The *All of Us* Research Program and Libraries

PA Literacy Summit
Monday July 15, 2019
Veronica Leigh Milliner
National Network of Libraries of Medicine
The All of Us Research Program and the National Library of Medicine partnership

Health Resources and Opportunities

Health Programming in Your Library
NNL....Huh?

- **NIH**
  - National Institutes of Health
  - Nation’s research agency

- **NLM**
  - National Library of Medicine
  - World’s largest biomedical library

- **NNLM**
  - National Network of Libraries of Medicine
  - Program of the NLM comprised of 8 Regional Medical Libraries (RMLs) and 6 offices
National Network of Libraries of Medicine

Regional Medical Libraries (RMLs)

<table>
<thead>
<tr>
<th>Region</th>
<th>University</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greater Midwest Region (GMR)</td>
<td>University of Iowa</td>
</tr>
<tr>
<td>Middle Atlantic Region (MAR)</td>
<td>University of Pittsburgh</td>
</tr>
<tr>
<td>MidContinental Region (MCR)</td>
<td>University of Utah</td>
</tr>
<tr>
<td>New England Region (NER)</td>
<td>University of Massachusetts</td>
</tr>
<tr>
<td>Pacific Northwest Region (PNR)</td>
<td>University of Washington</td>
</tr>
<tr>
<td>Pacific Southwest Region (PSR)</td>
<td>University of California Los Angeles</td>
</tr>
<tr>
<td>South Central Region (SCR)</td>
<td>University of North Texas</td>
</tr>
<tr>
<td>Southeastern/Atlantic Region (SEA)</td>
<td>University of Maryland</td>
</tr>
</tbody>
</table>

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.

National Offices (Institution)

- DOCLINE Coordination (UMD)
- Evaluation (UW)
- Public Health Coordination (UMass)
- Training (Utah)
- Web Services (Pitt)
The NIH All of Us Research Program & NLM Partnership
A federal effort launched in 2015.

**MISSION:** To enable a new era of medicine through research, technology, and policies that empower participants, researchers, and providers to work together toward development of individualized care.
Genes + Environment + Lifestyle = Health Status
NNLM All of Us Community Engagement Network

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

All of Us Research Program
nnlm.gov/all-of-us
Activities and Outreach

1. Training opportunities on trusted consumer health resources
2. Funded projects supporting public libraries and partners
3. Making community connections
Why Public Libraries

• Public libraries are community hubs and know their local communities.

• Public libraries are ideal for providing access to trusted health information for library users of all ages.

• NNLM’s *All of Us* Community Engagement Network is centered around public libraries in an effort to reach all communities in the United States.
Health Literacy

The degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.

Low literacy has been linked to poor health outcomes such as higher rates of hospitalization, less frequent use of preventive services, and more likely to report their health status as poor.

Health Literacy Basics
State of America’s Libraries

Nine in ten adults have difficulty understanding and making use of the health information they encounter every day.

Playing these important roles that help communities address critical needs in technology access, education, and health
<table>
<thead>
<tr>
<th>Library Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public libraries strengthen local economies.</td>
<td>84%</td>
</tr>
<tr>
<td>- Offer technology training to patrons in computer software use.</td>
<td></td>
</tr>
<tr>
<td>- Provide online health resources.</td>
<td>77%</td>
</tr>
<tr>
<td>- Offer programs to help Americans identify health insurance resources and get better informed on health topics.</td>
<td>60%</td>
</tr>
<tr>
<td>- Provide programs that assist individuals to apply for jobs, create résumés, and prepare for interviews.</td>
<td>73%</td>
</tr>
<tr>
<td>- Help people complete online government forms.</td>
<td>97%</td>
</tr>
<tr>
<td>Public libraries create healthier communities.</td>
<td>59%</td>
</tr>
<tr>
<td>- Provide programs on finding health insurance.</td>
<td>58%</td>
</tr>
<tr>
<td>- Provide programs to help people find and evaluate health information.</td>
<td>23%</td>
</tr>
<tr>
<td>Public library access equals opportunity.</td>
<td>100%</td>
</tr>
<tr>
<td>- Offer access to the internet.</td>
<td></td>
</tr>
<tr>
<td>- Offer free Wi-Fi.</td>
<td>98%</td>
</tr>
<tr>
<td>- Help patrons with basic internet skills.</td>
<td>90%</td>
</tr>
<tr>
<td>- Help people complete online government forms.</td>
<td>97%</td>
</tr>
<tr>
<td>- Offer access to ebooks.</td>
<td>90%</td>
</tr>
</tbody>
</table>

Data for this list was retrieved from the 2014 Digital Inclusion Survey. For more information about sources and citations, contact the ALA Library and Research Center at alalibrary@ala.org. Learn more at the Libraries Transform web page.
The Opportunity for Libraries

Health Happens in Libraries

40% of health outcomes are influenced by socioeconomic factors

- Education
- Employment
- Income
- Family & Social Support
- Community Safety

Libraries are in a unique position to bring together the people, programs, and partners necessary to make health information and services accessible to everyone.
Libraries advance equal access to health information and services in many ways.

