

## **FINAL REPORT**

# **Testing of Opportunistic Infection Brochures**

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*Submitted to:*

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# Introduction

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## Purpose of the Project

In response to the need of people living with HIV and those caring for them to understand the opportunistic infections associated with the virus, the Centers for Disease Control and Prevention (CDC) has developed a series of 11 brochures describing a variety of opportunistic infections (OIs). The brochures, which encourage people living with HIV to consider the preventive and treatment options available and adopt protective behaviors, provide information about transmission, symptoms, treatment, and the behaviors that impede and facilitate people's likelihood of contracting opportunistic infections.

The purpose of the project described in this report was to: 1) obtain feedback regarding the brochures' format and content; and 2) gain an understanding of the most appropriate ways to disseminate the brochures. To that end, we (the four-person research team from Macro International, a health research firm in Atlanta) tested three of the brochures with a diverse sample of individuals living with HIV and/or caring for individuals with HIV. The interview questions focused primarily on four specific aspects of the brochures: 1) clarity; 2) value of information; 3) format; and 4) appearance. Interviewees were also asked which information was new to them, how to disseminate the brochures, and what sources (other than brochures) would be useful for disseminating pertinent opportunistic infection information.

It is expected that the findings in this report will be used for determining how best to provide essential information to people living with HIV and their caregivers. To this end, this report is divided into three sections. The first sets forth the methodology used for selecting study participants, collecting data, and analyzing data. It also describes the demographics of the individuals comprising the study sample. The second section presents the study findings. It first examines the patterns that emerged across the three brochures, then pinpoints issues related to each brochure.

Finally, to maximize the likelihood that the valuable and thoughtful input provided to us by study participants will contribute to future revision and dissemination efforts, the third section sets forth salient recommendations. Mirroring the format of the study findings section, the recommendations section first contains recommendations for all three brochures, then sets forth suggested changes for each of them. At the end of this report are appendices containing the document used for describing this project, the data collection protocol, the demographic information form, the three data collection forms, a table featuring all closed-ended responses and key comments, and a list of raw data counts for all open-ended questions.

## Methodology

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In all, 85 individuals were interviewed during August and September 1998. Each person read and responded to questions about one of the following brochures: 1) *Opportunistic Infections and Your Pets* (35 interviewees); 2) *You Can Prevent Cytomegalovirus (CMV) Infection* (32 interviewees); and 3) *You Can Prevent PCP in Children* (18 interviewees). One interview, which was being conducted about the *You Can Prevent CMV* brochure, was discontinued half-way through due to time constraints; therefore, the count for some of the interview items is 84 rather than 85.

Data collection ended after the 85<sup>th</sup> interview because it had become increasingly clear that further data collection would produce diminishing returns. This is because respondents' feedback was consistent across individuals and groups, and no new issues had been raised for quite some time. Also, at the time that this decision was made, we discerned that if we were to continue recruiting we would need to begin an entirely new recruitment effort. This would require identifying more groups or adopting another recruitment strategy (such as clinic intercepts) because we had contacted all the group leaders on our lists (described below) and had visited all the groups that showed an interest.

### Selection of Study Participants

Data were collected through one-on-one interviews with individuals who participate in support groups for people infected with HIV and for people who care for people living with HIV (including parents, partners, and others) across the metropolitan Atlanta area. Visiting support groups proved to be a highly practical, effective way of collecting the type of data needed for this project. The approach was especially successful due to the fact that talking to support group leaders in advance gave them the opportunity to consult with their clients a week or two before our arrival to ensure they would be comfortable with our presence. Advance notice also enabled the leaders to determine the approximate number of people who would participate in interviews. Consequently, Macro staff were able to plan ahead, ensuring that the size of the research team would be sufficient to both maximize the number of interviews and minimize the waiting time for participants.

In addition to decreasing the logistical burden, the support group methodology allowed us to identify people living with HIV without needing to ask their serostatus. This approach contrasts greatly with clinic intercepts, which require employing creative ways to encourage potential participants to disclose their status without infringing upon their right to confidentiality.

The seven support groups that participated in this study (listed in Appendix E) were selected based on recommendations made by clinic and CDC staff and consultation of a list of support groups in the area. Attention was paid to the characteristics and locations of support groups in an effort to obtain as diverse a sample as possible. To arrange visits to the groups, we telephoned leaders of support groups whose member characteristics and geographic location contributed to our effort to obtain a diverse sample. When leaders requested written information we faxed or mailed them a one-page description of the project (Appendix A); a few leaders also requested and

received copies of the brochures. Interested group leaders spoke to their groups and, if the members agreed to participate, contacted us to determine the date of our visit.

## Data Collection

*Development of interview forms.* The interview forms (Appendix F) were developed by Macro staff with substantial input from CDC staff. It was decided that the three forms would be identical except for the first section, which addresses the content of each section of each brochure. It was also decided that some of the questions should be closed-ended and some open-ended to ensure standardization while allowing participants the opportunity to expand on their responses and offer suggestions.

After visiting the first support group, the data collection team met to discuss issues that arose during the interviews. This valuable discussion led to the following changes in the interview forms: a section was added to the pets form to ensure interviewees had a chance to comment on a box depicting various illnesses carried by pets; a text box was inserted to provide a location for entering interviewees' unsolicited comments about what they liked about the brochures; and the response options in the first section of the forms were changed to more accurately reflect the ways in which people were responding to the questions. Due to the addition of questions after the first visit, we do not have responses to those questions for the first 15 people interviewed.

*Data collection protocol.* Three to four Macro staff members participated in each support group visit; the number depended upon the expected number of interviewees. During each visit, we gave a general presentation to the support group about the purpose of the project and how the findings would be utilized. (The data collection protocol is in Appendix B.) We then explained that participation was completely voluntary, participants could end the interviews at any time, names would not be linked to responses, and each participant would receive a \$10 Kroger grocery store gift certificate as compensation for his/her time. We also explained that, while it is legally required for participants to sign informed consent forms, they could use any name they wanted.

We followed this with a description of the three brochures. Although participants were free to choose any of the brochures, we stated that we had the following preferences: 1) interviewees who had pets, were thinking about having pets, or spent a fair amount of time with people who have pets, should consider selecting *Opportunistic Infections and Your Pets*; and 2) people who cared for or spent a fair amount of time with children living with HIV should consider selecting *You Can Prevent PCP in Children*. There were no criteria for selecting *You Can Prevent CMV*. The participants were provided pens for marking the text and noting any questions they might have while reading the brochures. When each participant finished reading, he or she sat down with one of the researchers. The interviews took place in areas (such as separate cubicles or rooms) that were as private as possible to decrease the likelihood that the interviews would be overheard by other participants.

Before beginning each interview, interviewers completed a demographic information form (Appendix C) and noted the code number of the interview form that would be used. This ensured that demographic data would be correlated with interview response data during analysis. (Because

there were three brochures, a different series of codes was assigned to each one so that data analysis could be conducted by brochure as well as aggregated across brochures.) Interviewers then asked each participant to sign an informed consent form (Appendix D).

During the interview, interviewers and participants referred directly to the brochure as they talked to be sure they were referring to the same items when discussing specific issues. In several cases, interviewees indicated they had had significant problems reading the brochures; in response, the interviewers assisted them in understanding the content.

## Data Analysis

The process used to analyze the interview data included three phases of analysis: content, thematic, and logical analysis.<sup>1</sup> The critical first step was to organize the data in a manner so that each type of analysis could be conducted efficiently.

*Organization of the data.* First, the quantitative data, including demographic information from the demographic information form, were entered into LotusJ, translated with a database management software package (DBMS/COPYJ), and imported into SPSSJ for analysis. Frequencies were run on all items. Concurrently, the qualitative responses from the open-ended questions were summarized in a WordPerfect 6.1 file (Appendix H). Then, a table was created in WordPerfect 6.1 to import and organize the quantitative and qualitative data for comparison within and across brochures (Appendix G). For three items (AWhich pictures seemed out of place?@, AIs there anything in the brochure that offends you?@, and AWhat other questions do you have about PCP in children?@), all responses were recorded in the table because only a small number of participants gave a response other than Ano@or Anone.@

For the remaining open-ended items where the majority of respondents provided feedback, the raw data were summarized in the table to describe the most salient themes. For example, if a significant minority (defined as 10 percent and upwards within each sample) of participants gave the answer Amedical terms@in response to the question, AWhat was hard to understand?@, then Amedical terms/technical language@was entered next to that survey item in the table in order to identify it as a theme for that specific brochure. However, it is worth noting that responses given by only one or two participants may be found in the raw data summary and that many of these offer concrete suggestions for improving the brochures.

It is also important to note that because the feedback provided by the participants was elicited individually rather than in a group setting, there is no way of knowing how many of the suggestions would have met with approval by other participants.

*Analyzing the Data.* As the first analytical approach, a **content analysis** was performed. This involved the identification, labeling, and categorization of the data so that primary patterns could

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<sup>1</sup> Patton, Michael Quinn. *Qualitative Evaluation and Research Methods*, Sage Publications, Newbury Park, 1990.

be detected. For this purpose, the raw data summary was developed as a place to organize responses that appeared to be similar in content. These patterns were further examined through **thematic analysis** to determine the themes that emerged within a set of items and across brochures. In addition to assisting with the identification of patterns and themes in the data, content and thematic analyses allowed the qualitative data collected to be distilled to a more easily studied format. From the content and thematic analyses, a **logical analysis** was performed, aimed at identifying patterns and themes that are not immediately obvious. In short, by looking for patterns of difference and similarity that emerge from cross-classifying the data, new patterns can emerge.

