"Understanding AIDS" — The National AIDS Mailer

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Synopsis

The Centers for Disease Control (CDC) of the Public Health Service made public health history in 1988 by mailing the pamphlet, "Understanding AIDS," to every household in the United States. Approximately 126 millon copies were distributed, reaching at least 60 percent of the population according to several national polls. The pamphlet

was produced and mailed at a cost of about 20 cents per copy.

The impact of "Understanding AIDS" by itself on AIDS-related behavior was not fully assessed. Extensive message pretesting and other commercial marketing techniques to improve the effectiveness of the brochure, however, helped "Understanding AIDS" achieve an increase in awareness and concern about AIDS.

A number of lessons were learned during the process. They included the importance in such an enterprise of setting a deadline, doing formative research, receiving active support from senior management, achieving a consensus on scientific knowledge, using communications experts, centralizing the final decision-making function, maximizing publicity surrounding the mailing, building a base of support among constituency groups, planning distribution logistics from the very start, and designing evaluation into the process from the beginning.

In 1987 THE CONGRESS mandated the Centers for Disease Control (CDC) of the Public Health Service to distribute an AIDS mailer to every household in the United States by June 30, 1988 (1). While the law required CDC to send a mailer to all households, it did not stipulate that the same material be sent to every household. The decision had to be made whether to send all households the same document or to vary the materials for different target households.

Based on focus group research conducted on the content and language of CDC public service announcements (PSAs), two packages of materials were suggested. One package was intended for areas of high AIDS prevalence and another for the rest of the country. No practical way existed to identify high-risk households, however. Dividing the mailing by zip code or by census tract, for example, would have inevitably resulted in persons with low risk receiving the high-risk package, and vice versa. The decision was made, therefore, to send the same mailer to all.

It was also suggested that the mailing include a reply card to request additional information. Such a card could have provided an indication of response, demographic information, and other valuable data. The concern was that this would generate more requests than could be handled, as was the case in Britain following its national AIDS mail-out. This idea was discarded.

The target population was analyzed in two formative research activities. First, focus group discussions were conducted in 10 high- and low-prevalence cities (cities were paired so that similar groups were studied in both types of cities). A total of 31 community meetings were held in 28 cities to get input from people interested in AIDS, and leadership forums were convened that involved more than 600 leaders of various constituency groups (including blacks, Hispanics, youth, women, health professionals, and members of the communications media).

The second analysis, conducted later in the developmental process, consisted of testing a prototype brochure with 12 focus groups and with 21 health educators and AIDS prevention specialists. The results of these brochure pretests would influence the entire development of "Understanding AIDS."

CDC also decided to provide the brochure in both English and Spanish. The question arose as to whether the Spanish version should be a translation of the English version, a Spanish "foto novella" (picture book), or a culturally generated version.

The consensus was to make it essentially a translation with some photo changes. Later, the brochure would be printed in Braille, Chinese, Portuguese, Haitian-Creole, Vietnamese, Laotian, and Cambodian, as well as the original English and Spanish. It was also recorded on audio tape.

The Brochure's Content

The first concern identified in the analysis of the target audience was the difficulty of making the scientific details about AIDS understandable to the general public. Throughout the developmental process, the constant objective was to be scientifically accurate and to communicate clearly with a very broad audience.

The first part of the audience analysis and other data revealed several communication problems:

- There were areas of confusion. For example, no one seemed to know what "casual contact" meant.
- Many people did not trust the government.
- The language had to be frank and unequivocal. Euphemisms such as "bodily fluids" for blood, semen, and vaginal secretions did not have the clarity the public wanted, according to the focus groups' reactions.
- The content had to focus on behaviors, not risk groups. Many people who engaged in homosexual acts or intravenous drug use did not consider themselves "gay" or "drug addicts," nor were they at risk of HIV infection merely because of those behaviors alone.
- Encouraging condom use or monogamy conflicted with cultural norms in some groups.

