



## Infusing Health Literacy Principles into Cultural Communication: What's Being Done to Meet the Health Needs of Diverse Populations?

HARC Conference October 2016



#### **Presenters**

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#### Outline

- What is Health Literacy?
- Overview of Office of Minority Health
- Research: Best practices to communicate to diverse populations
- Practical Solutions: FDA's innovative strategies to reach diverse populations



# What is Health Literacy?

# Jovonni Spinner



#### **Communicating.....**

# FDA's communications may not reach diverse audiences due to language and health literacy barriers.







#### **Health Literacy & the FDA**

 "Health literacy results from the match between the health information and services created for the public and people's capacity to find, understand and use them."

 FDA Strategic Priority: Promote better informed decisions about FDA-regulated products



#### **Linguistic Barriers**

- Linguistic barriers contribute to health disparities experienced by many racial/ethnic groups.
  - 18.7% of Americans do not speak English as a primary language
  - 8.4% of Americans have limited English proficiency (LEP)
    - 20% of Spanish speaking Latinos do not seek medical advice due to language barriers

Reference: Flores G. Language barriers to health care in the United States. NEJM. 2006;355:229-231.



#### Low Health Literacy

- Low health literacy (LHL) is linked to poor health outcomes and health status. LHL is more prevalent among minorities, older adults, and those with low socioeconomic status.
  - Only 12% of adults have "proficient health literacy"\*
  - Asian Americans and Hispanics report not understanding written information from their doctor and on prescription labels
  - Up to 40% of African Americans have difficulty reading health information

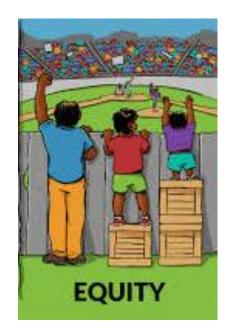
\*Note: Proficient health literacy- the skills needed to mange health and prevent disease ; e.g. navigate the healthcare system, engage in self-care for chronic disease management, share health history with providers



# Overview of the Office of Minority Health



## Office of Minority Health's (OMH) vision is to create a world where health equity is a reality for all.





Our mission is to promote and protect the health of diverse populations through research and communication of regulatory science that address health disparities.





#### **OMH Goals**

- Goal 1- To improve and strengthen regulatory science informing the research and evaluation of sub-population data associations with race and ethnicity.
- Goal 2- To strengthen FDA's capacity to address minority health and health disparities across the Agency.
- Goal 3- To promote effective communication and the dissemination of information to the public, particularly underserved, vulnerable populations.



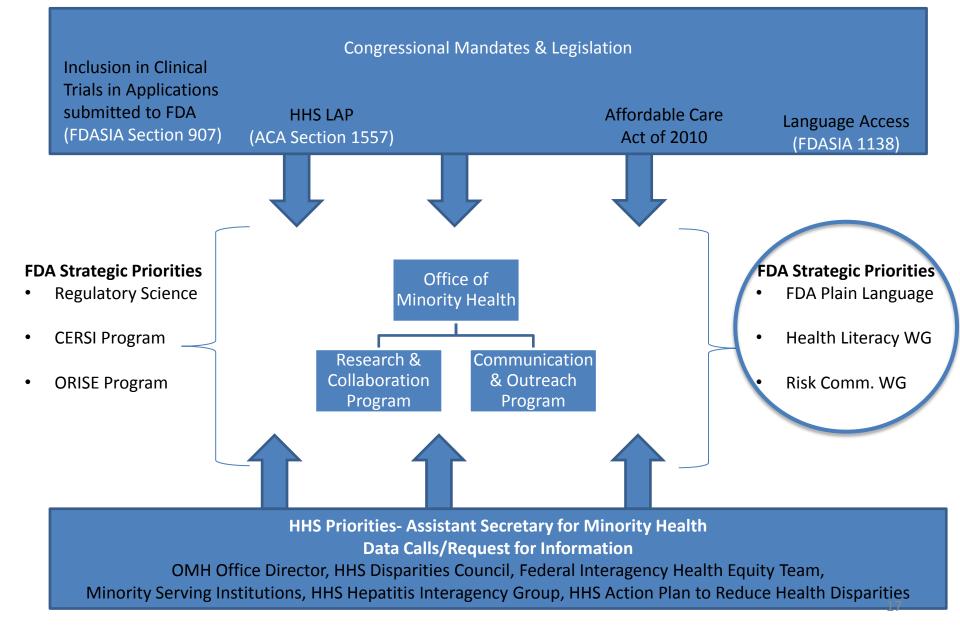
#### Why do we exist?

