



A COMMUNICATIONS STRATEGY FOR THE NATIONAL CHILDREN'S STUDY

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

Centers for Disease Control and Prevention

U.S. ENVIRONMENTAL PROTECTION AGENCY



HEALTH GROWTH ENVIRONMENT

COMMUNICATIONS STRATEGY

This strategy describes the overall direction of communications for the National Children’s Study. State and federal health officials, national and local partners, Study coordinators, and other supporting organizations are encouraged to use this document to prepare communications activities and materials that meet their specific needs. Although this strategy is intended to promote consistency of communications about the Study, it is not an outline of specific communications campaigns or tactics.

The sections that follow provide details on the Study’s key communications issues, insight into audiences and message development, and details

on the multiple communications phases of the Study. This document focuses on the initial phases of the Study; additional detail will be added to the communications strategy for later phases of the Study as implementation unfolds.

This strategy is designed to guide message and materials development for all audiences over the length of the Study.



INTRODUCTION

The National Children’s Study is the largest long-term study of children’s health and development ever to be conducted in the United States, involving 100,000 children from before birth to age 21. The Study aims to better understand the link between the environments in which children are raised and their physical and mental health and development. By looking for relationships between environments and children’s physical and mental progress, the Study seeks to find basic causes of many of today’s major childhood diseases and disorders and to determine not only which aspects of the environment are harmful, but also which factors are harmless or helpful to children’s health and development.

The Study will focus on a set of key scientific research questions that address some of the most pressing health and development concerns for children today, including:

- *Pregnancy-related outcomes*
- *Injury*
- *Asthma*
- *Obesity, diabetes, and physical development*
- *Outcomes related to child development and mental health*

Examples of research questions to be examined include: How are prenatal exposures to pesticides linked to increased risk for learning and developmental disabilities? How are early childhood viral infections linked to the occurrence of asthma? How do individual, family, and community factors affect childhood injuries?

The Study will provide information to help generations of Americans meet the health, economic, and social challenges associated with many serious health conditions. It will build a source of data that may answer questions about links between environments and the origins of childhood and adult diseases.

The National Children’s Study will recruit more than 100,000 women from across the United States who are pregnant or are



likely to have a child in the near future, will follow their prenatal health, and will then follow the health and development of their children from birth through the age of 21. These women will represent a cross section of ethnic, geographic, and socioeconomic groups. By including families from varied backgrounds and family structures, the Study can better investigate issues of vital interest to all communities and shed light on health disparities.

For the Study to be successful over so many years, and for it to maintain the participation of tens of thousands of families, will require a significant mobilization of people, funding, and leadership at all levels. It will also require careful attention to privacy and confidentiality, timing for reporting Study findings, and ethical considerations that arise in research involving children. This effort can go forward only with the enthusiasm of scientists throughout the country and can meet its objectives only with the support of local community institutions and organizations.

The National Children's Study is a collaborative effort led by the U.S. Department of Health and Human Services (DHHS)—through the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC)—and the U.S. Environmental Protection Agency (EPA).

Led by the NIH's National Institute of Child Health and Human Development (NICHD), the Study will benefit from input of more than 40 other federal agencies and departments.



The Study will be implemented by study teams at university hospitals, community hospitals, local health clinics and sites, and/or physicians' offices across the country. These teams will recruit participants in or near their hometowns.

In addition, Study planners will build partnerships among local communities, health care providers, and federal and non-federal scientists, as well as parent, advocacy, and private industry groups, to inform the Study throughout its duration and ensure the greatest benefit to the nation's children.

Each local partner, team member, and participant brings unique perspectives and insights to help build a supportive environment in which communities are engaged and participants are enrolled.

UNDERSTANDING THE COMMUNICATIONS CHALLENGES, BARRIERS, AND OPPORTUNITIES

The National Children’s Study is unprecedented. A study of this magnitude, with extensive research goals and involving participants from many ethnic and social backgrounds, has never been attempted. In fact, no clear frame of reference exists to aid in communicating with the combination of audiences the Study seeks to reach. Therefore, a large part of communications about the Study, whether with health care providers, partners, or potential participants, will outline the intent, scope, and value of the Study.