These problems were addressed during the revisions and pretests of the brochure. Pictures of people were added and the layout changed to make it more attractive. Many phrases were reworded to make the text less judgmental and more scientifically accurate relative to HIV transmission. For example, the phrase "avoid IV drugs" was changed to "avoid sharing needles."

The readability was also tested. Using both the Gunning and SMOG Readability Formulas, it scored a seventh grade level. This was higher than the target fourth grade reading level, but lower than the twelfth grade reading level previous AIDS material had scored. The higher reading level was "artificial," however, caused by the necessary inclusion of the terms "Acquired Immunodeficiency Syndrome" and "Human Immunodeficiency Virus."

At first, CDC writers assumed that if the communication issues could be solved, the brochure would be satisfactory to the scientists. The first administrative review of the prototype ended that assumption. Because the scientific knowledge about AIDS was rapidly expanding, it was not easy to obtain scientific consensus on what was known. CDC was responsible for the scientific accuracy of the information in the brochure, and all internal reviews emphasized this need for accuracy.

Changes that occurred during these reviews are illustrative. Instead of, "the blood supply is safe," the final version stated, "all donated blood in the U.S. is tested for the AIDS virus." A later draft explained, "The risk of getting AIDS from a blood transfusion has been greatly reduced....donors are screened for risk factors and donated blood is tested for the AIDS antibody."

Developing consensus in a very short time required having one final authority to resolve conflicts. A structured review process was created. Key staff members met daily with the Director of CDC to review new drafts and suggested changes, which were often contradictory and conflicted with the need for definitive messages. Dr. James O. Mason, the then CDC Director, had the final word on resolving conflicting suggestions and needs. This review process, by involving so many of CDC's program staff members, served to educate CDC decision makers in the public communication process and secured the necessary support for the brochure.

Building Support

Political and organizational concerns. The law mandating the mailer specifically exempted it from clearance by CDC's parent agencies, the Public Health Service (PHS) or the Department of Health and Human Services (HHS), but the potential for conflict existed. Therefore, the CDC Director sought ways to involve top PHS and HHS organizational officials in the process. The explicit language and the choice of a "sponsor" (the government official who would endorse the brochure) were expected to be top concerns among PHS and HHS officials. To prepare for this, both issues were tested during the formative research. Research results indicated that the public expected and preferred frank, unequivocal language, which eased the fears of officials on this issue.

The mailer design had always included a government official's endorsement. Four potential officials' names were tested in focus groups. The four

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were Surgeon General C. Everett Koop, HHS Secretary Otis R. Bowen, Assistant Secretary for Health Robert E. Windom, and President Ronald Reagan. Dr. Koop and President Reagan received the highest positive ratings, but Dr. Koop, as a physician, was perceived to have higher credibility on medical issues than Mr. Reagan.

Dr. Koop was then added to the approval process. CDC officials and senior advertising staff met with Dr. Koop to review the draft brochure entitled "Understanding AIDS." Dr. Koop agreed to the layout, but had some specific modifications to the text. Four days of intensive work were required to make and clear the changes generated by Dr. Koop. On March 11, 1988, the CDC Director signed the camera-ready copy, and "Understanding AIDS" was on its way to the Government Printing Office.

Constituencies. CDC made major efforts to gain the support of as many interested groups as possible. This process had begun during community meetings and leadership forums in 1987, during the release of the "America Responds to AIDS" campaign, when links were formed with community-based organizations and AIDS service organizations. During the last stages of the review process, these groups and other major constituency groups were invited to review the brochure and comment on key issues.

The preview process had several goals. One was to notify relevant organizations of the content so they could prepare for its impact. This was particularly crucial for physicians (American Medical Association), public health workers (American Public Health Association), State health departments, and laboratories. Other goals were to build good will and prepare for any criticism. Through this preview process, CDC was able to create a supportive environment for the brochure. Several organizations volunteered to call news conferences to promote and defend the brochure, if necessary.

General public. CDC wanted the general public to read the brochure, not consider it just another

piece of junk mail. Therefore, CDC conducted a publicity campaign to attract the attention of the public. "Understanding AIDS" had a built-in news factor, being the first national mailing dealing with a public health issue.