### Participant Characteristics

The characteristics of the participants in the study are similar to those of people living with HIV in the Atlanta metropolitan area. In all, we interviewed 68 people who identified themselves as African American, 16 who identified themselves as Caucasian, and one who identified as Native American. In a separate question about ethnicity, one individual selected Hispanic while the remaining 84 selected non-Hispanic to describe themselves. In terms of gender, 29 of the respondents were women and 56 were men. The age range was from 22 to 75 years old, with an average age of 39 years. The number of years in school ranged from 8 to 20, with an average of 13 years.

Table 1 presents the ethnicity, race, and gender of participants by brochure.

**Table 1**  
**Demographic Data for Reviewers of Each Brochure**

	<b>PETS (n=35)</b>	<b>CMV (n=32)</b>	<b>CHILDREN (n=18)</b>
<b>Ethnicity</b>	34 non-Hispanic 1 Hispanic	32 non-Hispanic	18 non-Hispanic
<b>Race</b>	25 African American 10 Caucasian	27 African American 4 Caucasian 1 Native American	16 African American 2 Caucasian
<b>Gender</b>	10 Women 25 Men	12 Women 20 Men	7 Women 11 Men

## Study Findings

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In the discussions of general and specific findings, several data analysis rules should be acknowledged. The primary rule applied during the translation of raw data into the text of this report concerns attention to the number of people responding in similar ways. For questions that were closed-ended, computer-generated statistics made trends very clear. For open-ended questions, the general rule was to view points mentioned by 10 percent or more of respondents as more prominent than those mentioned by fewer respondents (this usually meant no more than two people raised the issue). However, when one or two people raised a particularly poignant or helpful comment, we ensured that it was represented in this report. Still, as mentioned earlier, all comments recorded by interviewers are listed in Appendix H for reference purposes should additional analysis be desired.

### General Findings

Many interesting and revealing patterns emerged during our analysis of responses regarding the three brochures. Whereas the sections on each brochure focus on content-specific issues, the findings discussed in this section center on questions that delve into characteristics of all the brochures in the series and the reactions readers have had to the three that were tested. These characteristics and reactions include: letter size, readability of the letters, situations in which people would feel comfortable reading HIV-related brochures, sources people would consult should they have questions after reading the brochures, and other themes that emerged during interviews.

*Are the letters big enough? Are the letters easy to read?*

Of the 85 respondents, only 2 maintained the letters are not big enough and 3 said the letters are not easy to read. The majority of respondents (83 percent) replied *Ayes* to these questions, with 13 percent saying *A sort of*.

*Would you read the brochure if it was in your clinic/doctor's waiting room? Your nurse/doctor gave it to you? You received it in the mail?*

Seventy-two of the 85 participants in the study said they would *A probably* or *A definitely* read the brochures in a waiting room, 81 said they would *A probably* or *A definitely* read them if a doctor or nurse gave them to them, and 67 said they would *A probably* or *A definitely* read them if they received them in the mail. The contrast between the first two contexts and the third may be due to people's concerns about friends and relatives discovering their HIV status should they see them with the brochures at home. However, at other times during the interviews, several participants stated they would not pick up *C* in any public location *C* any brochure that had *A HIV* written on it. Others indicated they would not pick up an HIV brochure if it had pictures of adults on it, indicating they might pick it up if it did not have pictures of adults.

*If you had questions about anything in the brochure, which of the following people would you be likely to talk to?@*

Of the nine response options for this question, doctors were by far the most often cited as the sources people would turn to with questions about brochure topics. Almost half as many would talk to a counselor. Next in line were nurses, friends, and people experiencing the situations discussed in the brochure. A few people listed sources that were not response options and were particular to the brochure topic. For example, one interviewee said that readers of the *You Can Prevent PCP in Children* brochure might consider talking to pediatricians. Other respondents said that readers of the *Opportunistic Infections and Your Pets* brochure might consult veterinarians, the Humane Society, and someone who has a pet.

*Other pertinent issues raised in regard to the brochures*

*Difficulties understanding the language.* Interviewees across brochures volunteered that they had difficulty understanding the medical and technical language, which appeared to be above some respondents' reading level. This came up numerous times, making it a significant issue in regard to the content of the brochures.

*Computer-generated images.* All three brochures contain what appear to be computer-generated images, and readers who commented on them were unanimous in their desire to replace them with images of real people, pets, and other subjects.

*Graphics and pictures.* The general perception among respondents is that the brochures would benefit from improved, and additional, graphics and pictures.

*Contact information.* Many respondents noted that they greatly appreciated the phone numbers (and one web site) for various AIDS services on the back of each brochure.

## **Specific Findings**

This section presents the most prominent findings related to each of the three brochures. It discusses responses to each of the brochure-specific questions, including closed-ended and open-ended responses. Importantly, although many of the comments from interviewees included in this discussion are suggestions, a separate section (*Recommendations@*) elaborates on them to make concrete recommendations for improving the format, content, and marketing of the brochures.

*Opportunistic Infections and Your Pets*

*What was new?@What was hard to understand?@*

The first part of the interview requested that respondents reply *Yes,@Sort of,@or No@* regarding whether each section in the brochure was *new@* and whether it was *hard to understand.@* The *Opportunistic Infections and Your Pets* brochure proved to contain a great deal of information that was new to readers. The minimum number of people maintaining a section was new to them

was 11, constituting almost one-third of the sample. The section most often cited as new was *What can I do to protect myself against infections spread by animals? (specific precautions).*

When discussing aspects that were hard to understand, one-fourth of respondents said the sections *Should I have pets?* and *What can I do to protect myself . . . ?* were hard or sort of hard to understand. When asked to elaborate on what was difficult, 15 of the 35 interviewees made statements that fell into the theme of *hard to read*, particularly among those with low literacy levels. Specific reasons given for this were terminology, technical words, and new words. Often cited was the box entitled *Infections carried by animals*, which some respondents found daunting due to the long words that are unfamiliar and difficult to pronounce. However, others volunteered that they liked the box and suggested addition of a column on *treatment*.

Another significant issue raised by some participants is their confusion about the following: 1) whether the brochure was advising them to have pets or not to have them; 2) whether people can transmit HIV to pets; 3) why relatives and friends should not have pets; and 4) whether, in some instances, the brochure was referring to people or animals.

*What did you like?*

Nearly one-third of the time a respondent volunteered a comment regarding something he or she liked in the brochure, it was to express the view that the brochure is informative, comprehensive, and helpful. Others mentioned liking the attractiveness of the brochure, the color, and the artwork on the cover.

Although it did not pertain directly to the brochure itself, many interviewees were glad to learn that it is safe for people living with HIV to have pets if they follow common precautions; this contrasts with the impression of others that the brochure indicates people with HIV should not have pets. In fact, this brochure was the most popular of the three because, as interviewees demonstrated by talking at length about the topic, pets are very important to them. As one interviewee said, *[The brochure] sends a message that you can have a pet, you just have to be very careful. Being HIV positive is hard enough. Don't take pets away. They are something that makes you comfortable with [HIV].* Another commented, *Pets are important because of loneliness. Bringing something positive into something negative is good.*

*Is the brochure easy to understand? Does the brochure use simple, clear language? Does the brochure sum up the information well?*

Approximately two-thirds of the study sample said the brochure is easy to understand, uses simple and clear language, sums up the information well, and is attractive.

*ADo the pictures/drawings go with the information?@AWhich pictures seemed out of place?@*

Over 75 percent of interviewees were of the opinion that the pictures and drawings were appropriate given the content of the brochure. Among those who said the pictures sort of correlated or did not correlate with the text, the following observations were made: the picture of the bird should be placed closer to the section discussing birds, the picture of the vet seemed out of place, the pictures are dated and not hip, and the computer-like images should be replaced with real pictures.

*As there anything you would do to improve the brochure?@*

A great variety of suggestions for improving the brochure was provided by the 24 (of 35) interviewees who offered advice. While all suggestions provided are listed in Appendix H, the most prevalent and pertinent follow. In terms of appearance, the people and animals should be real (not computer images), and the way in which the person is interacting with the animals is misleading because the text contradicts this carefree image. Suggestions about the brochure in general include making it more colorful, changing the color, improving the graphics and headings to make them stand out more, and adding pictures.

When speaking of the content, several interviewees sought more information about changing cat litter, particularly regarding the importance of wearing masks and explaining the dangers of dust particles and cat litter. Many also emphasized the importance of: 1) not discouraging people to have pets or to work with pets, 2) discussing treatment for the diseases/infections mentioned, and 3) providing information about other animals (especially fish and dogs).

*As there anything in the brochure that offends you?@*

The two responses to this question tapped into the speakers' and others' concerns (expressed during other parts of the interviews) that information in the brochure will lead readers to take more drastic measures than warranted. Therefore, although only two people brought up these issues when asked this question, the same issues were brought up by others at other times during their interviews. The first response echoed others' concerns that the *AI have a job that involves contact with animals . . .* section seems to say, ill-advisedly, that people with HIV should quit such jobs. The second reflected other comments that the information about changing litter boxes makes it seem more dangerous than it is, even when one follows precautions.