In developing this communications strategy, the Study planners sought to gain greater insight into audiences’ current knowledge of longitudinal or observational studies. They also sought to learn the key issues,

A thorough, formative research phase aided communication planning. Small focus groups were conducted by Study leaders at the EPA and the NICHD. Results from this research are incorporated into the strategy, particularly in the opportunities and barriers, and in the discussion of the phased approach to communications. In addition, Study planners conducted reviews of the media environment related to children’s health and the environment and searched published reports related to research involving children. A media audit, Web site audit, and literature review were key components of the research.¹⁻⁶



barriers to, and opportunities for communications that result from the Study’s unique design.

A series of focus groups were conducted with each of the following audiences:

- **Health care professionals:**¹
 - Obstetricians;
 - Pediatricians;
 - Family practitioners;
 - Nurses; and
 - Nurse practitioners.
- **Community leaders:**¹
 - Social service agencies;
 - Environmental advocacy groups; and
 - Maternal health support organizations.
- **Potential Study participants:**^{2,3}
 - Pregnant women and pregnant teenagers;
 - Couples considering pregnancy; and
 - Parents.

Despite the unprecedented nature of this study, Study planners are benefiting from lessons learned throughout the long history of longitudinal health research, including:⁴

- The **Framingham Heart Study** supported important discoveries about the linkages among health, diet, and heart disease that have been adopted into medical practice. The Framingham Study's ability to gain community support across organizations, from physicians to school principals, in order to maintain consistent success over so many years has influenced the National Children's Study design.
- The **Women's Health Initiative** has shown how mass media can be used effectively to support recruitment for a national study, and how frequent news about study results encourages retention and keeps partners engaged.

CHALLENGES

This section focuses on Study challenges and addresses how communications strategies can help overcome them.



■ Study Design and Participation Requirements

The design of the Study, especially its length, scope, goals for recruitment, and requirements of participation, presents major challenges to successful communication. Unlike a clinical trial, in which participants take medication or engage in a prevention or treatment activity, an observational study like the National Children's Study collects information about participants' lifestyles at home, at school, and at play. At designated points in time, scientists will collect information about children's and parents' daily activities. Participation will involve:

- Office visits to a Study site on a few occasions during pregnancy and in the baby's first year of life, and less frequently in subsequent years;
- Collection of participant samples, such as urine, blood, or hair, and other information regarding the child's environment and health status; and
- Home visits for the collection of environmental samples, such as indoor and outdoor air, water, or other components.

Study leaders will conduct ongoing correspondence with participant families through in-person contact, telephone, mail, the Internet, and home visits.

The extent of these requirements and the length of the commitment may be obstacles for both recruitment and retention. In focus groups conducted for the Study, parents expressed concern about the frequency of visits to the Study site, as well as about the types of samples that will be collected.^{2,3}

- **Communications Approach:** Study planners are sensitive to unique cultural and regional issues participants will face and will help Study teams customize messages and channels to be effective with each audience. An established network of community advocates will help to bolster these

efforts to educate potential participants about sample collection, its rationale, and various measures to ensure participants' safety and comfort. Participants will also be surrounded by supportive information from the Study site, their physicians, and community-based advocates.

■ **Children as Study Subjects**

Research with children requires special protections for many reasons, among them the fact that they themselves cannot give permission to participate until they reach a certain age.

Medical studies have established precedents for the safe and responsible recruitment of children, and institutional regulations govern ethical conduct of research involving children. National Children's Study planners are committed to following these regulations to ensure participants' safety. Furthermore, they are designing the Study to ensure minimal risk to participants.

Generally, the participation of children is achieved with at least one parent's or guardian's informed consent.

► **Communications Approach:** Study teams will discuss all important aspects of the Study's structure, intent, and methods with every mother, father, or guardian interested in taking part in this endeavor. The Study will adopt a policy of frequent, two-way communication that emphasizes clarity and accessibility, and employs multiple modes of information distribution. Informational materials, Web sites, informed consent forms, and possibly interactive computer programs will be made available at appropriate reading levels and in the languages spoken by the families involved to ensure they get the information they need. A supportive community environment, where being a "National Children's Study child" is

valued, will also reinforce parents' decision making. Advocates in schools, places of worship, and physicians' offices will all play important roles in informing participant families about the Study.

■ **Reaching All Audiences**

Health disparities are a key focus of the National Children's Study. To ensure that health disparities are adequately addressed in the Study design, Study teams may recruit extra participants from minority populations using many channels.

