US/UK Collaborative Meeting on Racial & Ethnic Health

Second Report on the US/UK Collaborative Initiative on Racial and Ethnic Health

**Collaborative Work Group Meeting
Held September 23-25, 1998**

Contents

Section 1

Introduction

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Disturbing statistics on health profiles of racial and ethnic minority groups have begun to converge in the world's most advanced industrialized Nations. Two NationsCthe United States (US) and the United Kingdom (UK)Chave taken an important step by agreeing to collaborate in developing an understanding of the similarities in disease conditions most prevalent in their minority sub-populations.

As representatives of those national governments, health systems, and research communities, we have begun to ask why differences exist and what we can do to eliminate racial and ethnic health disparities. For example, we want explanations for the following figures[1] on one of the best indicators of population health qualityCinfant and perinatal mortality:

C In the UK, the perinatal mortality rates of Pakistani-born women are nearly twice the national average.	C In the US, the infant mortality rate among African Americans is almost 2-1/2 times the rate for white infants.

We want to understand reasons for the following differences in cardiovascular health:

C In the UK, the death rate for stroke for individuals under 65 from the Caribbean is almost twice the average for individuals from England and Wales.	C In the US, the rate for coronary heart disease among African Americans is 40 percent higher than whites.

We need to explore all factors that lie behind the following facts about reproductive health:

C In the UK, cervical screeningCwell known as a cost-effective measure to reduce deaths of women from cervical cancerCis less than half the rate among Bangladeshi women, compared to the	C In the US, prostate cancerCwhich is often quite treatable if caught through routine screeningCis twice as high for African American men as white men.

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[1] The figures referenced here are from the first report of the Collaborative Initiative, "Health Gain for Black and Minority Ethnic Communities" (see Appendix B).

general population.

Similarities between these two countries and *differences* between their general populations and minority groups lie at the foundation of important program and policy questions. Leaders in these countriesCeach with an enviable health care system when compared to many other systems around the globeCare troubled by these statistics. They cause us to seek out explanations that ultimately will provide the foundation for new policies and programs.

This report summarizes accomplishments of the second meeting of the US/UK Collaborative Initiative on Racial and Ethnic Health, held in September 1998, in Washington, DC. The 1998 meeting followed the 1997 signing of a statement of intent by the Minister of Public Health of the United Kingdom, The Right Honorable Frank Dobson, and US Deputy Secretary of Health and Human Services, The Honorable Kevin Thurm, reaffirming their countries' active support for minority health and pledging their commitment to collaborate in sharing public health information. They agreed to establish a joint agenda that tackles challenges both countries face in meeting the health needs of their ethnic minority population groups (see Appendix A for the Text of the Joint Statement).

Discussions that took place in 1998 went far in fulfilling the sense of the 1997 Joint Statement by providing a forum for sharing information on research, access to quality health services, inequalities in health, and coalition building. The 1998 meeting was guided by a full agenda of activities involving two principal Work Groups. Those work groups developed strategies for increasing (1) culturally sensitive access to health services, and (2) consumer-grass roots voices in voluntary sectors of the US and UK. During that time, a Steering Committee met to identify strategies for developing resources to sustain the Initiative's activities. UK participants in the second meeting of the Collaborative Initiative took time to make important site visits to the Office of Minority Health's Resource Center in Silver Spring, Maryland, Mary's Health Center, Washington, DC, and the National Minority AIDS Council, Washington, DC. These activities provided an opportunity to share experiences in meeting the health needs of minority population groups and went far in developing links between US and UK health professionals, managers, and researchers who have common interests in addressing ethnic and minority health needs.

We hope these discussions will help to build a stronger foundation for joint activities between our two countries, as they come to grips with challenges posed by racial and ethnic health disparities. As we enter the 21st century and look forward to developing new and better ways to deliver health care to all people, we must look back in order to discover reasons for successes and failures. The lessons we draw from our experience will enable us to move forward, confront the barriers to access for racial and ethnic minority groups, and understand better how we can implement sound strategies to remedy racial and ethnic health disparities that characterize our two countries. In a sense, one reason for our joint meeting was to identify useful action models that have served groups well so we can apply them to problems we face today and tomorrow. In this instance, we learn about history so that we *can repeat it*.

However, we want to identify new models that have not yet been defined well or implemented fully, so that we can explore uncharted territory. We do not believe that all program models and components that could help to deliver effective health care to minority groups have been tried. We want to identify them, encourage their demonstration, and derive useful lessons from these approaches.

Addressing racial and ethnic disparities in selected health areas is one of six priority public health areas identified by the US Surgeon General, and is the focus of the President's Initiative to Eliminate Racial and Ethnic Disparities in Health. We see our participation in the second meeting of the US/UK Collaborative Initiative on Racial and Ethnic Health as a constructive expression of US policy to understand and thereby to help eliminate differences that exist in the health profiles of minority Americans and the remainder of the US population. Our experiences in public health have shown us that so-called "top-down" approaches rarely work as well as grass roots movements. However, in this instance, we appreciate the leadership shown by President Clinton and we will work to fulfill our agenda of cooperative activities with the UK knowing that our work is consistent with the Presidential Initiative.