*AWhat other questions, if any, do you have about opportunistic infections and your pets?@*

Indicative of respondents' strong interest in pets and pet ownership, the following questions and issues were raised.

- \$     AWhat about animals eating their own stool?@
- \$     ADo latex gloves protect when handling animals' stool?@
- \$     AWhat about vomit? Do latex gloves protect from that?@

- \$ ACan you catch opportunistic infections from breathing the fumes of feces in cat litter?@  
(Two people asked this)
- \$ AAre scoopable litters preferred?@
- \$ AWhat are the timeframes you might expect to see these symptoms after exposure so you know when to stop worrying?@
- \$ AAre there other infections I should worry about with my pets?@
- \$ AWhen a person is disabled [from AIDS-related illnesses], what should he/she do [if he/she wants to have pets but cannot carry them]?@
- \$ AWhat about handling meat?@
- \$ AI=am still not clear about pets getting HIV or other things from me@
- \$ AWhat is the effect of mycobacteriosis on me?@
- \$ AAre there other things you can get from fish or birds? Is the aquarium water the only concern?@
- \$ AIs it safe to leave your pet in your house while you=are at work [because saliva and feces may spread]?@
- \$ AHow long is it safe to keep a pet [in terms of CD4 counts and the time transpired since an AIDS diagnosis]?@
- \$ AWould it be better not to have a pet because you=ll be exposed to these things again and again?@
- \$ AIs there more information about treatment? How about home remedies? Alternative therapies?@
- \$ AWhere can I find out more detailed information?@

*AWhat, if anything, might you do differently because you read this brochure?@*

Respondents definitely took the information in the brochure to heart and resolved to weigh the issues carefully before getting a pet and to be more careful with the pets they have. Some were leaning toward not getting pets due to the knowledge they had obtained from the brochure. In fact, indicating the information had prompted him to make drastic changes, one interviewee expressed the intention to give away some kittens. He was also thinking about giving away the mother cat if he could not get her fixed. However, others were going to continue considering getting and keeping pets. When speaking of their future behavior when dealing with pets, the majority of respondents who said they would act differently spoke of plans to take precautions. These include washing hands more frequently, wearing gloves, and getting pets tested for diseases.

## *You Can Prevent Cytomegalovirus Infection*

*What was new? What was hard to understand?*

In the first part of the interview (which asks respondents which sections of the brochure were new and which were hard to understand), more than half to upwards of two-thirds of respondents consistently reported that the information was new. The newest information was that provided in the section entitled *How can I protect myself?*, with 71.9 percent responding *Yes*.

When discussing what was hard to understand, one-third of the interviewees replied that the section, *How do I know if I am infected with CMV?* was hard (15.6 percent) or sort of hard (18.8 percent), making it by far the most often mentioned. Second in the running was the first section of the brochure, *What is CMV?* All the other sections were found to be easy to understand (meaning respondents answered *No*) by 84 percent to 87 percent of respondents.

When discussing the more difficult sections, many respondents explained that the text was hard to understand because the information was new and/or the language was difficult and overly technical. Other comments fell under the umbrella impression that CMV itself, and symptoms related to it, are very common. Therefore, some found it confusing and disconcerting to learn that CMV is pervasive. On the one hand, respondents reasoned, the symptoms of CMV are similar to those associated with colds, other illnesses, and general reactions to HIV infection; people may become anxious that they might have CMV. On the other hand, the news that CMV is more easily transmitted than the virus that causes AIDS led to concerns about the fact that not only do people with HIV need to monitor their behavior to prevent transmission of HIV, they need to alter their habits even further to decrease their likelihood of contracting CMV.

*What did you like?*

As with the other brochures, those who offered comments regarding what they liked were most likely to maintain that learning new information about preventing illness was the highlight. Specific to this brochure were three laudatory comments about the color (this constitutes 10 percent of all who read this brochure), the font, and the pictures.

*Is the brochure easy to understand? Does the brochure use simple, clear language? Does the brochure sum up the information well?*

Two-thirds of the sample stated that the brochure is easy to understand and just under one-third said it was sort of easy to understand. This proportion is similar to responses regarding the language used, in that 75 percent said it was simple and clear and 21.9 percent replied that it was sort of simple and clear. Almost two-thirds of the sample (62.5 percent) answered the question about whether the brochure sums up the information well in the affirmative; the remainder replied *sort of*.

*Is the brochure attractive? Do the pictures/drawings go with the information? Which pictures seemed out of place?*

Less than half of the respondents (46.9 percent) considered the brochure to be attractive and the pictures to be appropriate for the information provided. However, the pictures that were regarded as out of place are numerous: Of the 13 who had something to say, 5 mentioned the picture depicting floaters in the eye. They commented that the building and tree did not seem to go with the caption and that it was hard to tell that floaters were being illustrated. Three interviewees remarked that the picture of the girl playing in the sandbox did not seem to go with the text, and two said the people on the cover should be real rather than computer-generated. Later in the interview, when participants were asked what they would do to improve the brochure, the topic of the pictures resurfaced. Two suggested deleting the picture of the girl in the sandbox and six made comments about improving the pictures and making them more appropriate. It was also suggested that the people on the cover be replaced by another image because people cannot identify with them and they do not look happy.

*Are there anything you would do to improve the brochure?*

Including the above comments regarding the pictures in the brochure, nearly two-thirds of the sample had advice for improving the brochure. General comments focused on the language and content, with remarks about tailoring it for the general population to render it easier to understand. In terms of appearance, one person suggested changing the color because it is too hospital-like, another believed adding more color would be beneficial, and another called for more pictures.

When speaking of the brochure's content, *the most frequent comment centered on the very important need to update the section on CMV retinitis*; the detailed recommendations are provided in Appendix H. Next in line were requests for more specific information about CMV symptoms in the section, *How do I know if I am infected with CMV?* Others wanted more information about CMV testing (including the desire to know the name of the test for CMV) and the origin of CMV. Other questions about CMV are listed in the *Other questions* section below.

*Are there anything in the brochure that offends you?*

Two respondents replied to this question. One said it was not offensive, but that he wondered why the drug ganciclovir was mentioned if it is not recommended. The other person said that the saliva part concerned him due to the implication that kissing posed a risk; he stated that it was disconcerting to think that kissing, which had become an alternative to sexual intercourse (due to efforts to reduce HIV transmission), might be prohibited as well (due to CMV risk). This comment reflects the theme of fear about transmission and symptoms raised in the section on responses to *What was hard to understand?*

*AWhat other questions, if any, do you have about CMV?@*

One-fourth of the interviewees raised the following questions and issues:

- \$ AI=am still not sure whether or not it is something I should be concerned about.@
- \$ AHow do you know if you have it? I have runny eyes like the retinitis.@
- \$ A[I would like] more details, especially how to know if [CMV is] reactivating, how to tell whether my symptoms are indicative of CMV or something else.@
- \$ ACan you kiss people? What kind of kiss should you do or not do?@
- \$ A[I have a] remaining concern about medications to treat CMV.@
- \$ AHow does this disease get in your eyes?@
- \$ ACan people without HIV contract CMV?@
- \$ AWhat are the medication side effects?@
- \$ AWhy aren't there CMV tests with HIV tests?@
- \$ AThe drug is expensive and has side effectsCwhy aren't there trials for those who can't afford it?@
- \$ AIs there a lot of research conducted on this disease? If so, it would be helpful to say where to get more information.@

*AWhat, if anything, might you do differently because you read this brochure?@*

The majority of interviewees reported that they would behave differently because of the knowledge they gained from the brochure. The comments covered a range of behaviors and indicated a deep concern about CMV infection. As one interviewee said, *AIt gave me something to think about. Id rather know than not know.@* Most of the comments can be grouped around the general intent to be more careful, with elaborations regarding washing hands more often, not smoking nor drinking *Abehind@* others, and using separate utensils. Numerous other intended behavior changes are listed in Appendix H. The other key category of responses is related to the intention to consult a doctor and to get tested for CMV. In fact, some said they were having some of the symptoms mentioned in the brochure and would take it with them to show it to their doctors.

### *You Can Prevent PCP in Children*

*AWhat was new?@AWhat was hard to understand?@*

In the first part of the interview (regarding sections that were new and hard to understand), respondents were very likely to say that the information was new to them. For instance, for 7 of the 12 sections, at least 50 percent (and as high as 77.8 percent) of respondents said the information was new. For three other sections, one-third or more of the sample said the information was new.

When discussing what was hard to understand, half of the respondents reported that they had difficulty understanding the first section, entitled "What is PCP?" This set the tone for their subsequent answers regarding other sections, as the other sections are reliant upon people's understanding of what PCP is. For instance, approximately one-third of respondents reported having difficulty understanding all the subsequent sections, with the exception of the last one, which discussed research being done to determine ways to prevent PCP. When probed about specific sections that were particularly hard to understand, the following were mentioned: the section that describes PCP, the section that discusses CD4 cells, and the section that discusses ways in which children can contract PCP.

The main reasons given for problems understanding the text were that the information is new and there were too many unfamiliar medical and technical terms (six people raised this issue). Two respondents commented on the style of writing throughout the brochure, citing awkward sentence structure, wordiness, and redundancy.