- **59%**: support patrons in identifying health insurance resources.
- **58%**: support patrons in locating and evaluating free health information online.
- **48%**: support patrons in understanding specific health or wellness topics.
- **23%**: support patrons by offering fitness classes.
Health Programming and Outreach
NNLM All of Us Community Engagement Activities
Support for Health Programming

NNLM Reading Club
What is the NNLM Reading Club?
The NNLM Reading Club is a selection of "ready-to-use" fiction and nonfiction books along with free and downloadable materials designed to help libraries support health literacy and their communities’ health information needs by celebrating important National Health Observances® through the fun and intimacy of a book club.

How are books selected?
Books reference a health topic in support of the National Health Observances® calendar and are selected.

Community Engagement
Network Programming Page
Support for Health Outreach

Ordering Free Print Materials
Lifestyle

• What needs are in your community?
• Can focus on nutrition, physical activity, stress... or other health topics.
• Integrate NLM resources like MedlinePlus
Resource - Talking with your Doctor

BECAUSE HEALTH CARE ISN’T ONE SIZE FITS ALL.

[URL] for Engage for Health and [URL] for Talking with your Doctor Program
Demographic Groups

- Children and Teenagers
- Men
- Population Groups
- Seniors
- Women

Health and Wellness

- Disasters
- Fitness and Exercise
- Food and Nutrition
- Health System
- Personal Health Issues
- Safety Issues
- Sexual Health Issues
- Social/Family Issues
- Wellness and Lifestyle
Nutrition

Summary

Food provides the energy and nutrients you need to be healthy. Nutrients include proteins, carbohydrates, fats, vitamins, minerals, and water.

Healthy eating is not hard. The key is to

• Eat a variety of foods, including vegetables, fruits, and whole-grain products
• Eat lean meats, poultry, fish, beans, and low-fat dairy products
• Drink lots of water
• Limit salt, sugar, alcohol, saturated fat, and trans fat in your diet

Saturated fats are usually fats that come from animals. Look for trans fat on the labels of processed foods, margarines, and shortenings.

Centers for Disease Control and Prevention
Graphic Medicine
Learning by Creating - Graphic Medicine

Your library can use graphic novel displays to engage the public through book clubs, discussion groups, library displays, and programs where people create their own comics.

Can utilize educational resources and lesson plans on the NLM Graphic Medicine exhibit website.
"LEARNING ABOUT ILLNESS AND TREATMENT CAN BE AN EFFECTIVE COPING AND HEALING STRATEGY FOR THE AUTHOR, AND SHARING THAT INFORMATION WITH READERS CAN TRANSFORM A NEGATIVE EXPERIENCE INTO A POSITIVE ONE."
Graphic Medicine Examples

STEP TWO: THE FEAR
STEP THREE: FOOD ENTERS THE BODY

IT'S COMING

Note: "Bipolar Disorder" or "MA"

DON'T GO WHERE I CAN'T FOLLOW

By Amber Nilsen (with Cheryl Weaver)
Graphic Medicine - Activity

Symptoms for Flu

1. Achoo
2. Coughing
3. Fever
4. Sore throat
5. Fatigue
6. Headache
7. Muscle pain
8. Body aches
9. Nausea
10. Diarrhea
11. Runny nose
12. Sneezing
13. Congestion

Mom says I'm sick!!
Environment

• Explore how environmental factors affect health
• Can include health information from the NLM resource Tox Town
• Citizen Science - libraries can create and circulate kits to help people examine environment around them
Welcome to
TOX TOWN

Tox Town provides consumer-level information on everyday locations and situations where you might be exposed to toxic chemicals. This site will help you better understand risks of exposure, potential health effects, and how to protect yourself.

Tox Town
toxtown.nlm.nih.gov
Sources of Exposure
Explore places and situations where you might be exposed to hazardous chemicals and contaminants. Learn how you can minimize your risk.

Chemicals & Contaminants
Learn about common hazardous chemicals and contaminants, their possible health effects, and how you can protect yourself.

Diseases & Conditions
Learn about possible associations between environmental contaminants and select diseases and conditions.
Chemicals & Contaminants

Learn about common hazardous chemicals and contaminants, their possible health effects, and how you can protect yourself.

FEATURED CONTENT

**Acetone**
Read about health effects of exposure to this common solvent. Reduce your risk.

**Bisphenol A (BPA)**
Concerned about health risks of BPA in plastics? Visit this page.

**Chlorine**
Exposure to chlorine can cause negative health effects. Learn more. Protect yourself.

**Pesticides**
Exposure to pesticides can harm your health. Find out how to reduce your risk.
Citizen Science

- Citizen science is the involvement of the public in scientific research – whether community-driven research or global investigations.
- Anyone can participate.
- Data can help scientists come to real conclusions.