► **Communications Approach:** Communications with community supporters and partner organizations will be essential to meeting this challenge. Messages will be tailored so that language, education, or access to information do not limit participation. Study information will be disseminated through multiple outlets, including places of worship, libraries, retail outlets, and community centers. Study coordinators will develop materials inclusive of and appealing to ethnically diverse audiences, and in formats conducive to distribution in nontraditional settings. Communications and media audits will be conducted in each community to fully research the unique cultural issues surrounding health and the environment. This research will help counsel supporters on how to reach their communities with Study messages.



BARRIERS

Implementing this study will also involve overcoming or addressing many barriers to participation. This section focuses on barriers and addresses how communications strategies can help overcome them.

■ Length

The 21-year length of the Study may prove to be the largest barrier to recruitment and retention. Mothers and families face many immediate concerns, including their health, their pregnancies, or becoming pregnant; they may find committing to the Study too difficult. Community leaders polled about the Study noted that, for women and families who face challenges with transportation and difficulty in leaving jobs for health appointments, issues such as access to care and adherence to Study requirements will be major barriers to participation and may ultimately affect recruitment and retention.

The length of the Study may also make partner organizations hesitant to commit to such a long-term effort. In focus groups conducted to aid the Study design, both health care providers and leaders of community organizations indicated that frequent feedback on Study data or results would be a key incentive to their participation.¹

► **Communications Approach:** The National Children's Study will frame the Study's length in balance with the participation requirements over time. Providing a timeline for Study families that shows levels of participation and that breaks the



Study into multi-year segments will help to present the Study as a manageable commitment. In addition, communications will emphasize the benefits of sustained monitoring of the child's health from infancy to adulthood. Health professionals and supporting organizations will also benefit from a segmented timeline and from a plan that includes key milestones for periodic reporting of data that highlight a return on the time invested. Ongoing communications among Study sites, referring health care professionals, and community organizations about participants will also help sustain interest and involvement over time.

■ **Study Requirements/Samples**

The schedule of biologic samples that participants will be asked to provide for the Study may pose another barrier to participation. Among various cultures, planners will face specific challenges in communicating the need for sampling of blood, for instance. The time and inconvenience of participating may also seem burdensome to many prospective participants. Making participation as convenient as possible for participants will be an additional implementation challenge.

► **Communications Approach:** Study leaders must explain the purpose of the sampling requirements and must speak to the individual barriers and motivators among various audience groups. To do so, they will need to develop written materials, particular to the sampling requirements, that are both culturally inclusive and appealing to many audiences. In addition, one-on-one discussions will offer another opportunity to explain procedures, to answer questions about the importance of the samples, and to address any sensitive Study requirements. Study planners may also develop videos that illustrate sampling techniques and reinforce benefits of the Study to those who enroll. Among other logistical factors, socioeconomic background and access to regular health care will

help determine how physicians' offices and community organizations might best work together to deliver such information to potential participants.

■ **Privacy/Confidentiality**

In Study-related discussion groups, expectant and current parents and other stakeholders consistently raised privacy as a key issue to participation.^{2,3} Community leaders and health care providers echoed these concerns.¹ These groups all believed that participants must clearly understand the Study's benefits and promise, and its processes for protecting the privacy of personal data.¹⁻³ Many prospective participants may feel intimidated and insecure about the data collection and use, especially because many aspects of the Study will not be determined at the point of enrollment. Prospective participants may wonder about the ability of any large-scale study to protect their family's private information over the long term. They might also fear that employers, health insurers, and other third parties will gain access to their information.

► **Communications Approach:** The National Children's Study is devoting careful attention to personal privacy. From the initial recruitment, through ongoing communications with Study staff, to the distribution of materials to participants, every aspect of the Study must convey that individual privacy is held in the highest regard. All procedures for data collection must include opportunities for clearly conveying confidentiality. All staff members will be trained and certified in confidentiality procedures to ensure uniform, secure handling of data. In addition, the Study will provide an environment and materials to support individual decision making to allay privacy concerns by reinforcing the value, purpose, and importance of the Study.



■ **Incentives**

Most health consumers are aware that clinical trial research can provide health benefits either from the medical intervention being tested, or as a result of getting additional medical care for a specific condition. However, because this Study will observe and record exposures and health status and will provide only certain specific interventions, there is no direct medical benefit to weigh against the requirements of participation. There may be incidental benefits for participants, who may receive more medical evaluation through the Study than they would otherwise. Although some participants may have altruistic tendencies and share in the promise of improving the health of future generations, this motivation may not be sustained over 21 years. The more burdensome the requirements for observation, the more important incentives become. In the pre-Study focus groups, potential participants, health care providers, and community leaders all spoke of a need for incentives to ensure sustained participation. Planners will assign incentives to Study participants that are appropriate to levels of participation and life stage. For instance, the Study will provide incentives at major milestones, such as on the children's birthdays or after the completion of a segment of the Study.