In the United States, it remains a troubling fact that many people who have a Medicaid card do not receive services. While Medicare is designed to provide universal health care for elderly, there are racial gaps in coverage for most commonly used procedures. In spite of the Veterans Administration's intention to provide health benefits equitably to all races and groups, there are wide differences in treatment. Native Americans are often excluded by distance as well as by culture and may not receive much needed health care at all. These inequities are paralleled by experiences in the UK and other industrialized nations.

We believe that it is important to see the work of the US/UK Collaborative Initiative on Racial and Ethnic Health as an example of an unavoidable, but nevertheless striking new trend**C***the internationalization of public health*. No longer do we live in a world where health and health care are completely isolated by geopolitical boundaries. The AIDS epidemic has taught us that boundaries mean nothing to some public health problems. As with AIDS, factors that contribute to heightened rates of infant mortality for minority groups seem to know no boundaries. Stress, poor nutrition, domestic violence, substance abuse, and late prenatal care are culprits in the distressing disparities in maternal and infant health for minorities in most industrialized nations. We need to share what we know about solving those problems so that our citizens will start out on a level playing field, with a life expectancy the same for all.

We acknowledge that our systems of health care in the US and UK are different. However, they are *comparable*. We believe that by comparing similarities and differences, useful lessons will emerge that can be shared with other professionals in our respective countries. In many ways, experiences of our two health care systems in treating racial and ethnic minorities are more similar than different, in part because of external factors. Migration, war, famine, and political oppression have created significant, new minority groups in all of the world's wealthier countries. All industrialized nations are confronting problems similar to the ones discussed in this report.

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The internationalization of health care issues is certain to continue into the 21st century and beyond. Two priority health areas identified by the Surgeon General are pointedly international in nature, including the health consequences of terrorism and safety of the blood supply. These global health concerns affect Americans. We believe that the issue of racial and ethnic disparities in health is an international issue. It is also one that the US Office of Minority Health can address effectively in bi-national and multinational forums like the collaborative work group meeting documented in this report. We anticipate that sharing of information across borders will help both countries devise important new strategies for closing gaps in health status and access to quality care between racial and ethnic groups and the remainder of the populace. Our two national health care systems differ, but in spite of these differences, many of the same disparities in health still occur. We want to know why. We want to understand processes behind the health statistics. We want to know what we can do to engender equity in the health care systems of all nations. We want to be able to fulfill everyone's right to being heard and being understood in health care settings through culturally appropriate health care delivery.

So, we must join together now and in the future to ensure the sharing of information and strategies on addressing important public health problems. It is my hope that after reading this report, you will come away with a broader and more inclusive definition of health care. Our health care systems must serve everyone, including those whose language or culture may be different from the dominant group's. So this is the challenge I present to youCFind your role in helping to close the gaps in racial and ethnic health. Help us to build a bridge between the present and the future, one in which all citizens have equal access to quality health care services.

Section 2
Executive Summary:
Recommendations from the Second US/UK Collaborative Meeting on Racial and Ethnic Health in 1998

Participants in the second meeting of the US/UK Collaborative Initiative on Racial and Ethnic Health, convened on September 23-25, 1998, in Washington, DC, to develop a set of recommendations as part of their overall task of establishing a framework for the US/UK collaborative process and identifying joint future projects. These recommendations summarize a consensus reached by the Steering Committee after reviewing recommendations from two Work Groups. Sections 5 and 6 of this report describe in greater depth the discussions of the two Work Groups: the first, on developing access to culturally sensitive health services, and the second, on developing grass roots voices of minority communities and the voluntary sectors who can help them.

It is important to remember that, while general consensus was reached on many important points, the participants in the second meeting of the Collaborative Initiative from both the US and the UK were fully aware that fulfilling these recommendations could take very different strategies in the two countries. There are large and important differences in the ways that sub-populations achieve their political goals in the US and UK, including the improvement of health care services for racial and ethnic minorities. Nevertheless, the Members agreed that similarities in the health profiles of minority sub-populations argue for cooperative, joint, and mutually advantageous actions that the Initiative can support. They agreed that the goal of encouraging appropriate health care changes in the two Nations is well served by the following actions.

Recommendation 1
!   Participants in the second meeting of the Collaborative Initiative on Racial and Ethnic Health recommend working within the general policy making frameworks now established by the US and UK, and in those instances where change is both necessary and desirable, using well proven strategies to approach, convince, lobby, and gain a larger role in the existing policy-formulation processes in the US and UK. Toward this end, the participants recommend:

1.A.   Assisting the health secretary and health minister of the two Nations in promoting their long-range agendas, especially those agenda items that target improved health indicators for racial and ethnic minorities. In large measure the national agendas focus on setting goals for the improvement of health indicators and do not conflict with the purpose of the Initiative.

1.B.   Selecting priority projects that are consistent with the objectives already identified in the US's *Healthy People 2000/2010* and the UK's *Health of the Nation*.

1.C. Developing the advocacy skills and communications capacities of groups representing racial and ethnic minorities, so that they may enjoy a greater voice in national policy making.

Recommendation 2

! Participants in the second meeting of the Collaborative Initiative on Racial and Ethnic Health recommend identifying, developing, and supporting a set of educational strategies to disseminate the existing knowledge base on effective health care delivery and health care advocacy for ethnic and racial minorities. Toward this end, the participants recommend:

2.A. Collecting and redistributing information on Best Practices related to health care advocacy and to the delivery of culturally sensitive health care for ethnic and racial minorities. Best Practices would describe tested and workable strategies at the national, community, family, and individual levels that contribute toward the improved health of racial and ethnic minority sub-populations. Benchmarks to assess progress would be included.