## March 2010 Affordable Care Act- Section 10334 mandated creation of OMH across all HHS divisions





#### **OMH's Drivers**





# Outreach and Communication Program (OCP)



#### **OCP** Aims

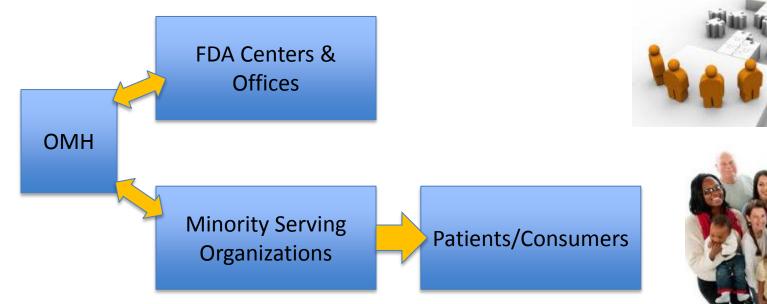
 To strengthen FDA outreach to diverse communities, such as minorities, limited English proficient, and low literacy.

 To partner with external stakeholders to identify and reduce health disparities.



#### **OMH's Role in Stakeholder Engagement**

#### We are conveners & connectors





#### **Outreach & Communication Strategies**

Stakeholder Engagement	<ul> <li>Meetings with minority serving institutions (MSIs), organizations, &amp; patient and disease advocacy groups</li> <li>External Meeting Participation and Presentations</li> <li>Webinars</li> <li>Limited English Proficiency (FDA Language Access Plan)</li> </ul>
Raise Awareness	<ul> <li>Meetings, Speaker series (internal)</li> <li>OMH Website</li> <li>Newsletter and Email Blasts</li> <li>Blogs and Consumer Updates</li> <li>Social Media: Twitter, Pinterest, Facebook</li> </ul>
Targeted Consumer Education	<ul> <li>Editorial Calendar</li> <li>Campaign on targeted disease areas of significance to health disparities/Million Hearts Initiative and Health Disparities</li> <li>Materials Development (fact sheets, infographics, videos, brochures)</li> <li>Clinical Trial Diversity</li> </ul>
Translate & Adapt Materials	<ul> <li>Coordinate and support FDA Language Access Plan Implementation</li> <li>Represent FDA on HHS Steering Committee</li> <li>Health Literacy, Risk Communication, Plain Language , Limited English Proficiency, Low Literacy</li> </ul>



#### **OMH Key Topic Areas**

2 x a day?

Take with food?

- Health Topics
  - Cardiovascular Disease
  - Cancer
  - Hepatitis
  - HIV/AIDS
  - Diabetes
  - Sickle Cell Disease
- Clinical Trials
- Language Access/Health Literacy

#### **Sample OMH Resources**



FRA.

FDA

#### THE UNIVERSITY OF CHICAGO







**AWARE**forAll



**CISCRP** 

Association of Black Cardiologists, Inc.

Saving the Hearts of a Diverse America







NCAPIP National Council of Asian **Pacific Islander Physicians** 

ALLIANCE INC.