The data regarding difficulties understanding the brochure correlate with responses to the question, "Was the brochure easy to understand?" in that over half (55.6 percent) of respondents said it was "sort of" or not easy to understand. It is worth noting that this contrasted with responses about the other two brochures, for which nearly two-thirds said the brochures were easy to understand. There is also a correlation with the responses to the question, "Does the brochure use simple, clear language?" to which one-half of those who read this brochure offered that it "sort of" does (11.1 percent) or does not (38.9 percent); this is significantly higher than similar ratings for the other two brochures.

*"Did the brochure sum up the information well?" "Did the pictures and drawings go with the information?" "Which pictures seemed out of place?"*

Other questions received more positive responses. For instance, two-thirds of the interviewees believed the brochure summed up the information well and that the pictures and drawings go with the information.

*"Is the brochure attractive?"*

Nearly half of the sample (44.4 percent) found the brochure attractive, with one person stating "it's cute" and another commenting positively about the color of the people the front being mixed so that their race is not apparent.

*"What did you like?"*

Given that this question was not directly asked, interviewees wrote down participants' voluntary comments indicating a positive impression of something in the brochure. It is notable that three of the eight interviewees who had something to say stated they liked the opportunity to learn new information. Other aspects that interviewees liked include "the whole thing," "the way in which it covers everything," and "the fact that it read well."

*"Is there anything about the brochure that offends you?"*

The few interviewees who responded affirmatively to the question regarding whether the brochure offended them cited factors such as unpronounceable words and the section *What research is being done . . . ?* because it implies children are *slack* when they do not take their medicine.

*Is there anything you would do to improve the brochure?*

In regard to suggestions for brochure improvement, those who commented had many suggestions about its appearance, content, and writing style. While the raw data in Appendix H features all the comments, the primary ones include suggestions to: 1) change the appearance by adding more color, particularly to set off headings and call attention to important text; 2) add more pictures and make all the pictures larger; 3) simplify the language to make it easier to read; and 4) improve the writing style by removing redundancies, correcting perceived grammatical errors, making the content more consistent, and explaining abbreviations. Another pertinent comment was that listing the signs of PCP can cause alarm among readers because many children exhibit these signs when they do not have the infection.

*What other questions, if any, do you have about preventing PCP in children?*

The small proportion of people who believed they had not received all the information they wanted posed the following questions.

- \$ *If a child is born HIV positive and has shed the virus, should she continue to be tested [for PCP]?*
- \$ *Is a baby always checked for HIV when it is born, if the mother is positive?*
- \$ *Would massages help children who have PCP?*

*What, if anything, might you do differently because you read this brochure?*

Approximately 75 percent of respondents replied to this question, with many of them stating they would be more careful. One person was concrete about how he or she would do this: *I would be very careful about bringing babies into the world.* Others offered that they would tell others about what they had learned *either verbally or by providing them the brochure* to increase the likelihood that infected infants would be tested for CMV and receive treatment when needed.

## Recommendations

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As the discussion of interview comments has indicated, study participants were vocal in their expression of the many positive aspects of the brochures. According to them, the brochures are clearly appreciated, needed, and timely. However, to capitalize on this opportunity to meet the needs of people living HIV and their caregivers, there are several concrete changes that can be made to improve the content and appearance of the brochures. There are also some creative ways to disseminate them to those who will most benefit from them.

The general recommendations section below features suggestions for improving the appearance and content of all the brochures as well as suggestions for better informing people about opportunistic infections. The section on each brochure delves into the key issues raised by respondents and sheds light on the ways in which they can be addressed. It is important to note that a moderate amount of suggestions is listed here; should CDC decide to make more or fewer changes, we would be pleased to provide advice for doing so. It is also important to clarify that the intention here is for the recommendations to be read in conjunction with the sections on study findings and the data provided in Appendices G and H because they go into greater depth than the recommendations.

### General Recommendations Regarding All Three Brochures

Respondents' comments clearly point to several substantial ways in which the brochures can be improved. Following are the major categories of recommendations; while they do not include all the recommendations featured in the previous sections and the data provided in the appendices, they are the most prominent and pertinent ones that emerged during data collection.

#### *Simplify and Clarify the Language*

There is a substantial need to reconsider the use of at least the degree of use of medical and technical language in the brochures. This is a particularly poignant issue that should be seriously addressed, particularly given that many individuals living with HIV tend to have low literacy rates.

While it is clear that eliminating technical terms may be difficult due to the importance of using appropriate terms, interviewees were adamant in their statements that they were not gaining as much knowledge as they would like (and, probably, as CDC expected), due to their difficulties getting past the unfamiliar language. *Further, some interviewees who did not understand the information actually believed they had; in other words, misunderstanding led some to mistakenly believe they had learned that they should not have pets or cannot kiss others when this was not the intended message of the brochures.*

It is important to note that, when low literacy and illiteracy prevent people from reading the brochures, simplifying the language will not suffice. For more recommendations regarding alternative ways to disseminate the information, please refer to the section, *The Usefulness of Brochures and Suggestions for Disseminating Information.*

### *Improve the Appearance of Brochures*

Many insights from the diverse study sample honed in on the ways in which the appearance of the brochures can be changed to make them more esthetically appealing to their target audience. First and foremost was the unanimous opinion among those who mentioned computer-like images that they are far less desirable than photographs of real people, animals, and other subjects. A general impression of the images was that they are not Ahip@or modern looking. In addition to the fact that the computerized nature of the images was disliked was the common impression that many of the images do not go with the text (specific suggestions are featured in the sections on each brochure) and the desire for more pictures. It is interesting that these two suggestions would be raised simultaneously because they imply that the current pictures should be removed and replaced with even more pictures. This issue may be difficult to address because it will be challenging to find enough pictures that would be considered appropriate for the subject matter.

### *Consider Ways to Make HIV Less Prominent on the Brochure Covers*

Another challenge presented by respondents' comments is the implied suggestion that AHIV@not be so prominent on the covers. This is due to some interviewees' declarations that they are not likely to pick up brochures in public if they have HIV on themCparticularly when they have pictures of adultsCbecause others will surmise their status. This calls for identification of a creative way to attract people with HIV to the brochures without calling others' attention to the topic. One suggestion would be to remove AHIV@from the cover altogether; another would be to distribute the brochures only in places where people feel safe disclosing their status. It is hoped that there may be another option that would address both of these issues so that the content of the brochure would be apparent from the cover without making people feel uncomfortable about picking it up in any setting.

### *Address the Advantages and Disadvantages of Sending Brochures in the Mail*

Related to the discussion above about people's concern that their HIV status will be revealed if others see them with the brochures is the opinion of many that they would not read the brochures if they arrived in the mail. Based on overall discussions about ways to disseminate the information, respondents would much rather receive the brochures in clinical settings or get the message through other media such as videos, radio spots, the Internet, and other means.

### *The Usefulness of Brochures and Suggestions for Disseminating Information*

Recommendations presented in this section are based on interviewees' responses to the following questions:

- \$ *AIN your opinion, are brochures a useful way to learn about HIV-related infections?@*
- \$ *AIN what other ways would you rather get this information?@*
- \$ *AHow can we make information like this more useful to people affected by HIV/AIDS?@*

The majority of interviewees (77 percent) maintained they believe brochures are Adefinitely@a useful way to learn about HIV-related infections. Although this was a closed-ended question,

many interviewees offered comments about how much they appreciated brochures and that they read as much as they could about HIV-related issues. One interviewee said, "Brochures are good because you can read it in private and can look back at it."

Most important, said interviewees, is the need to ensure brochures will be available in places where people with HIV are going to be for reasons related to their infection *and* in public places where they and others would generally be. The former include: doctors' offices, clinic waiting rooms, shelters/transitional housing facilities, and outreach organizations. The latter include: grocery stores, schools, libraries, and bus stops. Pet-specific locations suggested are animal shelters, pet shops, and veterinarians' offices; the children's brochure could be provided in pediatricians' offices.

When asked about other ways in which people would like to get the information provided in the brochures (meaning instead of or in addition to the brochures), the leading response was "from a doctor," followed by group discussion formats (such as seminars and workshops), educational television programs, videotapes, and posters. Other means mentioned include one-page sheets listing the information, magazines, the Internet, radio, billboards, and hotlines. When asked how the information could be rendered more useful, the advice to "put it out there" was loud and clear, meaning that the more widely disseminated the information, the better.

Due to the potential for many people with HIV to miss out on or misunderstand the information because of low literacy or illiteracy, simplifying the language and using fewer medical terms would not increase their ability to understand the information. As one interviewee said, "Be aware that the average person cannot read this." *Therefore, CDC should seriously consider the non-print means of disseminating the information mentioned in the previous paragraph.*

#### *Additions to the Brochures*

A useful suggestion provided by one respondent is to include information about how to get more brochures on the back of the brochures. Another respondent suggested adding a phone number accessible to people with hearing impairments.

### **Recommendations Regarding Each of the Three Brochures**

Following are recommendations that emerged during examination of responses about each of the three brochures. They cover the highlights of the findings and set forth constructive ways to improve the brochures, thus enhancing their effects on those living with HIV and those caring for them.

#### *Opportunistic Infections and Your Pets*

Following are the primary recommendations offered by interviewees. Additional comments are in Appendix H.

