

All of Us Digital Health Literacy Final Project Report

Approaches and Interventions Used:

The overall goal of the project was to provide digital health literacy resources for the Network of the National Library of Medicine (NNLM) members and *All of Us* Community Engagement Partners to support their communities as they access and use health information online and participate in medical research studies, particularly *All of Us*. A key component of this partnership is the aim of reaching people who are on the other side of the digital divide, those who experience challenges and barriers with accessing reliable health information online.

The objectives of the project were:

- <u>Objective 1</u>: Raise the capacity of the general public to make decisions about their own health by accessing, evaluating, and using online health information;
- <u>Objective 2</u>: Provide resources in English and Spanish for NNLM members and *All of Us* partners to offer in-person and virtual events to communities who are underrepresented in biomedical research (UBR) that enhance digital health literacy and digital literacy; and
- <u>Objective 3</u>: Increase the public's awareness of All of Us.

NNLM and the *All of Us* Community Engagement Network (CEN) worked with Wisconsin Health Literacy (WHL) to develop videos, program guides, and a virtual learning series to address the digital divide nationally. These materials were created for NNLM and *All of Us* professionals to engage with their communities both in-person and online. Additionally, The *All of Us* Community & Provider Gateway Initiative (CPGI) partnered with NNLM to co-create the project deliverables, ensuring that they were developed utilizing best practices for engagement with key populations, including imagery, wording, and other design elements. CPGI partner organizations who work directly with UBR populations were invited to participate in creation planning meetings facilitated by WHL and to provide feedback on the deliverables. The final deliverables were made available for use by the NNLM CEN and *All of Us* Community Engagement Partners.

Objectives were reached by creating a series of 7 educational videos to support digital health literacy curriculum. The videos were developed based on WHL's <u>Health Online: Finding Information You Can</u> <u>Trust Curriculum.</u> Video topics include:

- Search for trusted health information online
- How to read a webpage

- Compare websites to make sure they are credible
- Websites to visit for health information
- Use a checklist to evaluate a website
- Different devices and finding reliable internet locations
- Other online tools and health resources

WHL worked with the video agency, Green Clock, to script, record, and translate the videos. Videos are currently housed on Dropbox links:

https://www.dropbox.com/sh/zklxr2w9m5gbyp7/AAD-ecOcFmZXvO1wjMWHEj3Fa?dl=0 https://www.dropbox.com/sh/s6vz17xbbeq6ksj/AAB_yk4q5GtOyF8BT8RpxXKaa?dl=0

NNLM will be publishing the videos on the CEN website and NNLM All of Us digital health literacy resources webpage <u>https://nnlm.gov/all-of-us/resources/digitalhealthliteracy</u>.

There are 2 versions of each video in the series: a full version, approximately 6 – 8 minutes long, to share on websites and incorporate into classroom settings, and a 2-minute version to post on social media to give a brief overview and encourage viewers to learn more. All videos are in English and Spanish, with open captioning and ASL translations.

These digital health literacy resources are intended to use as online education, or for supporting inperson learning. Those who use these videos during in-person learning were encouraged to incorporate open discussion by pausing videos between new topics and giving participants an opportunity to work on an electronic device while they're learning from the videos. Having them apply the skills right away is an adult learning principle that will help them remember the content. This provides a hands-on learning approach. Patrons and community members were encouraged to watch the videos, especially:

- underrepresented populations,
- those at risk for low health literacy,
- low literacy learners,
- older populations, and
- beginner computer users.

Another series of resources were created to meet project objectives. WHL created five free, downloadable program guides focused on digital literacy and digital health literacy topics. The program guides are available in English and Spanish and will soon be made available on the CEN's <u>digital health</u> <u>literacy webpage</u>.

The program guides allow NNLM members and *All of Us* partners to engage with their communities on the topic of digital health literacy over a sustained period of time. Each program guide topic is directly connected to *All of Us* by promoting the program and showing how the skill the participants are learning will help them participate in *All of Us*.

The program guides are valuable for public libraries who already offer digital literacy and health information class and would like to add programming opportunities to their patrons.

Program guides provide resources and instructions for offering the program both online and in-person and include the use of the <u>Learn Internet Skills online modules</u> as part of the program activity. Program guides cover the following topics:

- 1. Get a Free Email Address
- 2. Avoid Scams & Phishing
- 3. Create a Strong & Easy-to-Remember Password
- 4. Find Reliable Health Information Online: Website Detective
- 5. Use MedlinePlus to Find Reliable Health Information

The guides include:

- Program Summary
- Program Plan
- Program Materials
- Intended Audiences
- Community Engagement
- Ideas of Local Partnerships
- Links to Relevant Resources (NIH, NLM, and NNLM)
- Outside Sources
- Evaluation Plan

A key component of the guides are the program engagement and ideas for local partnership sections. This focus in the guides was crucial to promote inclusive learning styles to meet the needs of diverse communities. To help in development of these sections, WHL worked with a team of subject matter experts, or cultural brokers, who provided representation from the intended audience groups to ensure understanding and cultural sensitivity to diverse audiences, information needs, and learning styles.