NATIONAL COUNCIL OF LA RAZA



AMERICAN HEALTH FORUM



UNIVERSITY OF

MARYLAND









#### HEALTH LITERACY RESEARCH AND THE FDA

#### **LEE L. ZWANZIGER**



#### **Regulatory Science Research**

- Key questions for promoting better informed decisions
  - What information do target audiences need?
  - What forms are most accessible to them?
  - What are the effects of existing communications?
- We need to know our audiences
- Audiences change



#### **Regulatory Science Research**

- FDA centers and offices devise, fund, and analyze regulatory science research studies for Goal 3, to promote better informed decisions
- Mechanisms include
  - Contracts and grants
  - Broad Agency Announcement (BAA, contracts)
  - University-based Centers for Excellence in Regulatory Science and Innovation (CERSI)



#### **Regulatory Science Research – other contracts and grants, examples**

- Prescription Drug Promotion
  - Effects of Animation in Ads (experimental, in progress)
- FDA Drug Safety Communications
  - Internet Panel Survey
- Tobacco Use
  - Fresh Empire focus groups
  - Effective communication that is understandable and not misleading to a lay person about Product Constituents (In-depth individual interviews)



#### **Regulatory Science Research - BAA**

 FDA Health Care Professional Communication Project

• Nurse Pain Educator Pilot Program

• Optimizing the Use of Opioids Following Surgery



#### **Regulatory Science Research - CERSI**

- Workshops, e.g., Clinical Trials: Assessing Safety and Efficacy for a Diverse Population
- Research awards, e.g., "Improving Health Literacy and Cultural Competency in Current FDA Risk Communication"
- On-going collaboration, e.g., Educational presentations such as FDA Science Forum



#### **Access to External Research Expertise**

- Risk Communication Advisory Committee
  - February Meeting Surveying Recent Research
  - Techniques for Reaching Underserved Populations
- K. "Vish" Viswanath, Ph.D.
  - Communication, Health and the Urban Poor
- Linda Aldoory, Ph.D.
  - The Role of Health Literacy in Mobile Health and Text Messaging Campaigns



#### **Internal Message Testing**

- FDA's Risk Communication Staff coordinates a Network of 500+ employees and conducts informal testing to uncover basic flaws and "red flags"
- Work within Paperwork Reduction Act restrictions to get timely feedback on draft communications
- Select for volunteers with particular demographics if needed



#### **Social Media Monitoring**

- Access by contract to the Brandwatch social listening tool
- Data collected from publicly available consumer conversations (Facebook, Twitter, blogs, etc.)
- Dashboards (tailor-designed by FDA) provide 24/7 access to real-time and historical data on adverse events, regulatory action/science, and influencers of online conversations
- Example: Watch for mention of particular audiences, to help us learn about their concerns and information needs
- "Buzz" reports available upon request when deep dives needed



#### **Message Testing**







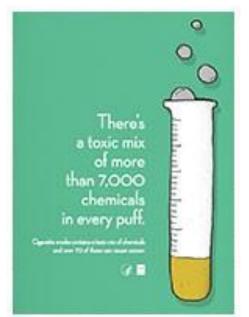


#### Tobacco

# FDA's Center for Tobacco products supports regulatory science research for better informed decisions and improved public health, partnering with other HHS agencies

Product Constituents; CTP Supplement to Parent Grant: Effective Communication on Tobacco Product Risk and FDA Authority

Principal Investigator: Kurt Ribisl
Optimizing Public Display of Information on Tobacco
Funding Mechanism: National Institutes of Health - Grant
ID number: 3 P50 CA180907-03S1
Award Date: 8/31/2015
Institution: The University of North Carolina at Chapel Hill





#### Language Access Plan

Cerca de un millón de latinas no saben que están en riesgo de desarrollar diabetes.

> U.S. Food and Drug Administration Office of Minority Health

**Nearly One Million** Latinas aren't aware they are at risk of developing diabetes. U.S. Food and Drug Administration Office of Minority Health



#### STRATEGIES TO COMMUNICATE-LANGUAGE ACCESS

#### **CARINY NUÑEZ**



#### Making the Case

- 60 million people speak a non-English language at home
- Of the 60 million, 25.1 million are limited English proficient (LEP)
- The top 6 non-English languages are Spanish, Chinese, Vietnamese, Korean, Tagalog, Russian.