2.B. Developing a communications infrastructure for disseminating knowledge by (1) establishing a roster of groups and organizations; (2) compiling a mailing list of organizations and professionals (their mailing and electronic addresses, telephone, and fax); (3) designing and uploading a web site to share information among participants in the meetings of the Collaborative Initiative, and others; and (4) supporting high-technology communications events such as teleconferences and lectures via satellite.

2.C. Augmenting the existing knowledge base by (1) supporting new, medical and health services research projects; (2) the evaluation and monitoring of existing programs and research projects; and (3) research agendas that enable tomorrow's researchers to answer important questions about the epidemiology and treatment of disease in minority sub-populations.

2.D. Supporting and encouraging specialized training programs for medical students, practicing health care professionals, and advocates so that they will know more about (1) culturally sensitive health care services; (2) the policy, law, and regulations that enable them; and (3) the advocacy strategies that encourage them.

Recommendation 3

! Participants in the second meeting of the Collaborative Initiative on Racial and Ethnic Health recommend developing resources for the support of the Initiative's framework and selected projects. Resources are defined as monetary funds, personnel, labor, facilities, good will, specialized information, and access to decision making. Toward this end, the participants recommend:

3.A. Seeking a limited amount of support from the general budgets of health agencies and ministries for administrative support such as telephone calls, office supplies, postage, teleconferencing, and word processing.

3.B. Seeking funding through the respective legislative and other governmental processes in the US and UK, and seeking to influence national budgets so that they address the health disparities of racial and ethnic minorities.

3.C. Seeking to draw on the resources of a broad network of organizations through partnerships, consortia, and other collaborative initiatives at the international, national, and local levels. Partnerships should ideally include members of the private and voluntary sectors, in addition to the public (governmental) sector.

3.D. Garnering resources in the form of good will, voluntary labor, and contributed service by physicians and other health care providers, with the purpose of encouraging the delivery of culturally sensitive health care services.

Section 3
Background on the First Collaborative Meeting in 1997

The recommendations forthcoming from the Second US/UK Collaborative Meeting on Racial and Ethnic Health in 1998 had their origins in the first collaborative meeting in 1997. The history of that meeting provides needed perspective on the selection of topics for the Work Groups who met in 1998. Planning that followed the 1997 meeting focused on two topics: culturally sensitive health services and developing the advocacy capacities of minority groups. Therefore, the recommendations from the second meeting fall into those general interest areas. There are other interest areas. They will form the focus of future meetings of the US/UK Collaborative Meeting on Racial and Ethnic Health as it continues its challenging work into the new millennium.

It is worthwhile to see the ongoing activities of the Collaborative Initiative on Racial and Ethnic Health as part of a loosely organized movement to internationalize public health policy and programs in response to migration, war, and socioeconomic forces which increase the numbers of minorities living in the world's most advanced industrialized nations. In a paper prepared for the 1997 meeting of the Collaborative Initiative, Marcia Bayne Smith observed that "Over the course of the last twenty-five years... migration worldwide has essentially been a movement of racial and ethnic minorities toward developed Northern countries, including the U.S./U.K... it has been a movement largely of people of color toward predominantly white societies thus creating *de facto* plural societies all over the world... This new migration is remarkable not only because it is racialized but also because in many instances, within various ethnic immigrant groups, women have outnumbered men... The make-up of this migration is due in large measure to the structure of capital worldwide..." (1997:24). (See Appendix B for the full reference to this paper.)

Even more complex factors of discrimination and oppression then function to isolate the same minority groups. These combined forces have increased the morbidity associated with so-called "diseases of civilization" among minority citizens and heightened the mortality rates associated with chronic and infectious disease. Poverty and cultural difference often combine to form an essentially deadly combination for reasons that are now only partially understood. Culture and poverty affect health within each ethnic community, within every health care delivery setting, and within the lives of individual people whose well being is mediated by the health care system's ability to deal with *difference*.

Therefore, while the importance of the Collaborative Initiative on Racial and Ethnic Health is great now, it will be even more so in the future. The forces creating the challenges joined by the Collaborative Initiative are not likely to lessen in the near future. They are likely to increase. So, it is important to document how the Initiative began in order to track its long term progress.

Role of the First Meeting in Setting an Agenda for 1998
At the request of Veena Bahl, the ethnic health advisor for the UK Department of Health, the US Office of Minority Health helped to organize a conference on "Health Gain for Black and Minority Ethnic

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Communities," which was held September 16-18, 1997, in London, England. The meeting was designed to provide a forum for the discussion of minority health needs in the US and UK, to facilitate the exchange of information on minority health needs, and to develop an agenda for long-term collaboration. Approximately 150 people attended the conference. Workshops were held on the following three topics:

C   Ensuring access and quality of services for minority groups,
C   Developing primary care, and
C   Involving minority consumers in the delivery of services.

All of these topics found their way into the discussions of participants in both the 1997 and 1998 meetings. Quality of services was once again an important focus in 1998, as Members of the Work Groups explored the role of minority residents in monitoring their own health care services and assessing the services in light of cultural competence requirements. Primary care continued to be an important focus in 1998 because the absence of primary care services often has the most devastating, long-term impact on families in minority groups. "Basic health care"C an increasingly standard package of services provided by a primary care physician, physicians assistant, or nurse practitioner C and the right to it are often mentioned in 1998, as in 1997. Finally, one of the two Work Groups that met in 1998 focused intensely on the involvement of minorities as consumers in making decision about their own health care services, and in developing a presence and a "voice" to be heard in important policy making venues.