The public relations plan, using this news angle and the existing interest in AIDS, had several goals:

- to ensure that the brochure was read, understood, and shared by all household members as a basis for dialogue about AIDS
- to involve a variety of target audience representatives in various events to draw attention and support to the brochure
- to increase the visibility of the government AIDS information and education program
- to gain increased media coverage

Specific target audiences included State AIDS coordinators; community-based organizations; State and local health departments; national organizations that represented medical, educational, or minority groups; political leaders; the health care establishment; news and other media; and the international community.

Various media events were created. Officials at CDC held teleconferences with State and local health officials, and PSAs featuring Dr. Koop and other public health officials received about \$5 million worth of free TV broadcasting time. A major news conference was held to release "Understanding AIDS" to the public.

The news conference on May 4, 1988, was the major event of the public relations campaign. It featured the Secretary of the Department of Health and Human Services, the Surgeon General, the CDC Director, and "key AIDS commentators" from constituency groups around the country in support of the brochure. Preconference publicity included distributing 8,000 advance information kits containing the brochure and background information, artwork, and suggestions for articles to AIDS commentators and the media.

A series of followup events was held to maintain interest. A congressional briefing was given, additional information was mailed to national media, top government health officials went on media tours across the country, a video news release was distributed, a teleconference was held, and the media were supplied with information for feature stories.

On May 10, a letter with an advance facsimile of the mailer was sent from Dr. Mason to approximately 1,051,000 members of the American Medical Association, National Medical Association, American Nurses Association, American Dental Association, American Public Health Association, American Pharmaceutical Association, American Hospital Association, and regional, State, and local health officers and directors. Special efforts were made to reach racial and ethnic minority groups in selected urban areas. A regional news conference was held in Puerto Rico on May 21, and local news conferences were held, usually with the mayor or a representative of the mayor, in Los Angeles, Cleveland, Houston, Philadelphia, New York, Chicago, and Atlanta.

Distribution and Response

Distribution. Information about mass mailing logistics, gathered in October 1987 during planning for the release of the public information campaign, saved significant time in the preparation of "Understanding AIDS." From the start, both the Government Printing Office (GPO) and the U.S. Postal Service were involved in the design of the brochure and planning for printing and distribution.

Several questions had to be answered by GPO and the Postal Service:

- How would all households be identified and reached?
- How would the brochure's format affect printing, postage, and distribution logistics and costs?
- What special arrangements could be made to get the brochure to the hard-to-reach?
- How would printing and shipping be accomplished within the time period allowed?

There was not enough time to obtain individual mailing labels and to group the brochures for distribution. Instead, the brochure would have the mailing information printed directly on it, be addressed to "Postal Patron," and be presorted and bundled by carrier route. Postal Service data were used to calculate the number of households on each of 455,000 carrier routes and how many brochures to send via each of the 21 bulk mail distribution centers.

The postage was 10 cents per piece. A lower rate could have been obtained by using a different size brochure, but CDC determined the 8 1/2 x 11-inch format was the most effective for communication. This did cause distribution problems, however, because the brochure would not fit into some mail slots.

CDC wanted to use magazine-quality paper, but few printers had sufficient litho-coated paper available. The size of the printing job would have required many printers, raising issues of quality control. Because of these problems, the decision was made to use uncoated paper, which also lowered the cost.

The question about how to reach "unique populations" was answered by special mailings to the military, Americans assigned abroad, prisons and juvenile detention facilities, and homeless shelters. Some people were missed, mostly those living in multifamily dwellings in low income areas where unlabeled mail is often placed on a common "junk mail" table instead of into individual boxes.