► **Communications Approach:** The communications challenge will be to appeal to all motivators for each audience so that tangible incentives are paired with other important benefits, such as access to researchers, a feeling of helping others, and receiving information about one's health status.



OPPORTUNITIES

In addition to challenges and barriers, the National Children's Study presents numerous opportunities for benefits and progress in children's health.

■ **Creating New Possibilities for Health Promotion Initiatives, Future Research, and Interventions**

Like its predecessor long-term studies, the National Children's Study could have a measurable impact on health behavior. For instance, linking cholesterol and smoking to heart disease and stroke in the Framingham Heart Study led to changes in medical practice and resulted in numerous initiatives aimed at changing consumer behavior to improve the nation's health. Through discoveries of linkages between children's health and the environments

The data and potential findings will change how medicine for children and adults is approached in many ways. Communications about the Study can influence perceptions and even behaviors over time.

in which they live, the Study will potentially create opportunities for preventing disease through targeted interventions and for health promotion programs that can help address child health policy issues. The Study will also produce needed data to better inform strategies for environmental stewardship.

■ **Raising National Awareness of Children’s Health and Environmental Issues**

Discussions of the history, purpose, and goals of the Study will renew emphasis on the health of the nation’s children. Consistent messages and frequent news information based on Study findings will not only support recruitment and retention, but will also spotlight the major health challenges children face and the role of the environment in increasing or decreasing these challenges.

■ **Encouraging Local Networks of Children’s Health and Environment Advocates**

By creating partnerships between Study coordinators and community organizations, the National Children’s Study will promote an exchange of ideas and information among local child health and environmental advocates. This interaction will not only support the Study, but will also foster efforts to tackle child health and environment issues on the local level.



THE ESSENTIAL ROLE OF PARTNERS

The success of the National Children’s Study will depend, in large part, on the support of national partners who will provide access and credibility to the Study community and will enhance a network of partner organizations in the communities around the Study locations. Each community is unique, and each partner will bring special insight and expertise to the Study. Some of the key elements of successful partnerships rely on communications, including:

- Clear and common language and terminology that allows the exchange of information between research sites and community organizations;
- True reciprocity, in which community input to the progress of the Study is valued;
- Strategic planning that examines the profile of each community and tailors communication tactics appropriately; and
- Advisory committees of community leaders to help guide communications.

The extent of partner involvement, and the types of partners involved, will vary by community and will be driven by the target audiences of each Study site. Partners may take on multiple roles, from supporting the Study through advertising, mailings, or brochure distribution; to recommending Study enrollment to members or constituents; to reinforcing Study retention through ongoing involvement with Study site coordinators and with the participants themselves.

In many communities, churches, schools, and social service agencies may play a lead role in introducing the Study and reinforcing the recruitment efforts of the Study sites.

AUDIENCE ANALYSIS

POTENTIAL PARTICIPANTS

Who are they?

The typical National Children's Study family is every American family. Some may be working to balance family and career, others will be preparing for their first child, or even seeking fertility treatments to help them conceive. Some parents may be struggling to provide for their families, or they may be recent immigrants with extended families living in the home. Income level, time constraints, and lifestyle differences will be considered, among other factors, in the development of communications messages so that recruitment messages can be appropriately tailored to fit individual needs.

Focus groups with pregnant women have helped identify why someone would or would not enroll in the Study.^{2,3} Key findings about motivators and barriers to Study participation are summarized to the right.

How will the Study reach them?

The National Children's Study will address these barriers by maintaining open and clear communication with participants throughout the life of the Study. In addition, communications with potential participants will highlight and reinforce motivators to capitalize on the desire to help others. Study coordinators will need to consider needs of diverse groups and potential language barriers when developing communication materials. As much as possible, the National Children's Study will also consider participants' comfort and convenience in Study design. Pilot studies are currently under way to determine less invasive data collection methods for application in the Study. The organizers of the Study will try to coordinate site visits at convenient

MOTIVATORS

Families would join the Study if:

- It would allow them to learn more about and/or improve their children's health
- They would receive an incentive for participation, such as a gift or monetary incentive
- Joining the Study would improve children's health in the long term

BARRIERS

In regard to participation, families would be concerned about:

- The privacy of information collected and how it would be used
- Invasiveness of data collection methods
- Transportation to the Study sites and frequency of visits
- Feeling treated as research subjects, rather than as partners in the Study

locations and times for participants. In addition, Study planners are paying special attention to privacy and confidentiality to ensure participant information is safe for the life of the Study and beyond. And Study teams will work to foster trusting relationships and ensure families' successful and continued participation.