Commissioned Papers and Presentations for the 1997 Meeting
The Office of Minority Health commissioned five papers that were presented at the 1997 meeting in London, and revised later. These papers helped to stimulate discussion at the 1997 meeting and they also contributed to the development of the agenda for the 1998 meeting. The five papers, their authors and affiliations, are listed in the first section of Appendix B, Selected References. They are also cited throughout this report.

Model Inherent in the 1997 and 1998 Agendas
Participants at the 1997 conference identified the following five topics as priority areas for the future work of the Collaborative Initiative on Racial and Ethnic Health:

1.   Improving access to services
2.   Improving research on minority health
3.   Empowering minority consumers
4.   Improving data collection
5.   Enhancing leadership and organization in minority health.

Once again, all of these topics were mentioned and sometimes discussed at great length by Members of the two Work Groups at the 1998 meeting. Priority Area #1 in 1997, on "Improving access to services" was narrowed to "Develop Culturally Sensitive Access to Health Services" for Work Group A at the 1998 collaborative work group meeting. Priority Area #3 in 1997, on "Empowering minority consumers" ultimately gave rise to the focus of Work Group B, which met on strategies to "Develop Consumer-Grass Roots Voice/Voluntary Sectors" at the 1998 collaborative work group meeting.

The agenda that developed in 1997 and the agenda that was followed in 1998 clearly illustrate that the topics of greatest concern to the participants in the US/UK Collaborative Initiative form a consistent and integrated whole. All of the priority areas have important connections to each other. Together, the themes form an explanatory model that is often very useful in policy discussionsCespecially discussions focusing on education, information sharing, and developing a more solid knowledge base on minority health. Growth of the knowledge base on minority health has clear connections to community development, community empowerment, and organizational development (important topics for both Work Groups in 1998) because increased knowledge enables minority advocates to make persuasive arguments. "Knowledge" leads to "power and influence," which in turn lead to "better health care" in this model. Completing the circle, participants in both the 1997 and 1998 meetings addressed "Monitoring and Evaluation" of services by members of minority communities, themselves, so that further knowledge is generated, leading again to power, influence, and better health care. A special type of knowledge is developed when services are evaluated vis-a-vis established criteria for culturally competent services. Both Work Groups in 1998 voiced an awareness of the importance of developing methodologies for evaluating culturally competent services. It is an important theme for future exploration.

Synopsis of the First Report
The UK Department of Health published a report entitled "Health Gain for Black and Minority Ethnic Communities," on the "International Conference between the UK and the USA held 16/18 September 1997." This synopsis reviews some of the highlights of that report, which consists primarily of addresses by officials and experts to the participants at conference.

The report began with a "Welcome" by Secretary of State for Health, the Right Honorable Frank Dobson, and a "Response" by Deputy Secretary, US Department of Health and Human Services, The Honorable Kevin Thurm. Both officials summarized the central problem that brought the two Governments together. Secretary of State for Health Dobson (UK) found the common thread by noting that "In both our countries many people from black and ethnic minority communities are amongst the least healthy... we all know that people who are ill more often, also die sooner. And that's the ultimate inequality - there's nothing more unequal than the difference between life and death" (Department of Health 1998: 5).

In his response, Deputy Secretary of Health and Human Services Thurm (US) emphasized that disparities in health are "not simply a US or a UK problem. They are an international problem" (Department of Health 1998: 9). He explained that in the Department of Health and Human Services there has been "A complete and total change in the way in which we do business." He asked: "Are we creating a work force blessed with diversity and sensitive to the needs of minority populations? Are we supporting programs that target minority communities, programs that are culturally sensitive and appropriate and finally, and perhaps most importantly, are we holding ourselves accountable for results in measuring our successes by the only standard that matters, the health and well-being of every American?... I believe we are" (Department of Health 1998: 10). He went on to discuss programs in a

number of different agencies within the Department of Health and Human Services, consistent with the goals of the US/UK Collaborative Initiative.

Tessa Jowell MP, Minister for Public Health (UK), emphasized the diversity within racial and ethnic groups. She noted that "Not all minority and ethnic communities suffer the same patterns of health need. Our minority communities are not homogenous groups. Each group has its own distinct epidemiology and demography" (Department of Health 1998: 12). She reviewed important statistics on coronary heart disease, stroke, perinatal mortality, sickle cell disease, and cervical screening which illustrate the disparities in health profiles of racial and ethnic groups in comparison to national populations in England and Wales. Her examples focused on African groups from the Caribbean, on migrants from Pakistan, Bangladesh, India, and Somalia.

After remarks by top officials at the meeting, there were presentations on "Developments in Ethnic Health Policy." Veena Bahl, Adviser on Ethnic Minority Health provided "A UK View" and Dr. Clay Simpson, now former Deputy Assistant Secretary for Minority Health, presented "A US View." Together, their remarks illustrate some of the similarities and differences in the two governments' structures, policies, histories, and challenges. Both speakers discussed the frameworks and goals of their governments' policies on racial and ethnic health. Both speakers provided detailed examples of the efforts made by their respective agencies to improve access to health care, to hire more representative workforces, to disseminate information on minority health research, and to forge relationships both within government and with outside experts and organizations.