#### *Address Interviewees' Concerns about Having Pets*

Although some interviewees expressed relief at learning that people living with HIV are safe having pets as long as they take precautions, *several interviewees interpreted the information as advice to refrain from having pets and spending time with those owned by others*. This serious misinterpretation was a source of consternation for some respondents, who seemed dismayed at the thought of giving up their pets, abandoning plans to obtain a pet, or quitting jobs involving work with animals. Their and others' in-depth discussions about pets revealed that this is a truly salient topic to them. This underlines the need to take efforts to ensure that the message of the brochure is clear so that unintended perceptions are minimized when the brochure is widely disseminated to people who will not have instant access to someone (such as our researchers) who can explain they may have misinterpreted the message.

Several factors seem to have contributed to people's misunderstanding of the intent of the brochure, and they can be addressed individually in order to improve the brochure. First is the fact that the unfamiliar language is a major factor leading to confusion. As stated in the general recommendations section, technical terms may be unavoidable in some cases, but, for the target audience, the more they can be minimized, the better.

Second is the need to address people's deep concerns about exposure to cat litter (especially dust particles and fumes). Some interviewees maintained the precautions described worried them, while others emphasized that more precautions should be listed (such as wearing masks). This points to a need to reconsider the way in which the information is presented and to ensure that the true intent of the information is conveyed. An illustration of proper protective behavior would contribute to this effort by visually conveying to readers that protection is essential; this would also balance the more *Carefree* illustrations of people with pets.

Related to this is the importance of elaborating and clarifying the issues that most worry people with HIV. This includes elaborating on how people living with HIV can protect themselves from diseases, clarifying that people cannot transmit HIV to pets, and reconsidering the way in which various diseases are presented in the text box so as to decrease people's anxiety about the long words and their implications. (The numerous comments in Appendix H are a testament to the intense curiosity and concerns associated with pet ownership and HIV-related illnesses.)

### *Improve the Appearance*

Many respondents had suggestions for improving the appearance of the brochure, pointing to a general sense that reworking it would render a more attractive product. Suggestions touched on replacing the computer images with real ones, making the brochure more colorful, changing the color, making the graphics and headings stand out more, and adding more pictures. One person strongly suggested changing the picture on the cover because the *Carefree* image does not correlate with the perceived seriousness of the text.

### *You Can Prevent Cytomegalovirus Infection*

Following are the primary recommendations offered by interviewees. Other comments and specific suggestions for editing the brochure are in Appendix H.

### *Address Major Concerns about CMV Symptoms*

*The major issue surfacing during interviews about the CMV brochure was the deep concern that preventing CMV transmission means drastically altering everyday behavior.* It also means that common HIV symptoms could indicate infection with this serious infection. If these points are indeed intended to cause alarm, efforts should be made to acknowledge that readers of the brochure will react very strongly to the information and would benefit greatly from expert guidance and support. If nothing else, CDC and others should prepare for many information-seeking phone calls from people who read the brochure.

### *Update the Discussion of CMV Retinitis and Other CMV Research*

Many interviewees honed in on the discussion of retinitis, pointing out that new discoveries have been made and treatments introduced. There was consensus that this information and descriptions of current research (on retinitis and CMV in general) should be added to the brochure to make it as representative of cutting-edge findings as possible. (Specific suggestions are in Appendix H.)

### *Make the Brochure Easier to Understand*

One way to alleviate concerns about CMV transmission and symptoms is to address the common comment that the brochure is hard to understand. Concrete approaches would be to simplify language and adjust the tone so that it is more appropriate for the general population, rather than for medical professionals.

### *Improve the Appearance and Graphics*

As with the other brochures, interviewees strongly advocated replacing the computer images with real people, changing the color, adding more color, and adding more pictures. Specific to this brochure was the recommendation to delete the pictures of floaters in the eye and the girl in the sandbox.

### *You Can Prevent PCP in Children*

Following are the primary recommendations offered by interviewees. Other recommendations and specific suggestions for editing the brochure are in Appendix H.

### *Address Concerns about PCP Symptoms*

As with CMV, interviewees noted that PCP symptoms are similar to general HIV symptoms; this led readers to suggest that *readers may react strongly when learning the children they care for may be ill because they have symptoms that match those common among PCP patients.* This potential reaction calls for acknowledgment that readers may react very strongly to the information and would benefit greatly from expert guidance and support. If nothing else, CDC and others should prepare for many information-seeking phone calls from people who read the brochure.

### *Simplify the Language*

The brochure on PCP in children was by far the hardest to understand, reported study participants. This is evidenced by the fact that half of those who read it had trouble understanding what PCP is. To improve the likelihood of the target audience absorbing and acting on the information, unpronounceable and technical/ medical terms should be decreased as much as possible.

### *Improve the Writing Style*

Also contributing to readers' difficulties with the content was the writing style of the brochure, which should be improved through elimination of redundancy, awkward sentence structure, and wordiness. It is noteworthy that these recommendations were not made in regard to the other two brochures tested.

## **Conclusions**

It is clear that several concrete changes could greatly improve the target audience's reactions not only to the brochures tested but also to other brochures in the series on HIV opportunistic infections. First and foremost is the need to address the fact that many members of the target audience have low literacy rates. The primary response should be to replace the technical and medical terms with more common language; a secondary response should be to ensure that people who cannot read even the most basic text will receive the information through non-print media.

Another significant factor affecting respondents' acceptability of the brochures is their concern that reading the brochures in public places will reveal their HIV status. The most direct way to eliminate this concern would be to take HIV off the brochure covers and to determine another way to attract the attention of people living with HIV to the brochures. An alternate way to decrease concern about disclosure is to disseminate the brochures in places considered more safe, such as HIV clinics where people's status is already known. However, this contradicts many respondents' suggestion that the brochures be distributed as widely as possible in a variety of public places to greatly increase general knowledge about opportunistic infections.

The third way in which the brochures should be adjusted to respond to readers' recommendations is to revise their appearance. This includes: replacing the graphics with pictures of real people, animals, and objects; adding more images to break up the text; using images that are more clearly related to the text; and reconsidering the colors used (this includes using new colors as well as using more than one color in each brochure).

Finally, due to strong interest in the brochure topics and content, CDC should be prepared for a great deal of requests for information. Therefore, while the brochures contain most of the contact information readers might want, it is recommended that instructions regarding how to get more brochures and a phone number for people with hearing impairments be added.

## **Appendices**

## **APPENDIX A**

### **TESTING OF CDC OPPORTUNISTIC INFECTION BROCHURES**

**PROJECT PURPOSE:** Macro International, Inc., a health policy research firm, has been asked by the Centers for Disease Control and Prevention (CDC) to *test three informational brochures* developed by the CDC to provide practical information about ways to prevent and/or treat common opportunistic infections (OIs). Macro is conducting this research on behalf of the CDC's National Center for HIV, STD and TB Prevention (NCHSTP).

**IMPORTANCE:** Since many OIs are preventable, it is critical that people living with HIV/AIDS receive this information in a timely and user-friendly manner. To assure that people living with HIV/AIDS find the brochures clear, informative, and useful, Macro will pre-test the brochures with people living with or affected by HIV/AIDS. *The testing will examine audience perceptions of appearance, quality, value, readability, and clarity* of the information provided. Emphasis will be placed on identifying information, language, and other factors that are unclear.

**USE OF FINDINGS:** The information generated by this research will enable NCHSTP to *tailor the brochures* to the needs, wants, and preferences of individuals living with HIV/AIDS and to determine the *most effective ways of disseminating them*. Additionally, this endeavor will provide the foundation for *developing a standardized process for incorporating audience feedback* in subsequent CDC materials development projects.

**METHODOLOGY:** For this project, Macro will talk to a total of 150 persons living with or affected by HIV/AIDS. Each person will review one of three brochures: (1) *You Can Prevent PCP in Children*, (2) *You Can Prevent Cytomegalovirus Infection*, and (3) *Opportunistic Infections and Your Pets*. After reading the brochure (which should take 10-15 minutes), participants will be asked to take part in a 15 minute private interview. This means *the process should last around 30 minutes*.

**COMPENSATION OF PARTICIPANTS:** Respondents will receive a *\$10.00 Kroger gift certificate* in appreciation of their time and willingness to participate in this important effort.

**TIMELINE:** Interviews will take place during *August and September 1998*.

**LOGISTICS:** Macro can work with facility staff to determine the most convenient times for client interviews. Macro will also work with staff to identify appropriate ways to recruit participants and settings in which to interview them.

**CONFIDENTIALITY:** To assure participant confidentiality, a numeric code will be assigned to each participant in lieu of a name. Respondents will need to provide a name for informed consent purposes, but they can use any name they wish. Demographic information such as age, race, and gender will be used for analysis purposes.

**QUESTIONS AND CONCERNS:** Call Dr. Michelle Renaud or Kira Sloop at (404) 321-3211.

## APPENDIX B

### TESTING BROCHURES: *DATA COLLECTION PROTOCOL*

#### 1) EXPLAIN THE PROJECT TO THE WHOLE GROUP:

- \$ CDC has asked us to test these three brochures to see if they're useful and easy to understand
- \$ Each person will read one brochure then tell one of us what they thought of it.
- \$ Each person will be compensated for his/her time.
- \$ Names of participants will not be used in any way.
- \$ Each person needs to sign a consent form but may use any name.

#### 2) FOR THOSE INTERESTED, EXPLAIN:

- \$ As you read the brochures, please think about what is **new**, what is **hard to understand**, **how it looks**, what else **you would like to know**. (You can write on them if you want)
- \$ This **isn't a test** of your understanding, it's a test of how good the brochures are. So please **be very honest** about what you think about them. (It won't hurt our feelings)
- \$ This is a new project, so we'd also **like to know if our questions are OK**. If they are hard to understand or they don't seem like good questions, please let us know.
- \$ You're the experts on whether they're good, so **your opinions are really important**.
- \$ If you find the **brochure hard to read**, **PLEASE come see us**. It's important to us to hear your opinion about it.