The cultural brokers were from the following organizations: The American Association of Health and Disabilities, Denver Health & Hospital Authority, The Milwaukee Public Library, LGBT Detroit, Arab Community Center for Economic and Social Services, Latino Academy of Workforce Development, Generation onLine, CenterLink, and STEM Que3ns, LLC.

These two resources, the educational videos and program guides, were shared with community partners, specifically targeting NNLM members and *All of Us* partners, during a 4-day live virtual programming series.

WHL and NNLM organized a team of cultural brokers to help guide the delivery and content of the virtual programming series. This was conducted during two co-creation sessions. The first session was held on January 29, 2021. It included representatives from organizations that were a part of *All of Us* and NNLM CEC staff, and WHL staff who lead the session. The active participation of Involving *All of Us* partners in co-creation ensured digital health literacy virtual events and materials leveraged existing *All of Us* resources and programs for the general public.

During the meeting we discussed the project goals, objectives, and resources and sought input on resource development. Participants also provided guidance on additional communities that we should engage by adding representatives who could serve as cultural brokers and guide the presentation. Organizations that attended included: NNLM, *All of Us* Community Engagement Center, Wisconsin Health Literacy, The American Association of Health and Disabilities, Denver Health and Hospital Authority, and CenterLink.

The second session was held on March 30, 2021. During the meeting we discussed the responsibilities for those willing to present during the virtual programming series about how the resources could best be used with their communities, including any challenges and issues that must be overcome when enhancing digital and health literacy of diverse communities. All organizations agreed to move forward and participate in the program series.

Organizations that attended included: NNLM, All of Us Community Engagement Center, Wisconsin Health Literacy, The American Association of Health and Disabilities, Denver Health & Hospital Authority, The Milwaukee Public Library, LGTB Detroit, Camille White Health Care Consulting, Arab Community Center for Economic and Social Services, Latino Academy of Workforce Development, Generation onLine, and CenterLink.

After the meeting, one community representative decided that she could not participate in the project. The representative did not tell us why, but asked questions about the diversity of staff on the project team and the lack of community input from the outset of the project during the session. We were able to find a representative to replace them. The virtual program series, Tips and Tools for Closing the Digital Health Divide, was hosted April 19 - 22, 2021. The NNLM, *All of Us* CEN, and WHL team lead a four-day discussion addressing the digital divide and sharing tips and tools for implementing digital literacy programming in diverse communities. The organizations, listed above, joined the event to share insight and expertise on strategies for enhancing digital literacy with diverse populations including:

- Communities of Color,
- Latinx Communities,
- Refugee and Immigrant Communities,
- Older Adults,
- People with Disabilities, and
- LGBTQ Communities.

The series was broadcasted using Zoom as the primary platform with English and Spanish captioning and ASL translation. The event was then streamed to NNLM's YouTube channel and participating organizations Facebook pages. Professionals from the University of Washington were contracted with NNLM to provide production and marketing support for the virtual program series. All events were recorded for future viewing and can be found at the following links:

	URL
Event 1: Digital literacy, health literacy, and tools developed for program implementation	https://youtu.be/8UbQFsN0V24
Event 2: Addressing Health Literacy with African Americans and Latinx Communities	https://youtu.be/IKCSS4WTU0E
Event 3: Addressing Health Literacy with Refugee	https://youtu.be/7g6wlZbsrfl
and Immigrants and LGBTQ+ Communities	
Event 4: Addressing Health Literacy with Older	https://youtu.be/H_J3qK0ONEI
Adults and Persons with Disabilities	

Problems or Barriers Encountered:

The biggest challenge was time. Given our current state of the pandemic, participants involved in the project faced their own challenges and time restraints. With only four months to complete project deliverables, it made for a fast-paced turn-around and pivoting on the way deliverables were met.

For example, the project main focus was to include a co-creation process of the resources developed to ensure understanding and cultural sensitivity to diverse audiences, information needs, and learning styles. The original plan was to include participants from WHL, *All of Us* consortium partners, and community members. Community members were not invited to join the co-creation process, given the time challenges.

WHL worked with NNLM, members of the *All of Us* CEN team, and subject matter experts, also known as cultural brokers, to bring representation for audiences the *All of Us* Research Program is trying to reach. This includes:

- Communities of Color
- Latinx Communities
- Refugee and Immigrant Communities
- Older Adults
- People with Disabilities
- LGBTQ Communities

Another barrier was getting materials reviewed by all members listed above. The video production time was tight and needed to be fast-paced. Unfortunately, this limited the number of reviewers for the video to only WHL staff and NNLM staff.