The next two presentations focused on "Ethnicity and Health - Opportunities for Health Gain." Professor R. Balarajan reviewed the status of minority health and opportunities for improvement in the UK. Dr. Reed Tuckson reviewed the same for US minority populations. Their presentations provided additional statistics to illustrate the disparities in racial and ethnic health and health care. The two speakers presented conceptual frameworks for understanding the origins of the differences in health status, and tackled some thorny research questions. They posed questions about the roles of community-based factors such as language, religion, and values, and services-based factors such as quality of care and cultural competence. Their presentations showed that "opportunities for health gain" come at many different levels and along many different avenues.

The remainder of the report focused on activities that took place on the second day of the conference: A Welcome by Dr. Jo Ivey Boufford was followed by summaries of the following workshops, in which presenters from the US and the UK provided perspectives on their respective Nations:
1. Developing ethnic health strategies and setting targets
2. Assessing ethnic health needs
3. Assuring access and the quality of services for black and minority ethnic groups
4. Developing primary care
5. Establishing healthy alliances and coalition building with private sector and voluntary ("not for profit") organizations

6.	Involving black and minority ethnic users in delivery of services and empowering communities
7.	Managing for health gain for black and minority ethnic communities - a general management view

For each of the workshops, presenters were listed and key themes were listed that emerged during discussion.

Concluding remarks were presented by Chief Medical Officer, Sir Kenneth Calman, who focused in part on the issue of leadership. He emphasized its importance in efforts to reduce the disparities of health status among racial and ethnic groups in the US and UK. Although leadership was mentioned by both Work Groups at the 1998 meeting, it remains an important topic for future, in-depth focus.

The work accomplished at the 1997 meeting went far in helping to define the purpose, objectives, agenda, and roles of Work Groups and Steering Committee that met at the 1998 meeting. Follow-up planning by a US/UK delegation focused on two topics: access to health care by racial and ethnic minority groups, and assisting groups in developing a grass roots voice and voluntary efforts in both the US and UK.

Section 4
Objectives, Agenda, and Steering Committee for the
Second Meeting of the Collaborative Initiative

Objectives

The purpose of the second meeting of the US/UK Collaborative Initiative on Racial and Ethnic Health was to identify a framework for a cooperative process and to identify future joint projects. Toward that end, the representatives at the meeting were assigned to two Work Groups: Work Group A on "Developing Culturally Sensitive Access to Health Services" and Work Group B, which met on strategies to "Develop Consumer-Grass Roots Voice/Voluntary Sectors." A third, separate unit was the Steering Committee, whose role was to provide oversight and advice, and to make recommendations on resources (see also, Executive Summary and Section 7).

Three different "Objectives Worksheets" were given to the Members of the two Work Groups and the Steering Committee. The Worksheets focused participants on the following general topics:
C   the purpose and objectives of the collaborative work group meeting
C   identifying priority joint projects for the US and UK
C   identifying resource support for priority projects (from government, academic and community organizations, and colleagues and organizations in existing partnerships)
C   additional, potential roles
C   roles of individual Members in following up on projects identified at the 1998 collaborative work group meeting
C   schedule, interim activities

Agenda

The Members of the Work Groups met for almost two days of intensive discussions, followed by a visit to the Office of Minority Health's Resource Center and a day of site visits to local community health organizations in the Washington, DC area. See Appendix C for the Agenda.

Steering Committee

The role of the Steering Committee was to provide oversight and advice. The Committee's function was to facilitate relationships between the Collaborative Initiative and the government hierarchies in the US and UK, and to assist in helping to find resources and develop partnerships. Members of the Steering Committee were assigned to one of the two main Work Groups, and sat in on their discussions.

The Members of the Steering Committee also met amongst themselves to discuss ways to fulfill their role. The following list summarizes a consensus on their potential activities for the future:
C   overseeing the Work Groups and disseminating their work through government and community channels;
C   supporting the incorporation of the Collaborative Initiative's work into policy making and program implementations;

C   sharing the activities and reports of the Collaborative Initiative with other government departments and agencies that are not concerned with health care *per se*; and

C   meeting in person and via teleconference to discuss the Collaborative Initiative's work and work products.

Sections 5 and 6 follow in the next pages. They provide an in-depth description of the ideas explored in the two Work Groups. Some of these ideas eventually made their way into recommendations presented to the Steering Committee. Others did not, although they remain potential agenda items for future meetings of the Collaborative Initiative.

The Steering Committee worked carefully with all of the recommendations of the two Work Groups. They selected some, refined others, and put yet others aside. Because the Steering Committee also had a fact-finding role in terms of resource development, Section 7 is devoted to that aspect of their work. It also incorporates some of the findings and opinions on resources as they developed in the discussions of the two Work Groups.

Section 5
Issues and Opportunities for Developing Culturally Sensitive Access to Health Services in the US and UK: Findings of Work Group A

The second meeting of the US/UK Collaborative Initiative on Racial and Ethnic Health, held September 23-25, 1998, involved the separate meeting of two Work Groups composed of Members from both the United States and the United Kingdom. The Members of both groups came from various offices and agencies of their respective governments. Full rosters of the Work Groups are in Appendix D.

