The NIH Director's Council of Public Representatives (COPR)

Communications Work Group

Presentation to the NIH Director October 31, 2008

Presented by Anne Muñoz-Furlong

Work Group Day Participants

- Anne Muñoz-Furlong, Co-Chair
- James Wendorf, Agenda Co-Chair Liaison
- Linda Crew
- Valda Boyd Ford
- Nicole Johnson
- Cynthia Lindquist
- Eileen Naughton
- Jim Wong
- John Nelson, ACD Liaison

Communications Roadmap

- Natural outgrowth of the NIH Roadmap for Medical Research continuum
 - New science → 4 Ps → new communications
- Budget/cultural change relating to NIH-wide communications activity
- Integrated, unified communications and Web strategy
- Cross between awareness and branding

NIH Communications Study

- July 2008 Omnibus Data
- Edelman Focus Groups
- September 2008 Expert Panel Meeting
- Next step: Seek broader public input via Request for Information (RFI)

 Question 1: What is the appropriate purpose statement to elicit information about public information needs from NIH?

- Question 2: How will NIH reach new audiences and use new tools, such as social media? Consider questions that will elicit responsive information for the following categories of concern:
 - Health consumers (e.g., patients, physicians, local health services, community clinics, health plans, etc.)
 - Information needs
 - Accessible places to obtain health information, focusing on differing locations in rural, urban, and suburban areas and using new disseminators
 - Roles stakeholders can play and who they are (national, regional, local levels)

• Question 3: How can NIH best disseminate the RFI itself to reach the various health consumers for maximum public response?

 Question 4: How can the COPR help with dissemination efforts?

Work Group Response

- An RFI has certain limitations:
 - Target audiences do not read the Federal Register
 - RFI more likely to be answered by organizations than individuals
 - RFI is not consumer friendly

Work Group Recommendations

Response to RFI limitations:

- Base the questions on those used at the September Expert Panel
- Engage the COPR to:
 - Introduce the RFI in plain language to make it more consumer friendly
 - Disseminate the RFI to constituents by email/mail/phone, focus groups, etc.)
 - Involve the COPR alumni

Work Group Recommendations

Benefits of this process:

- Study immediately reaches a wide and diverse group of health consumers and state actors by involving COPR members' constituencies
- It could become a core responsibility of the COPR to conduct such a communication study yearly for an ongoing stream of information. This also relates well to the ambassador role of the COPR

Work Group Recommendations

• The bottom line:

"We can get more firepower from the people on the COPR than from the *Federal Register*."

- Communicate through a variety of methods: directly to health consumers, consumer/advocacy groups
- Develop a formal communications network that any nonprofit/advocacy group can sign up to receive information

- Partner with professional organizations that interact with large numbers of health consumers (e.g., AMA, etc.)
- Partner with state groups that set health policy and legislation

- Communicate information in traditional and nontraditional ways:
 - Establishments that exist in every community (e.g., pharmacies, grocery stores, barber shops, etc.)
 - Tailor communication vehicle to target audiences (e.g., places of worship, small/ethnic newspapers, etc.)

- Link an "NIH Awareness Month" campaign to high-powered television exposure, such as arranging for the NIH Director to appear on Oprah
- Provide lapel pins or stickers to COPR members, COPR alumni, physicians, health care providers, advocacy groups, etc., that say "Ask me about NIH."

 Blue sky: Use Facebook or MySpace to form a group, such as "Friends of NIH," to attract interest and encourage dialogue.

Next Steps for RFI

- Draft
- Determine the timeline
- Determine evaluation mechanism
- Post and distribute