URL for The Librarian’s Guide to Citizen Science
Bioblitz - Activity

How It Works

1. Record your observations
2. Share with fellow naturalists
3. Discuss your findings

URL for iNaturalist and URL for BioBlitz Program from National Geographic
Genetics

- Genes affecting our chances of having certain illnesses
- Can focus on family health history or incorporate Genetics Home Reference and My Family Health Portrait into a program to increase education and awareness
Genetics Home Reference

ghr.nlm.nih.gov
Sickle cell disease is a group of disorders that affects hemoglobin, the molecule in red blood cells that delivers oxygen to cells throughout the body. People with this disorder have atypical hemoglobin molecules called hemoglobin S, which can distort red blood cells into a sickle, or crescent, shape.

Signs and symptoms of sickle cell disease usually begin in early childhood. Characteristic features of this disorder include a low number of red blood cells (anemia), repeated infections, and periodic episodes of pain. The severity of symptoms varies from person to person. Some people have mild symptoms, while others are frequently hospitalized for more serious complications.

The signs and symptoms of sickle cell disease are caused by the sickling of red blood cells. When red blood cells sickle, they break down prematurely, which can lead to anemia. Anemia can cause shortness of breath, fatigue, and delayed growth and development in children. The rapid breakdown of red blood cells may also cause yellowing of the eyes and skin, which are signs of jaundice.
Genetics Home Reference provides consumer-friendly information about the effects of genetic variation on human health.

Health Conditions
Learn about the signs and symptoms, causes, and inheritance of more than 1,200 health conditions with a genetic basis.

Recently Added Pages
New Pages
- 48,XXXY syndrome
- 49,XXXXY syndrome
- Rosacea

Updated Pages
- Core binding factor acute myeloid leukemia
Help Me Understand Genetics

An introduction to fundamental topics related to human genetics, including illustrations and basic explanations of genetics concepts.

Cells and DNA

What is a cell?
What is DNA?
What is a gene?
What is a chromosome?
How many chromosomes do people have?
What is noncoding DNA?
NNLM Reading Club

Free kits to form book clubs around health topics

- Family Health History
  - Heart Health
  - Mental Health
- Future themes TBD
• Programming guides connected to summer reading themes incorporating health and wellness

URL for NNLM Summer Health Programming
Create a Plan

BECAUSE KNOWLEDGE IS THE KEY INGREDIENT IN NUTRITION.
Develop a Plan

Target Population → Type of Outreach → Available Resources

Information → Program
The Library Story

A Strategic Storytelling Toolkit for Public Libraries

The Library Story: A Strategic Storytelling Toolkit for Public Libraries was created by Michael Margolis and Kristina Drury of GetStoried.com in conjunction with input from Pennsylvania public library staff.

It was designed to help us think about how we can use the power of storytelling to more effectively promote our health and science programming.

Logic Models

Logic models are excellent tools to help with program development, planning, implementation and evaluation. They can serve as a visual representation of your program. A logic model includes what you invest in your program (resources), what you actually do (activities), and what you plan to achieve (outputs and outcomes). It is a way to communicate to stakeholders and the community the reasoning behind initiating a health outreach activity.

View the NNLM Outreach Logic Model Template to get started.

For more information on logic models and evaluation visit the NNLM Evaluation Office (NEO).

Building Partnerships for Health Outreach

Health outreach within the community is best done in partnership with other organizations. Below please find sample letters of invitation to participate, invitation to speak, and of thanks. These letters can be printed and mailed or modified to send via email.

- Partner for Health Fair at Library (Template)
- Speaker Request Letter (Template)
- Speaker Thank You Letter (Template)
- Thank You Note Health Fair Vendor (Template)
Funding Available Now!

NNLM MAR Members can apply by April 5 for up to $50,000 in support of health information outreach projects.

Current Opportunities
NNLM All of Us Community Engagement Awards

Support public libraries, and organizations who develop programming for public libraries, that focus on health information literacy and awareness about the All of Us Research program.

URL to NNLM All of Us Community Engagement Award Announcement
Funding Dates and Information

Funding Period:
Wednesday, May 1, 2019 to Thursday, April 30, 2020

Number of Awards Available:
Awards up to $50,000; awards of up to $20,000
Projects Should:

Focus on supporting health literacy of the public through programming, services, training, etc.

Integrate one or more National Library of Medicine health information resources into the project

Raise awareness of All of Us Research Program and related topics
How Can Libraries Get Involved

- Become an NNLM Network Member (if not already)
- Take consumer health classes through NNLM
- Get their Consumer Health Information Specialization (CHIS)
- Apply for funding to implement a health literacy project in their library
- Host or volunteer with the *All of Us* Journey
- Participate in a community of practice
- Other opportunities to come!
Questions?

Veronica Leigh Milliner, *MLIS*
NNLM *All of Us* Community Engagement Coordinator
VLM38@pitt.edu

nnlm.gov/mar
nnlm.gov/all-of-us
@nnlmAoU