#### 3) DESCRIBE THE 3 BROCHURES AND SAY THAT EACH PERSON SHOULD CHOOSE WHICHEVER ONE THEY WANT, GIVEN THAT:

- \$ For the **children** brochure they should be a care taker of a child living with HIV.
- \$ For the **pets** brochure they should have a pet, be close to someone with a pet or be thinking about getting a pet.
- \$ There are no particular criteria for the **CMV** brochure.

#### 4) HAND OUT THE BROCHURES AND EXPLAIN THAT WE WILL CALL ON THEM ONE AT A TIME AS QUICKLY AS POSSIBLE.

#### 5) FOR EACH PERSON: FILL OUT THE SCREENER/DEMOGRAPHIC FORM.

#### 6) HAVE HIM/HER SIGN THE CONSENT FORM.

#### 7) CONDUCT THE INTERVIEW.

#### 8) GIVE HIM/HER A CERTIFICATE EVEN IF UNABLE TO FINISH THE INTERVIEW.

## APPENDIX C

## DEMOGRAPHIC INFORMATION FORM

CODE: \_\_\_\_\_

DATE: \_\_\_\_\_

RESEARCHER: \_\_\_\_\_

LOCATION: \_\_\_\_\_

BROCHURE REVIEWED:

9 Children

9 Pets

9 CMV

Before we begin I need to ask you a few questions about yourself.

Is your ethnicity (choose one):

- a. Hispanic or Latino \_\_\_\_\_
- b. Non-Hispanic or Non-Latino \_\_\_\_\_

Is your race (choose one or more category):

- a. White \_\_\_\_\_
- b. Black or African American \_\_\_\_\_
- c. American Indian or Alaska Native \_\_\_\_\_
- d. Asian \_\_\_\_\_
- e. Native Hawaiian or Other Pacific Islander \_\_\_\_\_
- f. Refuse to answer \_\_\_\_\_

3. Record gender \_\_\_\_\_

4. How old are you? \_\_\_\_\_

5. What is the highest grade you completed in school? \_\_\_\_\_

Before continuing, you will need to sign an informed consent form saying that you are voluntarily agreeing to participate in this project and that you will receive a food certificate. You can use any name you want.

*Provide participant with consent form, briefly explain it, and sign as a witness. Next, conduct interview.*

**APPENDIX D**

**INFORMED CONSENT FORM**

The Centers for Disease Control and Prevention is developing a series of brochures related to HIV infections. To understand whether these brochures are informative and useful to people living with HIV or AIDS, we are seeking individuals willing to read one brochure (approximately 10-15 minutes) and participate in a brief interview (10-15 minutes) to discuss it.

If you decide to participate, here are some things you should know:

Participation is completely voluntary.

Your name will not be used in any reports about this.

Any questions you have about this study will be answered before you begin.

You may choose to stop at any time, for whatever reason.

You will be given a \$10 certificate to compensate you for your time.

Your signature below indicates that you understand the above and agree to participate. It also indicates that you have received the \$10 certificate. When signing, you may use any name you want.

Participant Signature \_\_\_\_\_

Witness \_\_\_\_\_

Date \_\_\_\_\_

## **APPENDIX E**

### **SUPPORT GROUPS THAT PARTICIPATED IN THIS PROJECT**

- 1) Outreach Incorporated (Campbellton Road location)
- 2) Outreach Incorporated (West End/Spelman College area)
- 3) Our Common Welfare
- 4) Positive Impact (AIDS Survival Project)
- 5) Psychological Associates
- 6) Absolutely Positive
- 7) Fulton County Health Department

**APPENDIX F**

**DATA COLLECTION FORMS**

## **APPENDIX G**

### **DATA TABLE**

## **APPENDIX H**

### **CDC OPPORTUNISTIC INFECTION (OI) BROCHURES STUDY FINDINGS**

#### **B Raw Data Counts from Open-Ended Questions B**

##### **YOU CAN PREVENT PCP IN CHILDREN**

###### **What was hard to understand?**

No response/nothing (4)

General comments

\$ The new information

Reading level

\$ Language is difficult, could be simpler (6)

< Most people would need for this information to be simplified

< Should be written so that someone with a 6<sup>th</sup> grade education could understand it

\$ Too much medical jargon/too technical (5)

< Some people will have a hard time understanding it

\$ Very hard for low-literacy individuals, who said things like **Amore** pictures would make it easier@

Specific sections/content

\$ First section not clear what PCP is (2)

\$ CD4 count section not clear

\$ What ways PCP can be given to children

Editorial comments

\$ Awkward sentence structure, wordy, and redundant (2)

\$ Pronunciation of words distracting

###### **What did you like?**

No response (10)

Appearance

\$ It's cute

\$ Liked the way the color of the person on the front is mixed so you can't identify the race

Content

- \$ AThe whole thing@
- \$ AIt covers everything@
- \$ Learned something new (3)
  - < Learned why to wait 4 to 6 weeks to give newborns TMP-SMX
- \$ It read well

### **Which pictures seemed out of place?**

No response/none (15)

- \$ Picture of lung
- \$ Pregnant woman B brochure discussing baby disease, not pregnancy
- \$ Child with keys B what does it have to do with symptoms? Need to show sick child

### **Is there anything you would do to improve the brochure?**

No response (5)

#### Appearance

- \$ Add more color (3)
  - < Perhaps orange
  - < Make headings a different color
- \$ Make pictures bigger
- \$ Add more pictures (3)
- \$ Put the most important text in red, like the questions and answers

#### Content

- \$ Put more information
- \$ Too much information in certain sections
- \$ Put PALS (Pets are Loving Support) number on back
- \$ Simplify the language, make easy to read (3)
- \$ Listing the signs makes it sound alarming (since many children exhibit these signs)
- \$ Say that children should be tested frequently
- \$ Explain treatment differences between children and adults
- \$ Emphasize that people should check with their doctor about treatment

Editorial comments

- \$ Don't use contractions
- \$ *Can a child catch PCP from other people?* section is not answered with yes/no format as in others
- \$ Remove redundancies
- \$ Don't end sentences with prepositions
- \$ Explain abbreviations

**Is there anything in the brochure that offends you?**

No response/no (15)

- \$ Slightly offended by *What research is being done to find out more about preventing PCP in children?* section B implies that children are slack by not taking medicine
- \$ Words I can't pronounce B it's overkill

**What other questions, if any, do you have about PCP in children?**

No response/none (12)

- \$ If a child is born HIV positive and has shed the virus, should she continue to be tested?
- \$ Is a baby always checked for HIV when it's born if the mother is positive?
- \$ Would massages help with children who have PCP?

**What, if anything, might you do differently because you read this brochure?**

No response (4)

Behavior

- \$ Be very careful about bringing babies into the world
- \$ Have safe sex
- \$ Be more aware with next set of grandchildren B tell mothers to be on the lookout for PCP
- \$ Continue going to the doctor and finishing the medicine they give him
- \$ Be more careful (2)

## Communication

- \$ Tell a friend with children to check on them every month
- \$ Tell people with babies to take the child to the doctor to get treatment (2)
- \$ If I knew someone who had it, I'd make sure they had a brochure

## **In what other ways would you like to get this information?**

ABrochures are good because you can read it in private and can look back at it . . .@

## People

- \$ From a doctor (wants information from a person because he/she can't read well) (2)
- \$ From a doctor (not literacy related) (2)
- \$ From my counselor

## Formats

- \$ Through the mail (2)
- \$ Group discussions/seminar/workshop (3)
  - < So it can be explained and questions can be answered
  - < This information is scary, so it would be good to have interaction
- \$ Make posters with pictures that are very simple
- \$ Educational TV program (3)
- \$ Video at a doctor's office (2)
- \$ Documentary style video

## Availability/access

- \$ Put them out on the street (2)

## **How can we make information like this useful to people affected by HIV/AIDS?**

No response (2)

## Process

- \$ Include people living with HIV in the development of these (2)

## People

- \$ Have a physician offer this information
- \$ Make it more personal; have doctors tell patients about these issues

## Format

- \$ Talk about it at group sessions (like these support groups)

\$ Simplify the language and style of writing

Availability/accessibility

\$ Put it in schools, libraries, office buildings, grocery stores, trains and buses

\$ Put in hospitals, clinics, shelters, outreach centers

\$ Placement in public places, like libraries and grocery stores

\$ Distribute all over, waiting rooms, and bathrooms (2)

\$ APut it out there@ (4)

## YOU CAN PREVENT CYTOMEGALOVIRUS INFECTION

### What was hard to understand?

No response/nothing (18)

#### General

- \$ AI didn't realize that attention was being given to prevention [of CMV] because almost everyone has it. Seems foolish.@
- \$ All new information, first time hearing about possible symptoms (2)

#### Reading level

- \$ Language difficult (4)
  - < Especially difficult for slow readers
  - < Too technical