In their own separate ways, the two Work Groups met to address the central purpose of the meetingСto establish a framework for the US/UK collaborative process and to identify joint projects. The Work Groups discussed essential but different aspects of health care for racial and ethnic sub-populations in the US and UK. The findings of the Work Group on Developing Culturally Sensitive Access to Health Care are reported here in Section 5. The findings of the Work Group on Developing Consumer and Grass Roots Voices and the Voluntary Sector, are reported in Section 6 of this report. The findings on the resources development by the Steering Committee, which had both fact-finding and oversight responsibilities, are reported in Section 7. The Sections on findings constitute the preliminary work of the Members of the two Work Groups that met during the second meeting of the Collaborative Initiative on Racial and Ethnic Health, September 23-24. The refinement of their work by the Steering Committee represents a later stage in the work of the Initiative.

The sections on the findings of the Work Groups have three basic components. First, each section describes a *Framework* that was developed by the group. The frameworks are composed of definitions, sets of values or principles, and/or a model that functions to support the values or principles. The Work Groups were careful to discuss and then define the words and terms that characterized their respective interest areas. The groups used somewhat different terminologies to describe the essential features of the frameworks that they recommended to the Steering Committee. The same terms are used in the Findings sections whenever possible, and parallels are drawn. The discussion of Frameworks goes far in fulfilling the first part of the purpose of the Initiative's meetingС to establish a framework for the US/UK collaborative process.

Second, the sections on findings address the main *Issues* identified by the Work Groups. Issues consist of questions, problems, and needs for which there are at least two (and often more) proposed solutions in the public arena. The essence of an issue is disagreement or difference. Otherwise, there would be no conflict between established health care practices and the culturally sensitive health care practices supported by the Initiative. There would be no difference between existing health profiles and the improved health profiles of racial and ethnic minorities targeted by the Collaborative Initiative. Without issues, there would be no need to develop grass roots voices. The Issues lay the foundation for identifying Opportunities for the Initiative.

Third, the sections on findings describe ***Opportunities***. They represent potential priority projects and selected strategies that were discussed in each Work Group. The identification and development of these project ideas goes far in fulfilling the second general purpose of the meeting of the US/UK Collaborative Initiative in 1998Cto identify future joint projects. However, it is important to note the discussion of potential projects by the Work Groups was not the same as selection of a priority project by the Steering Committee. The Work Groups addressed a wide variety of action projects, only some of which were targeted by the Steering Committee. The sections on Opportunities illustrate the range of thinking in the Work Groups and the potential range of influence and action of the Collaborative Initiative in the future, as it seeks to encourage changes in the health care of racial and ethnic minorities in the US and UK, so that health profiles improve.

Framework: Developing Culturally Sensitive Access to Health Services
Defining "Access." The Work Group on Developing Culturally Sensitive Access to Health Services began by defining "access" to health care, and what it means in the US and UK. The UK has a universal, national program designed to serve all who need it, the National Health Service (NHS). The US has no universal program, but it does have the Medicaid program for the poor and the Medicare program for the elderly. Members from both the US and the UK agreed that all of these national level programs have drawbacks that prevent many eligible individuals from using them, especially racial and ethnic minorities. The Members agreed that "access" meant more than simply "getting to the door." It means a willingness to seek health services and a certain comfort level when receiving them. The Members from the UK pointed out that some people come to the NHS, but then do not return because they are not comfortable. A Member from Scotland noted, "You may not see the next member of family, if the first member's needs were not met." The Members from the US pointed out that many people who have a Medicaid card still do not receive services. And, although Medicare is designed to provide universal health care for elderly, there are racial gaps in coverage for the 16 most commonly used procedures. Veterans health benefits, in spite of supposed equitable coverage, show dramatic racial differences in treatment received. Native Americans often have to travel great distances to receive any health care at all. After a discussion of the deficiencies in the systems in both the US and UK, the Members of the Work Group agreed that "people should get care close to home in a comfortable environment without concern about how to pay." That is the true meaning of "access."

To the extent that insurance helps individuals obtain health care in an acceptable manner, it is related to access. All Members agreed that "access" meant more than simply having insurance. The concept of "access" incorporates important aspects of the quantity and quality of services. Access to health care services for racial and ethnic minorities can become especially problematical when it involves specialized services, because the control of referrals to expensive specialists represents a major, cost-saving strategy for health care providers. In many cases, racial and ethnic minorities know less about how "to navigate the system," including all of the informal behaviors and words that encourage and enable service providers to refer them to needed specialists. Where health care providers are not trained to listen very carefully, language and cultural barriers can prevent the communication of needs and preferences, which, in turn, makes the meeting of treatment thresholds difficult and referral to specialists

less likely. Members from both the US and the UK pointed to the difficulties that racial and ethnic minorities have in interacting with "gatekeepers" at health care facilities. They are less likely to receive appropriate initial care, needed tests, or follow-up because of the lack of cultural or racial sensitivity of all types of gatekeepers.

Establishing Principles. The Framework developed by Members of the Work Group included a set of two important principles that guide any and all efforts to ensure culturally sensitive access to health care services. Succinctly stated, these principles are:
1.   Service provision in any community must be able to meet the cultural, religious, social, linguistic, and health requirements of the community.
2.   Staff training and development should include all staff (from physicians to administrative staff). Staff must be informed of the requirements of the ethnic community being served; and when physicians accept an assignment, they must become familiar with the community's history.