# LEP Total and Percent for Top 6

Language	Total	Total LEP	% LEP
1. Spanish	37,458,470	16,344,440	43.63%
2. Chinese	1,867,485	1,054,885	56.49%
3. Vietnamese	1,399,936	839,237	59.95%
4. Korean	1,117,343	617,905	55.30%
5. Tagalog	1,613,346	516,522	32.02%
6. Russian	879,434	416,526	47.36%

Source: October 2015 Census Data

# How many LEP individuals live in a FDA community?

### Limited English Proficiency (LEP) A Federal Interagency Website



#### **LEP Information**

Frequently Asked Questions
Executive Order 13166
Resources by Subject
Interpretation and Translation
LEP and Title VI Videos
Demographic Data
LEP Mapping Tools
LEP Resources and Compliance
Federal Agency LEP Plans
LEP Guidance for Recipients
DOJ LEP Guidance for Recipients

#### Limited English Proficient (LEP) Maps

#### Language Map App

The Civil Rights Division's Language Map App is an interactive mapping tool that helps users find out the concentration of and languages spoken by LEP individuals in a community. Click on your state or county to identify the number or percentage of LEP persons, download language data, or visually display LEP maps for presentations. We encourage users to test the features of the Language Map App and provide feedback to help us improve functionality.

Language Map App Accessible Alternative with Downloadable Data

#### **Additional LEP Maps**

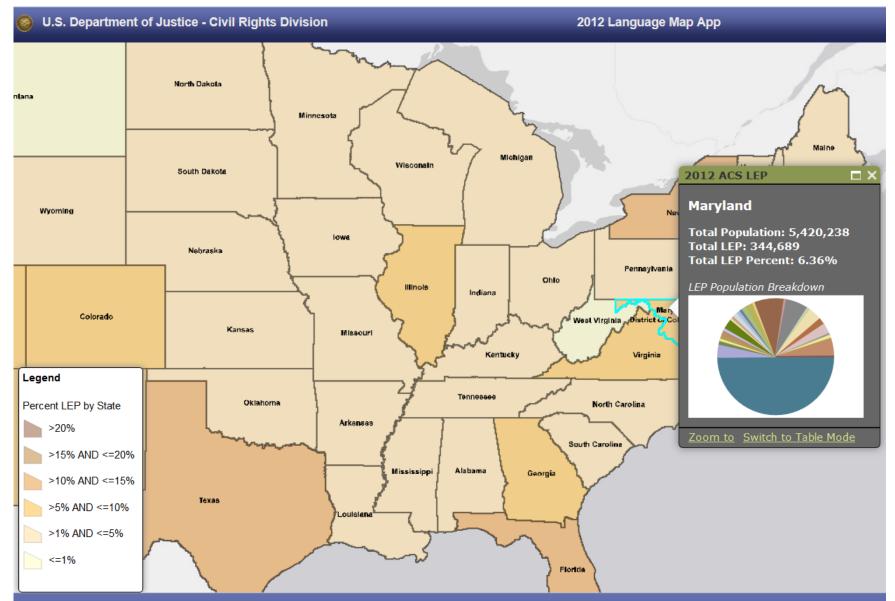


Total Persons 5 Years and Over Who Speak a Language Other Than English at Home and Speak English Less Than "Very Well"