NATIONAL PARTNERS

Who are they?

The National Children's Study has gained the support and interest of some key national organizations, such as child health organizations, environmental advocates, professional associations representing

industry and social science, child health foundations, academic institutions, and various corporations. Because of their national scope, the involvement of these organizations will help communicate to important constituents at every phase of the Study. As the Study proceeds, these supporters will be reached through individual contacts between Study planners and organization leaders. They will be called upon to assist with building awareness and supporting recruitment in Study communities.

HEALTH CARE PROFESSIONALS

Who are they?

The support of myriad clinicians, most specifically obstetricians, pediatricians, family practitioners, nurses, and other primary care providers, will help this Study successfully reach its goal of recruiting 100,000 participants. Health care professionals are uniquely positioned to help the Study build relationships with families and to encourage their participation. Therefore, an understanding of their knowledge, attitudes, and beliefs about the Study and about long-term studies is critical to informing communications and recruitment efforts with this group.

Study planners will begin to engage obstetricians, pediatricians, family practitioners, and other primary care providers through their professional organizations. Once the Study is launched, primary care practitioners throughout the Study site regions may also participate in recruitment.

During pre-planning discussion groups, health care providers expressed their excitement about the Study's potential contributions to children's health, as well as their concerns about participation. Their perceptions of anticipated participants' concerns often influenced whether or not they would feel comfortable supporting the Study themselves.¹

Key findings from health professionals about their motivators and barriers are summarized below.

How will the Study reach them?

Study planners will use tailored communications to allay the reservations that health care providers might have about participating and to reinforce the participation motivators for the audience. Health professionals usually see many patients a day, sometimes in combination with teaching, research, and other responsibilities. Study planners hope to make it as simple as possible for providers to

MOTIVATORS

Health care professionals would support the Study if it:

- Would make an unprecedented impact on children's medicine
- Could improve the health of people they serve in their communities
- Would address key issues they see every day in their practices
- Would offer personal or professional benefits to those connected with such a unique effort

BARRIERS

In regard to participation, health care professionals expressed concern about:

- Having the time and/or staff resources to participate
- Their patients' confidentiality being protected, and that requirements on patients' time and effort be reasonable
- The invasiveness of data collection and the ease of addressing transportation issues
- Losing patients to other providers

contribute and to allow various levels of support. Study planners will need to be clear and thorough in communicating with health care providers about what is expected of them, and about what resources will be available to help them participate. Planners will also have to work to build trust among the health care professional community so that providers feel comfortable referring patients for recruitment and working with Study teams.

COMMUNITY GROUPS

Who are they?

Families receive health care and support services from many community sources, including public health programs, non-profit organizations, and educational services; community, outpatient, and hospital-based clinics; and school-based programs. State and regional affiliates of national organizations also provide community services and support local health practitioners through research and advocacy efforts.

During focus groups held for the Study, community organizations reported that they saw their role in the Study as primarily informing and distributing information to potential participants and, in some cases, recommending participation to their constituents.¹ Reported motivators and barriers to their involvement are summarized to the right.

How will the Study reach them?

The National Children's Study will work closely with these organizations to obtain their input and to take advantage of their experiences and insights. Many of these groups already volunteer their time in Study planning efforts by attending meetings of the Study Assembly, which are open to anyone from the scientific community and general public who is interested in the Study. Some group members have also raised issues before the National Children's

Study Federal Advisory Committee, whose members provide review and advice to Study planners. As much as possible, the Study will work to consider the priorities of these groups and will craft messages that incorporate and address them, while highlighting the important role these groups will play in the Study.