Most of the copies of the brochure were printed by one printer in Houston, TX, but 19 other firms did special printing for the project, including the Federal Bureau of Prisons. Approximately 126 million copies were printed, using 6 million pounds of paper and 8 tons of ink. Printing, collating, stapling, and perforating were done on the same machine, which ran 24 hours a day for 6 weeks. The brochures were sorted and bundled by carrier route and loaded onto 187 trailers, which were then piggy-backed onto rail cars for shipment to the bulk mail distribution centers. Shipments were sent in stages from May 12 to May 26. The Spanish language version was mailed directly to Puerto Rico. Delivery by the Postal Service was completed June 15, 2 weeks ahead of schedule.

Response. Experts estimated that from 1 to 6 percent of recipients would call or write for additional information. CDC's National AIDS Hotline (NAH) and National AIDS Clearinghouse (NAC) were not the only organizations that would be affected by any response; State and local health information agencies and counseling and testing facilities could also expect increased contacts, as could private health care providers.

Hotlines. CDC helped establish telephone "hotlines" in every State and territory. Some were established without CDC funds, while others were funded by CDC. Since CDC's NAH was the only source of additional information mentioned in the brochure, CDC also expanded NAH and added a special 3-month supplemental telephone bank. A Spanish language service was initiated and remains in operation. The English language version of the brochure gave the new Spanish hotline number for requesting the Spanish language version of the mailer. Concerned about an overwhelming response, CDC made the English hotline telephone number less conspicuous in the pamphlet. The CDC hotline received a total of 270,902 calls from May 26 to June 30, about one quarter of 1 percent of households reached.

Clearinghouse. CDC's NAC was assigned to handle the special mailings to unique populations. all requests for Spanish language brochures, and any other requests that could not be handled by CDC's NAH. To keep response time under 48 hours, NAC sorted mail into various standard reply and special handling categories. Standard replies were prepared for complimentary letters; requests for the brochure; complaints; requests for additional information or information on AIDS and children, AIDS statistics, AIDS and the blood supply, and AIDS and drug abuse; and requests from health professionals. Special handling included requests for bulk quantities; letters with no return address, a change of address, or a foreign address or foreign language or both; requests from legislators or public health officials; and letters on issues not related to AIDS or not covered by existing form letters. From May 30 to August 18, 1988, CDC's NAC received 7,006 letters, mostly for bulk orders, and 84,815 telephone orders from NAH. Forty-five percent of the telephone orders were for the Spanish version of "Understanding AIDS."

Counseling and testing. To prepare for the number of people who might request counseling and testing for HIV infection, CDC encouraged the 20 manufacturers of HIV test kits to increase production, warned the 1,400 testing laboratories of the pamphlet's impending release, and worked with State and local health officials to prepare for increased demand for services.

Evaluation

CDC's goals were to comply with the law and to have people read and discuss the contents of the brochure. Extensive outcome or impact evaluation was not done because of time and budget considerations. The mailer was, however, assessed in some ways.

Data collection. CDC added questions about the mailer to the National Health Interview Survey (NHIS) from May through August 1988, so serial data were available for analysis for that 4-month period. However, there would be difficulty separat-

ing the effects of the mailer from those of the publicity campaign and other AIDS information activities

Both the Gallup Poll and researchers from the University of California, San Francisco (UCSF), conducted national telephone polls on receipt, readership, and response to the brochure (2,3). Other research groups conducted State or local polls (4). The Postal Service, in its regular Household Diary Study on mail, included the mailer in July 1988.

Some data were also obtained by monitoring testing sites, hotlines, and CDC's clearinghouse. Testing sites were selected on the basis of their willingness and ability to supply data, not at random or by demographic analysis. In addition, some sites did not have recent baseline data for comparison. It was also unclear whether generating a large response meant "Understanding AIDS" was successful in that it increased awareness or unsuccessful in that it created unwarranted fears. Consequently, data from this effort had limited value.

At CDC's NAH and 9 State hotlines, data collected for the first 5 months of 1988 served as a baseline and was compared with calls received during May 30-July 31, 1988. NAC also collected data on the volume and type of requests for publications.

Results. The main goal of "Understanding AIDS" was the simplest to measure. A pamphlet had been delivered to almost every household in the United States by June 15. The congressional mandate had been met.