### Language Map App

### www.lep.gov/maps

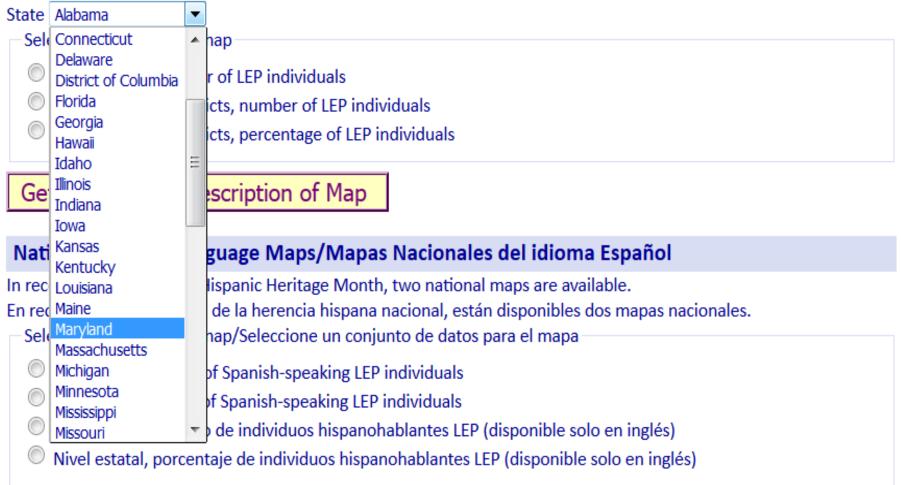


Note: These maps are for informational purposes only. Although demographic language data may be useful in considering how language assistance is provided in a particular contact or setting delivering services. Federal agencies are required to comply with Executive Order 13166. Recipients of federal financial assistance must comply with <u>Title VI of the Civil Rights Act of 1964</u> and i further information, please see LEP.gov or contact LEP@usdoj.gov.

### www.lep.gov/maps/lma/Final

#### **Mapping LEP Populations in Your Community**

This tool helps users access maps of the limited English proficient (LEP) population in any given judicial district, county, or state. Maps were created using 5-year U.S. Census American Community Survey data.



### www.lep.gov/maps



### **Executive Order 13166**

 In accordance with Executive Order 13166, Improving Access to Services for Persons with *Limited English Proficiency*, issued August 11, 2000, all agencies operating under the U.S. **Department of Health and Human Services** (HHS) must ensure that their programs are accessible to individuals with limited English proficiency (LEP).



### Timeline

- **February 2011:** Federal Government's Renewed it's Commitment to Language Access Obligations Under Executive Order 13166
- February 2013: HHS issues plan with directive to Agencies to submit agency-specific LAP to HHS by January 1, 2014 – adds 3 additional elements
- April 2013: HHS updates CLAS Standards
- July 2013: FDASIA 1138 "Ensuring Access to Adequate Information on Medical Products for All" – FDA response included the development of LAP as a deliverable
- January 2014: FDA submitted LAP for FY13-15 to HHS under it's Renewed Commitment for Executive Order 13166



### Language Access Plan (LAP) Areas of Focus

There are 10 elements within the action plan that HHS agencies are required to deliver, each creating steps that their agencies will take to meet these elements.

- 1. Assessment: Needs and Capacity
- 2. Oral Language Assistance Services
- 3. Written Translations
- 4. Policies and Procedures
- 5. Notification of the Availability of Language Assistance at no Cost
- 6. Staff Training
- 7. Assessment: Access and Quality
- 8. Stakeholder Consultation
- 9. Digital Information
- 10. Grant Assurance and Compliance



### **LAP Steering Committee**

 Created to oversee the agency's plan for expanding language access and implementation of the plan.

• Led by OMH and consists of 22 communication experts from each center and office within FDA.

# Translating Information To Meet the FDA Needs Of Our LEP Consumers

### **Machine Translation**

 Software or online applications that automatically translates written material from one language to another without the involvement of a human translator or reviewer.

### **Translator**

- Must maintain structure of original meaning, keeping ideas and facts accurate.
- Must transmit cultural references, including slang, and other expressions that do not translate literally.



### **LAP Volunteer's Program**

In August 2015, Office of Minority Health launched the agency's first Language Access Plan Volunteer Program.

- Purpose: to ensure that translated information for LEP consumer/patient, is accurate, culturally sensitive, and at a level they can understand and use.
- Currently, the program has over 80 volunteers that speak over 19 languages.



