

NCVHS WORK GROUP
“NOVEL HEALTH DATA”

September 17, 2013

What we are proposing to do

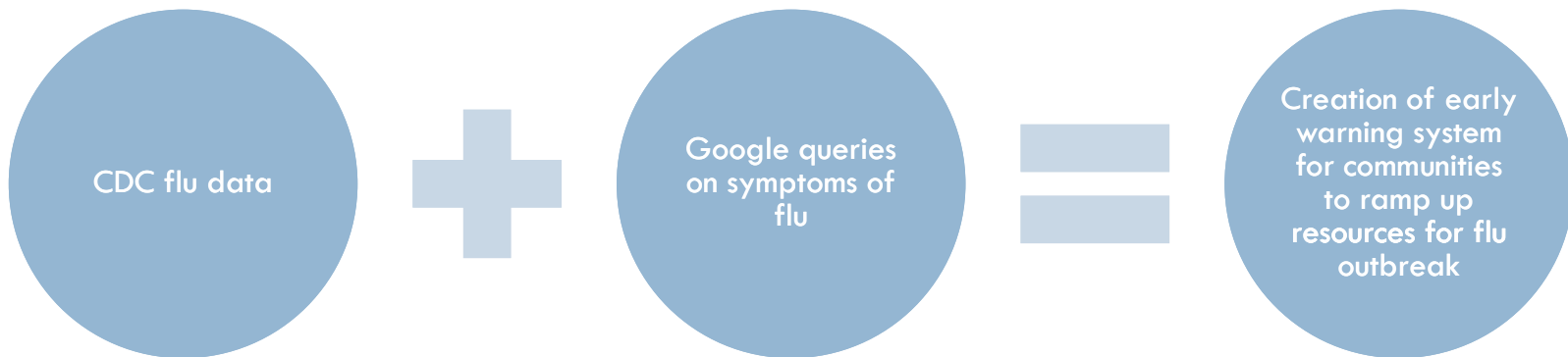
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- NCVHS is looking for a community partner to demonstrate novel use of HHS data to address a community health-related issue
- Requisites are:
 - ▣ Community with articulated need and individuals interested in working on this in a new way
 - ▣ HHS data
 - ▣ Unconventional data (e.g. social media data)

“Novel Health Data” Proposal

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- Demonstrate innovative use of HHS data, blended with unconventional data (e.g. social media), to address an issue identified as a priority by a community
- Critical elements
 - ▣ Problem solving must have strong support and leadership from the community and knowledgeable resources who can partner in developing solution.
 - ▣ Problem must be one for which HHS data is critical and relevant social media data is available
 - ▣ Problem should lend itself to development of community user friendly “tool kit”
- Example:



Why We Are Proposing This: NCVHS WG Charge

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- Through the National Committee on Vital and Health Statistics, the Working Group on HHS Data Access and Use will assist and advise the Department of Health and Human Services on recommendations to promote and expand access to and innovative uses and applications of HHS data to improve health and health care.
- Based upon knowledge and familiarity with:
 - ▣ HHS data resources
 - ▣ traditional and new information dissemination strategies, developments and technologies and social media and their application by the technology innovation community
 - ▣ needs for data and information by major participants in the health system,
- The Working Group will monitor and identify issues and opportunities and make recommendations to HHS on improving data access and innovative use, including content, technology, media, and audiences.

Outcome and Benefits

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- HHS learns about
 - ▣ Novel, innovative types of data (e.g., Facebook “likes”, supermarket purchases, etc.)
 - ▣ How HHS data can be blended with other unconventional sources and the skills and resources needed
 - ▣ Whether these data are strong enough to be useful, safe and secure
- Communities
 - ▣ Gain more information about the problem they are trying to address
 - ▣ Learn more about HHS data
 - ▣ Learn more about a potential role for unconventional data
 - ▣ Get a user-friendly “tool kit” for similar future applications

Measures of success

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- The requisites for this approach are identified
 - Team
 - Tools
 - Techniques
 - “Translator”
- The benefit to a community user are identified
 - Potential value of new information generated by this event
 - “Tool kit” for future uses of this new approach
 - Insights on how to approach to privacy and confidentiality
 - E.g. is there a potential for a whitepaper on “safe” use of social media?

Examples of requisites identified (4Ts)

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□ **Team**

- Expert user of HHS data
- Expert user of Social media data
- Community member knowledgeable about the issue
- Expert who can cross walk community question to available data

□ **Tools**

- Access to data
- Analytics for data

□ **Techniques**

- How to get information from social media data

□ **Translator**

- How to interpret and validate the data.

Finding a Community

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- NCVHS held three learning sessions with communities over the last year exploring their data needs, successes and failures for problem solving
 - ▣ Many communities identified interest in gaining more expertise with HHS data
 - ▣ Many communities expressed interest in partnering with NCHVS in further addressing issues
- **Actions:**
 - ▣ NCVHS Population Committee assisted in identifying communities that be appropriate for this project
 - ▣ NCVHS Privacy Committee initiated evaluation of privacy policies of Google, Twitter, Facebook, Google survey

Timeline

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- Several potential communities have expressed interest
- Additional discussion with communities by **September 13**
- Review of privacy policies of Twitter, Facebook, Google by **September 13**
- Work Group Activity for **September 17**
 - Discuss feasibility of interested communities
 - Relevant HHS data sets available (as well as other)
 - Relevant social media sources
 - Engagement of community
 - Availability of technical resource
 - Define deliverables, e.g.
 - SWOT analysis of entire process
 - Areas of focus for continued NCVHS full committee study:
 - e.g. Privacy, Confidentiality, Security
 - HHS data contribution to value
 - “How To” Narrative
 - “How To” Tool Kit
 - How to organize this event
 - Who/how to engage outside groups such as RWJ
- Designated day for development and findings **October**
- Analytics on findings and tool box **November** WG meeting