Translating the videos into Spanish, brought new observations in the way video production was able to do translations. Since the videos were captioning online resources and webpages, this content needed to be translated to show webpages in Spanish. However, not all webpages translated to Spanish and additional instruction was needed for viewers to learn how to use Google translate. Also, video production took longer to make the appropriate translations and work with bilingual staff.

Additionally, getting input from all participants on the guides was challenging. The guides were the last deliverable to be created in order to include feedback from the virtual program series and make the guides appropriate for program planning in diverse communities. There was not much time for review of the guides.

Due to these timing constraints and current NNLM website transitions, not all deliverables are posted for use at this time.

Evaluation:

The overall project has not gone through the evaluation stage. NNLM and WHL are planning for another phase of the program to carry out appropriate evaluation of the resources created during this project.

For the guides, the NNLM evaluation will be added by the CEC evaluation team. For the videos, the CEC will collect analytics from the number of views on the CEN website and NNLM *All of US* digital health literacy resource page.

The virtual program series included a NNLM Evaluation Office Training Form for all participants. Additionally, analytics were collected from the series and as of April 29, 2021 there were 817 total participant views of the event. Below is a breakdown of the views, based on the series session.

	Zoom Views	YouTube Views	Facebook Views	Total Views
Event 1: Digital literacy, health literacy, and tools developed for program implementation	80	109	40	229
Event 2: Addressing Health Literacy with African Americans and Latinx Communities	58	50	61	169
Event 3: Addressing Health Literacy with Refugee and Immigrants and LGBTQ+ Communities	49	40	116	205
Event 4: Addressing Health Literacy with Older Adults and Persons with Disabilities	60	52	102	214
Total Views				817

Continuation Plans:

The project reached the initial development of materials phase and is planning to continue with user testing and evaluation to strengthen the content and finalize for implementation. The videos will be piloted with community members from diverse groups to do a thorough evaluation of the context, images, and overall video quality. It will be important to do piloting with:

- Communities of Color
- Latinx Communities
- Refugee and Immigrant Communities
- Older Adults
- People with Disabilities
- LGBTQ Communities

The guides will be piloted with NNLM members and *All of Us* partners to do a thorough evaluation of the resources and usability of the programs outlined.

NNLM is working with WHL to create a plan for continuing the project. A proposal will be drafted to submit to the National Institutes of Health.

Lessons Learned:

The biggest lesson learned is not to rush through content development. The goal was to have all resources reviewed and developed in a co-creation process. This is an important step not to be overlooked and carefully access the time a diverse group of participants can give to make the program culturally sound. This lesson impacted the team positively by demonstrating the integrity participating organizations hold and maintaining standards.

A highlight from the virtual program series was the way the production team broadcasted the event. The production team from the University of Washington was very professional in preparing speakers for the event and using technology that was well equipped for disseminating to multiple channels (Zoom, YouTube, and Facebook). The production team requested speakers meet for an hour prior to the event, and we would recommend this for anyone doing a production with multiple speakers to go through transitions.

Recommendations for applying this project is to remember this is not a one-size-fits-all-approach. It is important to know your audience and location capabilities before you start program implementation. Don't plan a program and then take it to the community, plan *with* community members at the table and allow for cultural competency.

Impact:

All of Us identified digital literacy as a barrier to participation in the All of Us program. There is a digital divide among seniors and those at risk for low literacy due to difficulty accessing technology and the internet, along with intimidation from trying to navigate the internet and sifting through the dearth of

information found online. The COVID-19 pandemic has highlighted the widening digital divide. According to the Pew Research Center, "roughly half of U.S. adults (53%) say the internet has been essential for them personally during the pandemic."

This project provides resources and tools to address this barrier in accessing, navigating, and understanding reliable health information online, learning about *All of Us*, and increasing confidence in using everyday online resources, such as email, passwords, and internet safety. Having these resources available for in-person learning or online independent learning is decreasing the digital divide the U.S. is challenged with today.

Additionally, promoting these resources to community partners and creating guides for NNLM members and *All of Us* consortium partners allows for them to engage with their communities on the topic of digital health literacy over a sustained period of time. Initial feedback from participants of the virtual program series suggested the resources will be valuable in programming. A viewer commented:

"I recently watched the 4 webinars (virtual program series) from NNLM on digital health literacy. They were amazing. I am planning to share some of the resources with community health workers who work with migrant and seasonal farmworkers in North Carolina.... these materials are completely fantastic and I want to be able to hold some train the trainer sessions with outreach and community health workers."

-Laupus Health Sciences Library