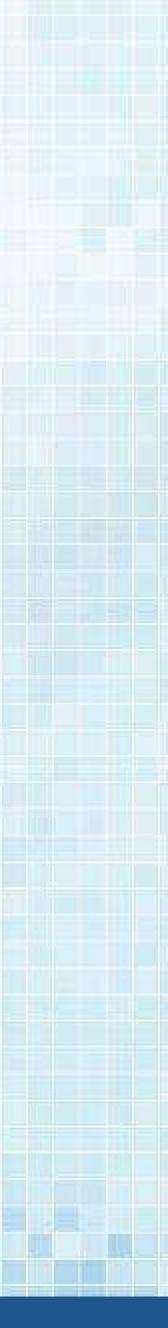








### Revised Materials



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U.S. National Library of Medicine National Network of Libraries of Medicine



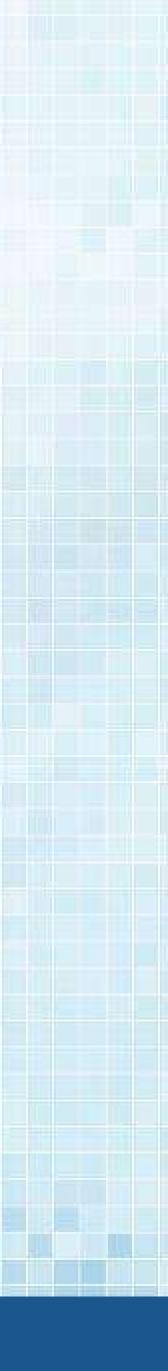




### Available from nnlm.gov/allofus







### 2018 NLM Exhibit Banners































Banner 1 (33.25x92)

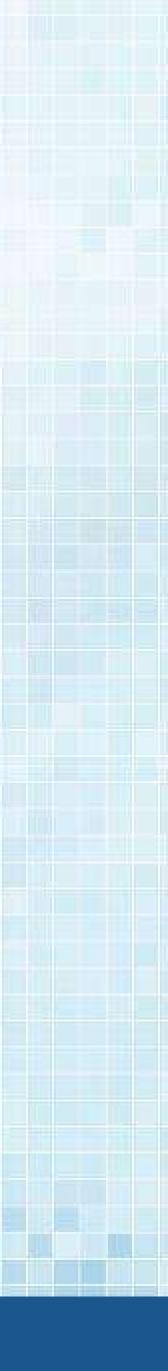
#### Banner 2 (33.25x92)

#### Banner 3 (33.25x92)

Banner 4 (33.25x92)

Banner 5 (33.25x92)



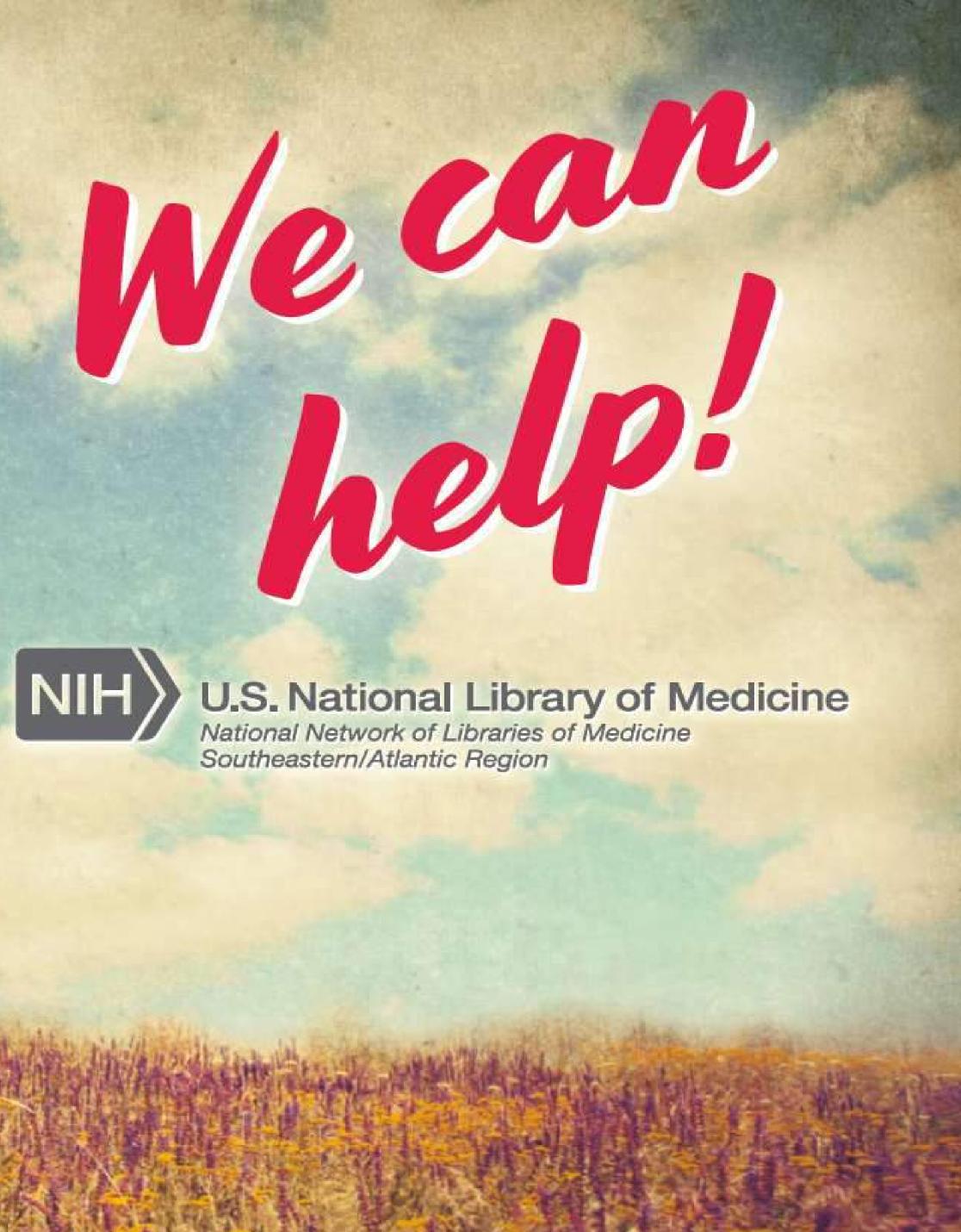


Short on time? Need funding? How about FREE health resources and materials?

Look no further.

and a straight the second





### Short on time?

### How about FREE health resources and materials?



### Look No Further! NNLM has the Answers.



### Need funding?

**U.S. National Library of Medicine** 

Southeestern/Atlentic Region







### Thank you!

### NIH NLM NNLM

### AlofUS **RESEARCH PROGRAM**

### https://joinallofus.org/nlm