MOTIVATORS

Community groups would support the Study because:

- This Study could improve the health of people in their communities
- The Study is aligned with their organizational or personal goals
- They would want to be a part of this unique study to significantly impact children's health

BARRIERS

In regard to participation, community groups expressed concern about:

- Whether or not Study planners would consider their organizations' key issues in Study design
- Whether or not the Study would have value for their constituents, e.g., health benefits and tangible incentives
- Confidentiality of data, the invasiveness of data collection measures, and other anticipated participant concerns
- Whether or not the Study would be sensitive to women and children with special needs and from diverse groups, as well as the potential mistrust of government in certain populations

MEDIA

The media will play a crucial role in communicating with the nation about the goals, progress, and findings of the National Children's Study. Unlike communications with other audiences that rely on addressing barriers and reinforcing motivators, the success of communications with the media will rely on the ability to provide consistent, easy-to-understand key messages. These key messages are items that the media will likely include in all of their pieces about the Study. To ensure that media outlets can easily incorporate these points into their own articles, newsletters, and other materials, with little change or need for translation, Study planners and partners need to make sure that the key messages are concise, clear, and in plain language.

Discussions among Study planners and partners produced the key messages to the right. It might be helpful to think of these key messages as "sound bites" that reporters, announcers, and other members of the media might include in a story about the Study.

Prior to the Study's launch, planners will engage reporters from national newspapers, television networks, news magazines, newswires, radio stations, print magazines, online journals, and other media outlets in frequent briefings about planning and recruitment progress. As recruitment continues, Study partners will also reach out to the local media venues, such as community newspapers and local access television, to maintain a steady stream of information that will help to retain and support Study participants.

The National Children's Study will also seek the attention of special populations' media, outlets that provide focused information to certain groups. These venues provide an important lifeline to communities

KEY MESSAGES

The National Children's Study can help pinpoint the root causes of many of today's major diseases and disorders, including those that impact childhood directly and those that take shape in childhood but that ultimately impact adult health. It will provide a vast data resource from which to develop effective prevention strategies, establish health and safety guidelines, and inform efforts to create cures and interventions.

The Study will help to determine not only the aspects of the environment that are harmful to child health and development, but also those aspects that are harmless or helpful to health and development.

The Study will be a massive collaborative effort between Study planners and supporting partners in the public sector, including federal agencies, local health departments, and public health programs, and their counterparts in the private sector, including health and environmental advocacy groups, professional organizations, and, most important, the communities that support the children who are enrolled in the Study.

that have a vested interest in the Study's findings. In providing information to these outlets, Study planners will reach constituents whose participation is critical to the success of the Study, including diverse populations, disease communities, and health care professionals.

The media is a vital intermediary to the National Children's Study. As planning continues, Study planners and partners will devise more specific tactics for communicating with the media to help convey consistent messages and to spur and maintain interest among communities.

COMMUNITY OF THE NATIONAL CHILDREN'S STUDY

This illustration shows how the various audiences from Study participants to health care professionals to the media make up the community of the National Children's Study.



National Children's Study Sponsors

- **U.S. Department of Health and Human Services**
 - National Institutes of Health
 - Centers for Disease Control and Prevention
- **U.S. Environmental Protection Agency**

THE STRATEGIC APPROACH: THREE PHASES OF COMMUNICATIONS

Communications for the National Children's Study will unfold in phases that are designed to build the necessary internal and external support from partners and the public about the need for the Study. Key messages will also generate dialogue to support the initiation of the Study, as well as its recruitment and retention.

Phase 1 includes activities leading up to the Study launch and the beginning of recruitment in 2007.

PHASE 1: PRE-RECRUITMENT

Goal: To build awareness and gain support for the overall goals of the Study from key influencers and the general public. To achieve this goal, communications will:

- Enhance the national dialogue concerning children's health and environmental exposures.
- Build public understanding that environmental exposures are a concern for child health and development.
- Inform potential supporters about the value of the Study in providing data for understanding why some children grow up healthy and why some face certain diseases, chronic conditions, or poor health.



PHASE 2: RECRUITMENT

Goal: To build a supportive environment for the recruiting efforts with a well-informed public, engaged partners, and active, referring health care professionals. To achieve this goal, communications will:

- Engage partners and health care professionals in discussing and recommending the Study to patients and constituents.
- Inform parents and prospective parents about the Study and its values for children.



- Surround potential participants with consistent, supporting messages throughout Study communities.

PHASE 3: RETENTION

Goal: To maintain consistent, persistent, reinforcing messages to participants and their communities.

To achieve this goal, communications will:

- Build and support relationships among Study participants, Study coordinators, and community partners.
- Maintain a national dialogue on children's health and the environment through the periodic announcement of Study results.