## **Connecting With LEP Consumers**

- Multilingual Workshop
  - "Education starts at home"
- Stakeholder Engagement Meeting
- First Multilingual Campaign



### FDA SPANISH-LANGUAGE COMMUNICATIONS

## **GLORIA SÁNCHEZ-CONTRERAS**



### Latinos in the U.S.

- **56.6** million of Hispanics
- **17** percent of the nation's total population
- **119 million (28.6%)** projected Hispanic population of the U.S. in 2060
- **15.2 million** The Hispanic population of California. This is the largest Hispanic population of any state.

Sources: Facts for Feature: Hispanic Heritage Month, U.S. Census Bureau, July 28, 2016



### iViva la DIVERSIDAD!





### **Latinos love their smartphones**



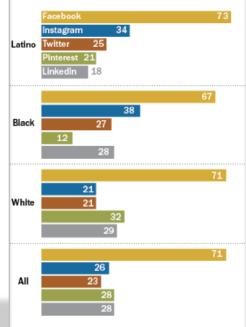


# Latino Technology Use

- About 80% of Latinos own a smartphone.
- 84% of Latino internet users (ages 18 to 29) use social networking sites.
- Latinos go online from a mobile device at similar and sometimes higher—rates than do other groups.
- Latinos are heavy users of mobile apps.
- Latinos are active users of Facebook and more likely to upload photos, comment, share, and "like" posts.
- Content that celebrates Latino culture or embraces the fusion of two cultures in the U.S. is most effective.

#### Latinos and Blacks More Likely Than Whites to Use Instagram, Less Likely to Use Pinterest

% of internet users who use each social media site, by race and ethnicity



Note: Blacks and whites include only non-Hispanics. Hispanics are of any race. Source: Pew Research Center's Internet Project September Combined Omnibus Survey, Sept. 11-14, 2014 and

Sept. 18-21, 2014. n=1,445 internet users

#### PEW RESEARCH CENTER



### Latinos don't like bad translations





### **Keep focus on your audience**





# Promote, Promote, AND Promote!



### FDA MULTILINGUAL OUTREACH PILOT

# GLORIA SÁNCHEZ-CONTRERAS & CARINY NUÑEZ



# **FDA Topic Considerations**

### How we select a topic for translation:

- Important consumer information
- Issues affecting a specific demographic group
- Feedback from regional public affairs / offices
- Requests from stakeholders & minority organizations
- Monitoring news and social media



### **FDA Pilot: Health Fraud**

**Topic:** "Some Imported Dietary Supplements and Nonprescription Drug Products May Harm You"

- Increase in health fraud scams
- Consumers are constantly bombarded by advertisements for fraudulent products, medical treatments and cures in various languages
- Some products have labels in Spanish and Asian-languages
- LEP populations more vulnerable to health fraud scams:
  - Limited or inadequate access to health care services
  - Limited health literacy
  - Language barriers and cultural beliefs
  - More prone to buy imported health products
- Languages for translation were selected based on populations affected and U.S. Census numbers for most spoken-languages (Spanish, Chinese/Mandarin, Vietnamese, Tagalog and Korean)
- Translated article, video script and images were reviewed and proofread by FDA SMEs and native speakers in the target language and for cultural sensibility. (Language Access Plan Volunteer Program)



# **Communications Strategy**

### **Outreach Activates:**

- Launched during National Consumer Protection Week (News Hook) – March 6-12
- Ethnic and traditional media outreach / media interviews with subject matter experts/spokespersons
- Google AdWords campaign in different languages
- Social media outreach (YouTube, Flickr, Facebook, Twitter and Pinterest)
- Stakeholder outreach Emails, Newsletters
- Blast consumer emails (English & Spanish)