#### Specific sections/content

- \$ Symptoms of CMV seem same as cold or other sickness (2)
- \$ Symptoms of CMV seem very similar to HIV
- \$ ACan reactivate or wake the virus@B which virus? CMV or HIV?
- \$ ACMV sounded like HIV and confused me by bringing up saliva and urine, nose and mouth B things not associated with HIV. Sharing cups and drinking, utensils, could have been more clear by distinguishing CMV from HIV. It is more contagious, so needs more attention drawn to it.@
- \$ AMentions sharing [ice cream] cones, but not kissing.@
- \$ Not enough detail in AHow do I know if I'm infected with CMV?@section

#### Pictures/drawings

- \$ AFloaters in the eye@picture and term B not familiar with it so hard to understand picture
- \$ AOver half exposed@graphic hard to understand

### What did you like?

No response (15)

#### General

- \$ It pertains to me (2)
- \$ Good for people who want quick information
- \$ Learned new information

- \$ Answered my questions
- \$ Clear for people who don't know anything about it
- \$ Pretty clear
- \$ Easy to understand (2)

#### Appearance

- \$ The pictures
- \$ The color (3)
- \$ Font is nice, not too fancy

#### Content

- \$ Explains a lot about the virus and what you can do to prevent it
- \$ Good to reinforce do's and don'ts
- \$ First and third section were most helpful
- \$ Information I didn't know about preventing infection (3)
- \$ Contact information on the back is excellent

#### **Which pictures seemed out of place?**

None/no response (19)

- \$ Afloaters in the eye@picture doesn't go with the surrounding text/doesn't make sense (5)
  - < Picture of building and tree next to Afloaters@caption
  - < Can't see the floaters
  - < How do floaters relate to the building?
- \$ Little girl playing in the sand doesn't seem to fit (3)
- \$ AThey could all be better@
- \$ Some of the pictures need more explanation
- \$ People on the cover (2)
  - < Can't tell if they are adults or teenagers, should use real people

#### **Is there anything you would do to improve the brochure?**

No/no response (11)

#### General

- \$ Make one for general population B this seems suited to medical professionals
- \$ ATell people to read it twice to absorb the information@
- \$ ADon't make it longer@

## Appearance

- \$ Change the color; it looks too hospital-like
- \$ Add more color to make it stand out more
- \$ Could use more pictures
- \$ Take out kid in sandbox picture (2)
- \$ Make pictures better/more appropriate (4)
  - < Should use real people rather than computer images **B** people don't identify with these
  - < Take the people off the cover **B** they don't look happy

## Content

- \$ Make the language simpler for those with less education (2)
- \$ Be more specific about symptoms (2)
- \$ Have more information about testing
- \$ Tell the name of the test they would use for CMV
- \$ Go more in depth in *How do I know I'm infected with CMV?*
- \$ Put symptoms right after *How do I know I'm infected with CMV?*
- \$ Give more information, more details about CMV, like where does it originate?
- \$ Update retinitis section (3)
  - < Implant information missing re: retinitis
  - < **A**From what I know about CMV retinitis, this seems outdated. There are better treatments that aren't mentioned, like implants in the eye that release medicine.
- \$ Need to add psychosocial and spiritual component; emotional, social, and physical self
- \$ Mention HIV more
- \$ Answer the question, **A**Can you get CMV if you aren't HIV positive?
- \$ Add TDD number on the back for deaf people
- \$ Add information about night sweats in the symptoms

## Editorial

- \$ *Why should CMV concern me?* section should come before the *What is cytomegalovirus?* section

**Is there anything in the brochure that offends you?**

No/no response (29)

- \$ No, but why mention the drug ganciclovir if it isn't recommended?
- \$ Saliva part concerns me [the fact that the brochure says kissing poses a risk]

**What other questions, if any, do you have about CMV?**

None/no response (21)

- \$ A Still not sure whether or not it is something I should be concerned about@
- \$ A How do you know if you have it? I have runny eyes like the retinitis@ [recently diagnosed respondent]
- \$ A More details, especially how to know if it's reactivating, how to tell whether my symptoms are indicative of CMV or something else@
- \$ A Can you kiss people? What kind of kiss should you do/not do?@
- \$ Still concerned about medications to treat CMV
- \$ How does this disease get in your eyes?
- \$ Can people without HIV get CMV? (2)
- \$ What are the medication's side effects?
- \$ Why aren't there CMV tests with HIV tests?
- \$ The drug is expensive and has side effects B why aren't there trials for those who can't afford it?
- \$ Is there a lot of research conducted on this disease? If so, it would be helpful to tell us where to get more information.

**What, if anything, might you do differently because you read this brochure?**

No response/nothing (5)

General

- \$ Worry about infection
- \$ A It gave me something to think about. I'd rather know than not know.@

## Behavior

- \$ Have more eye exams
- \$ Go to doctor/get tested by my doctor (7)
  - < Will mention it to my doctor; it's something I need to be tested for.
  - < Will ask my doctor more questions about it
- \$ Protect myself/be more careful (general) (12)
  - < Wear condoms
  - < Won't share anything
  - < Hygiene
  - < Wear gloves
  - < Careful touching body fluids (2)
  - < Won't smoke behind someone (5)
  - < Won't drink after someone (3)
  - < Will wash my hands more (10)
  - < Won't put my hands on my face
  - < Will use my own utensils (3)
  - < Will stop using dishwasher
  - < Won't share pipes
  - < Will try not to touch my kids' toys

## Communication

- \$ Will share it (the brochure) with other people

## **In what other ways would you like to get this information?**

### People

- \$ Talking to someone (5)
  - < Someone with knowledge about CMV
- \$ Call somewhere and get more information about it [numbers on the back]
- \$ From a doctor (6)
- \$ From outreach workers [Operation AIDS survivors]

### Formats

- \$ A lot of the people in this program [support group] can only read a little. This may lose their attention and it is important information
- \$ Lecture/seminar/workshop/presentation/slide show (6)
- \$ Support group (2)

- \$ Posters of each of the brochures (2)
  - < With simple pictures and text that covers the do's and don'ts
- \$ Make a one-page leaflet with the most important information
- \$ Seeing a movie about it
- \$ A cassette tape about it
- \$ Through the mail (2)
- \$ Program on TV or cable (3)
  - < That deals with STDs
- \$ Videotape (5)
  - < In doctor's office/clinic
- \$ Radio (2)
  - < And other things for people who can't read
- \$ Newspaper or magazine format because you could put more information in it (2)
  - < Magazine with a woman on the cover
  - < Because a lot of people don't want to pick up brochures because you don't know who'll see it@
- \$ Billboards
- \$ Pamphlets helped me a lot when first diagnosed, easy to read, simple. Would like to see more on TV, movies, that don't show the depressing side of HIV@
- \$ I like brochures because they are direct, to the point. Not much room for confusion. Easy to carry.@
- \$ Keep it confidential. If you had a confidential seminar, I would do it.@
- \$ From the Internet

### **How can we make information like this useful to people affected by HIV/AIDS?**

availability/accessibility

- \$ Put it out there@(3)
  - B Put it where people go/get services
  - B Put them in doctor's offices (3)
  - B Put them in shelters, outreach organizations, grocery stores, etc.
  - B Put in residential homes/transitional and supportive housing
  - B Put brochures in libraries
  - B Saturate the communities with this information (3)
  - B Pass out the brochure in high risk communities
  - B Have more of these in places where people with HIV are going to be, make it obvious
  - B Put them in outreach centers (2)
  - B Dissemination to ASOs for outreach
- \$ Keep it confidential [getting the information]

- \$ ADevelop more brochures. These are good because they break the big words down. I can understand the information.@
- \$ Discuss it in support groups/recovery groups [people are more likely to do the right things if in treatment than if still using]
- \$ Should get this information when tested for HIV initially

#### Process

- \$ Testing brochure ahead of time, like you are doing now
- \$ Keep doing what they are doing

#### Format

- \$ ANeed to see pictures I can relate to when I open the brochure@[as opposed to computer images or drawings]
- \$ Have at least one illustration of an adult to reiterate that this affects adults
- \$ Get mailing lists of people with HIV
- \$ Bring people together and tell them about it because they won't open their mail and read it
- \$ Put it on TV (3)
  - < A lot of people can't read or don't like to read; some are housebound and spend more time in front of the TV
  - < ANot a lot of people are aware of this. I am in the medical profession and wasn't aware.@
- \$ Put on the radio
- \$ Put on billboards
- \$ Make videos
  - B Show picture of what it looks like, the effects

#### Other

- \$ Add more information on treatment

## OPPORTUNISTIC INFECTIONS AND YOUR PETS

### What was hard to understand?

No response/nothing (16)

General

\$ AIt was just a little too much information@

Reading level

\$ Terminology (2)

< Technical parts (4)

< Big words

\$ AHard to read@B low literacy levels (4)

\$ AHave never seen some of the words before@(2)

\$ Disease names in the box, especially for people who can't read well (2)

Specific sections/content

\$ First section hard to understand

\$ ACan someone with HIV spread it to their pets?@ It's not clear

\$ Sometimes not clear if they are talking about people or animals in different sections

\$ Whether or not I should have a pet is not clear

\$ What's wrong with friends or relatives having animals?