The three national surveys agreed that at least 60 percent of people interviewed remembered receiving the brochure. Of the remaining 40 percent, 11 percent probably did not receive the brochure. The other 29 percent probably did receive it but either did not remember it or the brochure was received by someone in the household other than the person surveyed. More whites than blacks recalled receiving the brochure, as did more men than women and more high school graduates than those with less schooling.

Of those who recalled receiving the brochure, approximately 80 percent read at least some of it. Most reported reading at least half or more. This meant that almost 87 million adults read "Understanding AIDS," making it the most widely read publication in July 1988 (compared to the second most widely read publication that month, Reader's Digest, with 48.5 million readers). The 80 percent readership is notable. According to Postal Service

officials, only about 50 percent of third-class mail is read, and other data indicate that only 11 percent of mailings of this type are read more than halfway through.

Not only was the brochure read, but 40-50 percent of the recipients reported having discussed it with family or friends. About 30 percent of those with children shared the brochure with them. Thirty percent of those who read the brochure said they learned something new about AIDS, and most of those were in the difficult-to-reach categories—younger adults, blacks, and those with less than a high school education.

Most people approved of the brochure. The UCSF study found 85 percent thought it a good use of government money, and 84 percent were glad to receive it. Only 2 percent were offended. Only 1,020 complaints were received by NAC.

NHIS also noted significant changes in knowledge about AIDS. From May-June to August 1988, knowledge that AIDS is caused by a virus increased from 58 to 64 percent, and that an infected person can look and feel healthy increased from 42 to 47 percent (5,6).

Testing and calls to hotlines increased. During a 21-week comparison period, testing for HIV antibodies increased 38 percent compared with the same period the previous year. Some of that may be attributed, however, to an increased number of testing sites. States reported an increase of 83 percent in attendance at counseling and testing clinics in June, compared with the previous five months. Attendance increases were higher for blacks (more than 300 percent) than for whites (25 percent), and there was a significant increase in visits by people with no known risk for infection (more than 800 percent). The pattern was uneven, however, with about half the reporting States not noting any change in clinic attendance at all.

Response to the hotlines was more definitive. Although fewer than expected, calls to NAH increased 251 percent during the May 26-June 30 period, compared with March-April of the same year. State hotlines operating prior to the mailing of "Understanding AIDS" reported a 122-percent increase during the first week in June compared with the weekly average for the previous 5 months. Fifty-nine percent of these calls were identified as being prompted by "Understanding AIDS."

Costs. Development, printing, postage, hotline and clearinghouse services, and survey costs totaled \$25,544,853 (\$15 million for printing and postage alone), for an average cost of 20 cents per copy for

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the 126,453,800 copies in English and Spanish that were printed and distributed.

Conclusions

"Understanding AIDS" was a pioneer effort in many ways. It was the first government publication aimed at the general public that contained all the essential facts about AIDS. As a national mailer, it focused national attention on AIDS. It used explicit language to describe HIV infection and AIDS as pioneered in the "Surgeon General's Report on Acquired Immune Deficiency Syndrome." It made more use of commercial advertising techniques, especially formative research, than most government publications.

Doing something like this for the first time teaches many lessons—about combining good science with good communication, about reaching beyond traditional public health constituencies, and about educating the public through mass mailings. Many of these lessons can be applied to other mass mailings of this type. These lessons are

- 1. Impose a deadline.
- 2. Perform formative research.
- 3. Obtain the involvement and support of senior management.
 - 4. Centralize final decision making.
 - 5. Build a scientific base.
 - 6. Use appropriate communications experts.
 - 7. Maximize the public relations potential.
 - 8. Build a base of support.
 - 9. Build in logistics from the start.
 - 10. Build in evaluation from the start.

By most criteria, "Understanding AIDS" was a successful, cost-effective way to increase awareness, focus public attention, and distribute basic information about AIDS. While mailings on a national scale will probably continue to be rare, the use of mass mailings as a public health communication technique, if done with the care and commitment of

"Understanding AIDS," can be an effective means of informing the public about important issues.

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