PHASE 1: PRE-RECRUITMENT

While Study planners are developing the research protocols, defining the implementation plans, and pilot-testing sampling strategies, the emphasis of communications in this phase will be on setting the stage for a successful Study launch. The communications strategies for this phase are more thoroughly developed than for the later phases. Additional research and input into communications for later phases will be available as these phases begin.

Communications activities in this phase focus on creating a national dialogue about children's health and environmental issues, emphasizing the importance of the Study and illustrating its relevance to today's health concerns. Study planners will be charged with answering the questions of "why children?" and "why now?" among others.

Audiences

Pre-recruitment communications will have to engage the audiences that will help initiate a dialogue with potential Study participants, including:

- Communities;
- Media;
- National organizations;
- Policy makers and government organizations;
- Health care providers;
- Researchers and scientists;
- Private and non-profit organizations; and
- Advocacy and support groups.

Successful communications with these audiences will help to lay the foundations of Study benefits that will help in Phase 2.

Message Approach

Interviews with health care providers and community leaders indicated that messages should emphasize the impact and goals of the Study, specifically the impact that it will have on medicine and health care for generations to come.^{1,4} Messages for organizational and government leaders should be phrased as invitations, encouraging them to play a role in the Study's development and implementation.

Health care professionals reacted most favorably to the following approach:

The National Children's Study is the most comprehensive study ever conducted and seeks to discover the causes of and the means to prevent childhood diseases and injuries. Be a part of unprecedented research that will inform and impact children's medicine for generations to come.

In addition, pediatricians and family practitioners favored messages that compared the Study with previous longitudinal studies and that included more specifics on the Study goals:

Just as the Framingham Study brought new insight into heart disease, the National Children's Study can provide new research findings on children's health; you can help discover the factors that link childhood diseases and health risks to environment, genes, and exposures.

Messages that gave prominence to the length of the Study were unappealing to this audience:

The National Children's Study is addressing the children's health issues that are predominant in your practice in a national study that will include your patients and your community throughout the next 21 years.

Community leaders were most impressed by messages relating the Study to their missions and health concerns:

Over 21 years, the National Children's Study will discover what makes children in your community healthy and why some face diseases. This Study is your opportunity to be part of the first-ever effort with the scope to study and impact children's health care and environmental issues that concern the people you serve.



Channels

During the Pre-Recruitment Phase, Study planners reach audiences through many channels. The Study Assembly regularly brings together members of organizations with an interest in the Study to discuss important issues. Advocates and supporters interact and provide input on design and implementation planning. The Study Web site is up-to-date with details on the Study's development. Quarterly electronic updates also inform the Study Assembly and Web site users of Study news and progress. Additional communications channels include:

- Consumer media items targeted to audience segments in broadcast, online, and print formats;
- Professional association meetings and publications;
- Community organizations, schools, religious organizations, and retail outlets; and
- Government partners, including interagency communications vehicles.

Evaluation

Tracking the results of Phase 1 outreach will allow Study planners to improve communications efforts and to plan for Phase 2. Initial evaluation will include:

- Media monitoring, using clip services and Nielson's SIGMA encoding to assess coverage and reach of news outreach efforts;
- Electronic tracking to count visits to the Study Web site and other partner sites;
- Surveys to monitor primary and secondary audience awareness of Study messages over time; and
- Conferences and interviews with key stakeholders to compile message effectiveness data.

PHASE 2: RECRUITMENT

Recruiting 100,000 participants is one of the greatest challenges of the National Children's Study. Enrolling such a large number of participants will require a coordinated effort from research staff, health care providers, and supporters who can reach families and get them involved in the Study. Recruitment is slated to begin in early 2007 and will last through about 2011. However, the communications recruitment phase will begin before a single participant is enrolled. Using data collected in the Pre-Recruitment Phase, Phase 2 communications will develop networks to support the Study sites and will prepare them for outreach to potential participants once recruitment actually begins.

Audiences

Although both national and local outreach efforts are critical, Study planners anticipate that intense local grassroots campaigns will best support recruitment for each site. Such communications will promote the formation of community partnerships; build relationships with area obstetricians and other health care providers; and reach out to parenting groups, religious and community institutions, and other organizations that offer health information and support to families. In addition, because previous studies have demonstrated that endorsement and referral from trusted community leaders is a significant factor in encouraging Study participation, Study coordinators will form and maintain positive and solid relationships with such leaders via communications.