Issues: Developing Culturally Sensitive Access to Health Services

The Members of the Work Group addressed three issues on which there are widely varying points of view in the US and UK: (1) training the health care workforce in cultural competence; (2) incorporating traditional medicine into health care protocols; and (3) monitoring, evaluating, and linking cultural competence to outcomes. These issues form the substance of heated debate in today's government offices, medical school senates, and among health care services research professionals. In spite of the fact that on the surface they appear to be very rational and beneficent concepts, their implementation costs money, changes ingrained notions, and reorganizes standard protocols. Many people are not yet convinced that government and higher education should spend the money and make the effort to accommodate racial and ethnic minorities in such institutionalized waysCeven though they acknowledge that minority health profiles indicate unmet challenges. Needless to say, the Members of the Work Group strongly supported these and other efforts to achieve culturally sensitive access to health care.

Issue: Training the Health Care Workforce. Members of the Work Group discussed the issues of training and retraining the health care workforce in the US and UK, so that practitioners will be more sensitive to cultural differences during the delivery of health care services. As part of the same general issue, Members discussed the need to train sufficient numbers of minority physicians and to provide incentives for them to practice in communities where large numbers of racial and ethnic minorities reside. Minority physicians provide an important link to specialists who may be accessed outside the community. They serve as leaders to advocate for health care reform in the community (a topic addressed extensively by the Work Group on Developing Grass Roots Voices).

The Members discussed a number of different programs that are needed to train and retrain professional health care workers in cultural sensitivity or "cultural competence." Programs include special courses on culture and gender sensitivity in medical schools and special short courses for practicing physicians. Baines, in his 1997 presentation at the first meeting of the Collaborative Initiative, emphasized that physicians in the US and UK will be called upon to treat people with an increasingly large variety of

cultures, and that even within the general categories, for example, of Asians and Hispanics, there is wide variation from subgroup to subgroup. Therefore, there is a need to train physicians in the general set of skills and attitudes that come under the rubric of "cultural competence" and that facilitate the treatment of all types of racial and ethnic minorities. In this same vein, Hayes-Bautista, in his presentation at the same 1997 meeting, noted that there is "no single 'minority' norm" and never has been. He emphasized that as our knowledge of population-based medicine increases, we will see that different racial and ethnic minority groups and sub-groups are characterized by different health profiles—different chronic and infectious diseases, different infant mortality and crude death rates, and different rates of hospital utilization. There is no single health profile for the variety of minority groups that physicians will be required to interact with effectively, although there will be important knowledge that arises from the collection of accurate health data on racial and ethnic population groups. (See Appendix B for the full references to these papers.)

Several Members reminded the Work Group that race and ethnicity are only one component of culture; others include geography and socioeconomic status. Therefore, programs to encourage and facilitate appropriate health care of minority individuals in remote, rural areas are also badly needed. Cultural sensitivity is often needed among those groups because poverty and isolation tend to foster the use of traditional remedies and the non-use of effective modern services.

In spite of universal health care in the UK, racial and ethnic minorities withdraw from the health system because of its lack of cultural sensitivity. Areas of poverty have lower health coverage. It is difficult to recruit trained professionals and ensure quality service in those areas. The primary care service that minorities are most likely to use is the least-audited service in the UK. There is a lack of female doctors, convenient transportation, and range of office hours. Health care providers all to often show a lack of cultural sensitivity and awareness, and fail to adapt. In her 1997 presentation, Marcia Bayne Smith reviews the histories of the development of primary care in the US and UK, and emphasizes that both countries are aware of its importance: "Currently, both nations are now fully aware that further development and implementation of primary care is contingent on... addressing the racial and ethnic health disparities each of them face, and if they are to do so they must address the specific health needs of their various racial/ethnic populations." According to Smith, one of the most important themes in the development of primary care is community involvement: "It appears that there is considerable convergence in both the U.S. and the U.K. in terms of not only the components of primary care but also with regard to the development of systems that invite and encourage community participation..." However, she cautions that this theme can be problematic: "Community participation mean different things to different people. It can range from a simple, less powerful patient advisory board to a more powerful, consumer majority, governing board..." (See Appendix B for the full reference to Smith's paper.)

The development of primary care that targets racial and ethnic minorities will require that health care providers be trained in techniques for communicating with a wide variety of groups. Cultural competence" is a teachable strategy that ameliorates cross-cultural misunderstanding. It has three

components, "purpose, attitude, and skills," according to Chen, in a recent issue of *Closing the Gap*, published by the US Office of Minority Health. He writes, "The purpose of cultural competence is to achieve improved health outcomes. Attitude is a willingness to adapt oneself to others' needs. And skills are those competencies or behaviors that exemplify correctness of technique in interactions between the professional and the patient" (1998:6).

Members of the Work Group added that language and manner of acting (bearing) are also important. They emphasized sensitivity to religious and dietary habits of specific groups and suggested having prayer facilities, appropriate diets, and convenient visiting times in hospitals, as needed by members of specific racial and ethnic minorities. The Members also spoke about building a sense of trust and providing information to patients before attempting burdensome and administrative tasks like determining eligibility and enrolling patients for services.