Editorial comments

\$ None

### What did you like?

No response (12)

General

\$ Learned new and helpful information (4)

\$ Appeals to people with pets

\$ Raised my curiosity

Appearance

- \$ Nice artwork on front (2)
- \$ Color
- \$ Attractive (2)

#### Content

- \$ Informative, comprehensive (9)
- \$ First time I've seen issues such as working with pets
- \$ Liked the Ainfections carried by animals@section (4)
- \$ Like that it can be safe for people with HIV to have pets (2)
  - < ASends a message that you can have a pet, you just have to be very careful. Being HIV positive is hard enough. Don't take pets away. They are something that makes you comfortable with it.@
- \$ Phone numbers on back

#### **Which pictures seemed out of place?**

None/no response (29)

- \$ Birds should be placed closer to the section discussing birds
- \$ Picture of the veterinarian seemed out of place
- \$ Pictures looked Adated,@not Ahip@
- \$ All of them B need real people not computer images
- \$ The computer images didn't go with the information

#### **Is there anything you would do to improve the brochure?**

No response/nothing (11)

#### Appearance

- \$ Make people more ethnically diverse
- \$ Add more pictures
- \$ Don't use computer images of people B make them real (4)
  - < Make them personal; seems comical to have computer images
- \$ Use real pictures of animals
- \$ Front picture looks too carefree with the animals B contradicts what is inside; it's misleading
- \$ No pictures of children should be included
- \$ The graphics could use some work to make them stand out more
- \$ The headings don't stand out enough
- \$ The type of pets should stand out more
- \$ Make it more colorful (2)

\$ Make it a different color

## Content

- \$ Simplify a few of the terms/medical language (2)
- \$ If there are more diseases to be included in the *Infections carried by animals include* section, add them
- \$ Include treatment options for each of the diseases mentioned (5)
- \$ Mention that children should be educated about handling pets
- \$ Add information about parasites
- \$ Add information about masks and dust particles when discussing cat litter (6)
  - < Also say how often you should change cat litter and where to keep it
- \$ Clarify if illnesses pertain to animals or people
- \$ You should play up the benefits of having pets **B** the brochure just gives the negative (3)
  - < **A**Pets are important because of loneliness. Bringing something positive into something negative is good.@
  - < Perhaps make the last section why pets are great to have
- \$ Add a section about sleeping with pets
- \$ **AI** don't agree with the section about having a job that involves pets. Seems like this is saying you should quit, when you can prevent these infections.@
- \$ It should tell you what to do if your pet is sick
- \$ Add more information about other animals, especially fish and dogs (2)
- \$ There is too much emphasis on kinds of diseases; should have the list and then refer to all/any of them as *Infections*@
- \$ It should put the location where you can get more brochures on back
- \$ Tell more about how these bacteria are transmitted
- \$ Add some guidance about how to talk to an employer about your HIV status if you work with animals
- \$ Tell people to go to the doctor
- \$ People with HIV might not want to reveal their status to others with pets **B** give suggestions about what they should do
- \$ It needs more emphasis on being careful about HIV-infected children being around pets
- \$ It should include *A*cat scratch fever@ as well
- \$ It should have information for hunters on handling dead animals or, if pets die, how to handle them
- \$ It should put a definition of *A*parasite@ and *A*bacteria@ before this section

## Editorial

- \$ Put the table at the end so you can see it after you have read everything else
- \$ Set up types of infections as a table with shading; it doesn't stand out
- \$ Space out the text more
- \$ Should make the size of letters of questions larger

\$ Use bullets for the most important parts B it's too verbose (2)

**Is there anything in the brochure that offends you?**

No/no response (30)

\$ Picking up HIV-related material [people will see and judge]

\$ A The *I have a job . . .* section because it sounds like they are saying quit. That's a false assumption.@

\$ I wouldn't pick it up if it had a picture of adults on it and said HIV because people would assume I was HIV positive

\$ It seems to imply that you have to tell everyone that you are positive; it should emphasize the precautions you can take and not have to reveal your status

\$ Information about changing litter boxes is not presented positively [seems more dangerous than it is if you follow precautions and use masks and gloves]

**What other questions, if any, do you have about OI and your pets?**

No response/none (22)

\$ AWhat about animals eating their own stool?@

\$ ADo latex gloves protect you when handling animals= stool?@

\$ AWhat about vomit? Do latex gloves protect from that?@

\$ ACan you catch opportunistic infections from breathing the fumes of feces in cat litter?@(2)

\$ AAre scoopable litters preferred?@

\$ AWhat are the timeframes you might expect to see these symptoms after exposure so you know when to stop worrying?@

\$ AAre there other infections I should worry about with my pets?@

\$ AWhen a person is disabled, what should he/she do?@

\$ AWhat about handling meat?@

\$ AI'm still not clear about pets getting HIV or other things from me@

\$ AWhat is the effect of mycobacteriosis on me?@

\$ AAre there other things you can get from fish or birds? Is the aquarium water the only concern?@

\$ AWhere can I find out more detailed information?@

\$ AIs it safe to leave your pet in your house while you're at work [because saliva and feces may spread]?@

\$ AHow long is it safe to keep a pet [re: CD4 count/AIDS diagnosis]?@

\$ AWould it be better not to have a pet because you'll be exposed to these things again and again?@

- \$ Are there more information about treatment? How about home remedies? Alternative therapies?@
- \$ Where can I find out more detailed information?@

**What, if anything, might you do differently because you read this brochure?**

Nothing/no response (9)

General

- \$ I'm less likely to have pets in the future (2)
- \$ I might get a pet
- \$ I may not get pets
- \$ I will get even more information before getting a pet

Behavior

- \$ Be more careful/take precautions (general) (9)
- \$ Wash hands more frequently
- \$ Be very careful about animal diarrhea
- \$ Use gloves when handling and cleaning animals (7)
- \$ Would get a cat that is at least a year old
- \$ Will get rid of the kittens **B** too many feces. I might have to get rid of the mother cat if I can't get her fixed
- \$ I'll stay away from lizards and snakes
- \$ I'll get my pet tested/shots (2)
- \$ I will not let my dogs get next to anybody@
- \$ I would take a pet to the vet at the first sign of illness

Communication

- \$ I will pass this information on to someone else

## **In what other ways would you like to get this information?**

No response (3)

### General

- \$ Brochures are the best way (3)
  - < Reading it is the best way@
  - < They should put articles/books on back for people who want more information

### People

- \$ Word of mouth from someone with a pet
- \$ From doctor (7)
- \$ From a veterinarian
- \$ From a case worker

### Formats

- \$ Symposiums/lectures/workshops/educational program/group sessions (3)
  - < More personal communication (3)
  - < Especially for those who can't read (2)
  - < Because people need to talk about it
- \$ Hotlines
- \$ Through the mail
- \$ Posters; very simple posters (4)
- \$ One-page sheets are good because they are easy to absorb, especially for folks with literacy problems (3)
- \$ From a pet shop, even for people who aren't infected
- \$ Videotape in clinician's office (3)
- \$ From the Internet (2)
- \$ TV PSAs or programs (4)
- \$ Radio (2)
- \$ Magazines (2)
  - < With lots of pictures that show what to do and not do with pets
- \$ Rallies/demonstrations

## **How can we make information like this useful to people affected by HIV/AIDS?**

No response (3)

### General

- \$ Leave off HIV infection on front so that people with HIV can pick it up without others seeing
- \$ Make this information available for groups like PALS (they provide pets for people with terminal illnesses)
- \$ Get the community involved in this issue
- \$ You should give out masks and gloves when you give out the brochure

#### Format

- \$ Be aware that the average person cannot read this **B** you should develop something for low-literacy groups
- \$ Simplify it; make it clear and concise (2)
- \$ Put it in booklet form
- \$ TV, PSAs specific to pets (2)
- \$ A video or movie; something that people will be alert to
- \$ Billboards (2)
- \$ Give numbers they can call to talk to someone

#### Availability/access

- \$ Make very accessible/available: (general) (11)
  - < Put it out there any way you can
  - < Clinic/doctors= offices (3)
  - < Veterinarians= offices (2)
  - < Support groups
  - < Transitional/supportive housing
  - < Pediatricians
  - < Animal shelters (2)
  - < Pet shops (especially regarding reptiles) (2)
- \$ Distribute to all treatment centers

## SPECIFIC EDITORIAL SUGGESTIONS

### PCP

- 1) **A**First sentences in the box are awkward **B** try making one sentence that ends with >which can be fatal= instead.@
- 2) **A***Can a child catch . . .*@section is not answered with a **A**yes@ or **A**no@ as the others are. Also, it brings in the environment, which the heading doesn't indicate. Try **A**Can a child catch PCP?@ instead.
- 3) In the **A***Who should be given treatment . . .*@section, the sentence **A**especially common . . .@ is redundant **B** it was in the first box.
- 4) Leave out **A**also@ in **A***4B6 weeks*@section.
- 5) **A***Medical follow-up*@section has too much information **B** leave out CD4 count information and the part in the parentheses.
- 6) Section on medicine side effects should be moved up to just after who should be given treatment.
- 7) Prepositions at the ends of sentences make the text more difficult to follow.
- 8) Should use **A**AZT@ instead of **A**Zidovudine.@
- 9) Section on **A***Who should be given treatment . . .*@ contradicts **A***Why do we wait 4B6 weeks . . .* @because most children are on AZT for longer than 4B6 weeks (a year or longer sometimes).

### CMV

- 1) CMV should be printed horizontally on the brochure. It is already a big word; it's too much effort to turn in on its side to read it. (2)
- 2) **A***What is CMV?*@ would be a better title.
- 3) Make **A**HIV@ bigger on the front; that should be the emphasis and is what should catch the attention of readers.

### PETS

No suggestions