Message Approach

Communications campaigns for recruitment will focus on core messages that define the Study in ways that are meaningful to each participant. The Study will also develop and test messages and materials with potential participants to understand what methods might improve recruitment communications approaches.

Channels

Phase 2 will emphasize local communications channels. Study planners will aim to maintain awareness among the national audiences, while assisting local Study sites in working with the media and professional and consumer organizations to promote recruitment. Potential local communications channels include:

- Local television stations and newspapers;
- Regional and local medical, nursing, and allied health associations;
- Social service organizations;
- Physicians' offices and health clinics;
- Religious institutions;
- Schools;
- Consumer points of contact, such as supermarkets and pharmacies; and
- State and local government offices.

Evaluation

The true evaluation of Phase 2 will be in the tally of enrolled participants. Planners will look closely at enrollment at each Study site and will adjust communications efforts to support recruitment as needed. In addition, the Study may employ the following evaluative measures:

- Tracking forms to assess whether materials are reaching the right audiences;
- Enrollment status reports from Study sites to determine which audiences are not being reached; or
- Interviews with stakeholders to determine any barriers to participation.

Local communications campaigns will promote the formation of community partnerships; build relationships with area obstetricians and other health care providers; and direct outreach to parenting groups, religious and community institutions, and other organizations offering health information and support to families.



PHASE 3: RETENTION

Strong relationships and open communications will be essential to successful retention. Ideally, participants will come to rely upon and trust their Study representatives. Researchers will come to know individual participants over time, allowing for more personal approaches to retention. Community leaders can alert coordinators to changes in the community that may affect participating families' decisions to stay in the Study and can help coordinators address retention problems on an individual basis.

Audiences

As the Study progresses, the primary audience for communications will be the participants, who will be segmented in multiple ways. In addition, Study coordinators and the health professionals that surround and support each Study site will also constitute a critical audience. The Study will need many of the supporting organizations that aided recruitment to continue their support of participants throughout the length of the Study, in some cases providing tailored communications to their constituents.

Message Approach and Channels

During the previous phases, and as more is learned about the communities involved and the participants, Study coordinators can inform message development and channels for Phase 3. Localized and individual messages and methods will likely be most effective. Input from partners and supporters will also help shape messages so that, as the needs of communities



change and the children enter new life stages, participants are still getting the information and support they need.

Evaluation

Retention rates will be measured over time in many different ways. The communications support for retention may be evaluated through qualitative and quantitative research, including:

- Surveys of participants to help understand participation motivators and barriers as they change with time;
- Interviews with Study coordinators and community supporters to determine the effectiveness of messages and distribution methods; and
- Case studies in select areas to follow specific groups of participants and determine how communications efforts are received and interpreted.

STRATEGIC COMMUNICATIONS STRATEGY TIMELINE



Phase 1: Pre-Recruitment

2004–2006

- Establish initial Study sites
- Build data and specimen repositories
- Build awareness in local communities
- Establish confidentiality guidelines and rules for privacy

Phase 2: Recruitment

2007–2011

- Launch study
- Continue recruitment and enrollment through this entire period

Phase 3: Retention

2007–2032

- Conduct ongoing clinic and home visits
- Collect data about participants and their environments
- Share results regularly
- Provide informational feedback to participants and communities

EVOLUTION OF STUDY COMMUNICATIONS

Through monitoring, reporting, ongoing interviews, and conferences, Study leaders will seek to understand the outcomes of the communications initiatives and will use their evaluations to keep planning fresh.

Evaluations conducted before, throughout, and after implementation of communications efforts will help to refine, adjust, and assess current and future activities and strategies. The program of evaluation may include:

- Process evaluation to track communication efforts and determine whether communication links are in place and effective;
- Outcome evaluation to assess the extent to which communications activities have had the intended effects; and
- Impact evaluation to measure how much communications components contributed to the overall success of the Study.

As discoveries are made, as the environment changes, and as new public health issues are raised, the Study will evolve. Study communications will also adapt to meet and address those changes. Although partners need to work with a common understanding of communications strategy, Study planners encourage them to adopt their own tactical plans specific to the needs and challenges they are facing.

This document emphasizes the early phases of communications for the Study. Further research, findings, evaluation of early efforts, and, most important, input from partners and supporters will help shape communications over the length of the Study.



The National Children’s Study planners and coordinators welcome your feedback on this document. Please send your comments to NCS@mail.nih.gov and include “COMMUNICATIONS STRATEGY” in the subject line.

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