# **Communications Strategy**

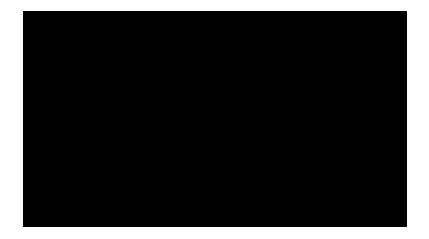
### **Communications Materials:**

- <u>Consumer article</u> (Web page / PDF)
- <u>One-minute educational video</u> in YouTube
- <u>Flickr videos</u> downloadable for Radio & TV PSA
- <u>Flickr graphic</u>
- Social media toolkit (Facebook and Twitter)
- FDA Voice Blog (<u>English & Spanish</u>)
- Pinterest pin (<u>English</u> & <u>Spanish</u>)
- Internal KMQAs English only
- Unique URL: <u>www.FDA.gov/SupplementSafety</u>

\*Consumer article, video, graphic and social media toolkit were translated into Spanish, Chinese (Mandarin), Vietnamese, Tagalog, and Korean



# "Some Imported Dietary Supplements and Nonprescription Drug Products May Harm You"



Link: https://www.youtube.com/watch?v=GXaOTkHBJfl&list=PLey4Qe-UxcxadPd4Ei1cVWKpSJYYa1x6N&index=2

### Conclusions



- 1. Think beyond traditional audiences and media
- 2. Select translation topics based on population needs and importance
- 3. Connect with consumers speak their culture
- 4. Proofread translations in-house by SME experts when possible (native speakers, cultural sensitivity)
- 5. Leverage multicultural consumers' natural digital behaviors
- 6. Partner with internal and external organizations
- 7. Promote, promote and promote the more channels the better.



### Discussion

- We have demonstrated value in building our brand by using multiple forms of communication to engage our audience.
- Our successes have been contingent upon prioritizing content areas, strategically selecting the best mode of communication, maintaining an open feedback loop, and being flexible with our implementation strategies.



### **Next Steps**

 In the future, more research needs to be conducted to assess the effectiveness of using different platforms (e.g. social media) to raise awareness on minority health issues and engaging minority audiences

### **Upcoming Events**

Key Outreach Activities for Health Literacy Month

- Share information
- Translate resources
- Consumer Update
- Blog
- Social Media
- Risk Communication Advisory Committee Meeting
  - November 7<sup>th</sup>, FDA Campus
- American Public Health Association Annual Meeting
  - 3 presentations
  - Exhibit Booth
- OMH Lecture Series
  - November- Diabetes Awareness Month- Dr. Griffith Rodgers, NIDDK Director









## **Health Literacy Activities**

October is Health Literacy Month

FDA's Key Activities:

- Share information
- Translate resources
- Consumer Update
- Blog
- Social Media





### **Stay Connected!**



Follow us on twitter @FDAOMH



OMH@fda.hhs.gov



www.fda.gov/minorityhealth





Note: all webinars and stakeholder calls are announced in our newsletter and you can sign up for our newsletter via the website



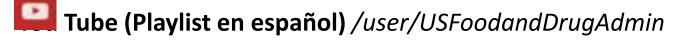
# Follow us in Spanish!





Facebook /FDAenEspanol

**Pinterest FDA en Español** / /usfda/fda-en-espanol/





Flickr /photos/fdaphotos/sets



### References

- Prescription Drug Promotion Research
  - http://www.fda.gov/aboutfda/centersoffices/officeofmedicalproductsandtobacco /cder/ucm090276.htm#research
- Tobacco Products Research
  - http://www.fda.gov/TobaccoProducts/PublicHealthScienceResearch/default.htm
- BAA projects
  - http://www.fda.gov/ScienceResearch/SpecialTopics/RegulatoryScience/ucm452378.htm
- CERSI projects
  - http://www.fda.gov/ScienceResearch/SpecialTopics/RegulatoryScience/ucm301667.htm
- RCAC Presentations (see Feb. 17)
- http://www.fda.gov/AdvisoryCommittees/CommitteesMeetingMaterials/RiskCo mmunicationAdvisoryCommittee/ucm486485.htm