Issue: Incorporating Traditional Medicine. The Work Group Members agreed that gaining access to appropriate health care services often involves cross-cultural misunderstanding. To remedy this, several Members mentioned the possibility of incorporating traditional or non-Western medicine into normal health care practice in the US and UK. To some extent, this has already been accomplished in a small number of health care facilities. For example, some hospital obstetrical units accommodate a "squatting" position for child birth if the woman is from a distant land and is accustomed to this position for giving birth. Other hospitals that serve large numbers of Native Americans have "healing rooms." However, there are no generally acceptable guidelines or protocols for the large-scale introduction of traditional medicine into Western health care for the purpose of improving access for racial and ethnic minorities. Medical schools are slow to educate their students in alternative approaches for minority groups, and physicians in the US and UK are usually not trained to value combination approaches. The Members of the Work Group concluded that all patients should be treated with dignity, respect, privacy, and compassion, and that "Everyone has a right to understand and be understood." Developing culturally sensitive access to health care was seen as part of those basic rights.

Issue: Monitoring, Evaluating, and Linking Cultural Competence to Outcomes. Developing culturally sensitive access to health care requires monitoring and evaluation in order to demonstrate that culturally competent health care fosters improved outcomes among racial and ethnic minorities. Without the data to prove that culturally sensitive services work better, proof of the efficacy of culturally competent services remains anecdotal. Of primary importance is the collection of data on the racial and ethnic identity of patients. Surprisingly, this information is not captured regularly and well.

The Members of the Work Group emphasized the importance of data collection in health care facilities serving large numbers of racial and ethnic minorities, and of encouraging physicians and managers at these facilities to support data collection and analysis so that access to health care can be evaluated. The Members emphasized that local communities should be involved in evaluating the adequacy and appropriateness of all health care services. They must be brought into the planning process.

Managed care is one area in which the US Office of Minority Health (OMH) is examining health care to determine if culturally appropriate services are being delivered. OMH is trying to determine the importance of cultural and linguistic competence in quality assurance, and the linkage between cultural competence, quality assurance, and patient outcomes. Some issues for concern are already apparent. For example, Marcia Bayne Smith, in her presentation at the 1997 meeting of the Collaborative Initiative, noted that "a critical issue is that managed care is only available to those who are insured... racial and ethnic minorities... are disproportionately found amongst the poor and the unemployed or in low income jobs, which means they tend in greater numbers to be uninsured, underinsured, and in worse health than the mainstream population."

Later in her presentation, Smith acknowledges the complexities introduced by the interplay between cost and quality of care in the US and UK, by noting that "Both nations are adapting different versions of managed care market forces in order to hold health care costs down." One way in which some States in the US are attempting to control costs and improve access is through Medicaid managed care programs. Trevino, in his 1997 presentation cautions that "While it is clear that Medicaid, the nation's major public program designed to increase access to health care for poor persons is increasingly moving toward managed care, it is less clear how ethnic/racial minorities who comprise a major segment of the recipients of this program will be impacted by this trend." (See Appendix B for full references to these presentations.)

Opportunities: Developing Culturally Sensitive Access to Health Services
This section describes four broad opportunities for future collaboration between the US and UK:
(1) discovering Best Practices, (2) assessing minority programs according to broad standards (vis-a-vis standard health care package definitions), (3) addressing barriers to access at every level, and (4) changing national health care cultures. If pursued, these opportunities would constitute a comprehensive and worthwhile set of future joint projects for the Collaborative Initiative on Racial and Ethnic Health.

Opportunity: Discovering Best Practices. Members of the Work Group were in unanimous agreement that the concepts of "Lessons Learned and Best Practices" cover a wide range of initiatives at all levels and in many sectors of society (government, health care, education, community organization, voluntary and charitable sectors, and religion). The most important question to ask when identifying a Lesson Learned or a Best Practice is about its *outcome*: Does the Initiative encourage culturally sensitive health care services and thereby improve health outcomes for racial and ethnic minorities? The "Best Practice" might be a local consortium, a course curriculum, a lobbying technique, a strategy for forging consensus in multi-ethnic communities, or the establishment of an entire agency in national government.

Essential to the discovery of Lessons Learned and Best Practices is information sharing. Toward this end, the US Office of Minority Health publishes *Closing the Gap* and maintains an information network among 10 regional health coordinators and 29 State Offices of Minority Health. The Department of Health and Human Services has a steering committee for Presidential Initiatives, with contacts in

operational and staff divisions. OMH maintains a Resource Center with a toll-free number. Through these linkages, Lessons Learned and Best Practices can be disseminated efficiently. OMH can provide local government offices with information quickly, so that communities can be reached the same day. There are a large number of minority State legislators and OMH is encouraging them to use its Resource Center and become linked to its network of resources.

The UK maintains a learning network throughout its eight health regions. The network has supported a range of efforts, including programs to encourage local ownership, learning exercises to communicate accomplishments, and provision of a national learning setCall of which help to prevent the re-invention of strategies already developed. The network provides examples that can be tailored to the specific needs of communities. For the last three years, the UK has delegated responsibility so that employers are able to specify how staff are trained. Scotland's volunteering initiative is designed to support the National Health Service. It now invites ethnic minority women to discuss health issues and share information more broadly and to serve as important links to their communities.

The concept of a Best Practice has the connotation of "a model" or "a good example" at even the highest levels of organization. For example, the Members of the Work Group discussed the background, impact, and role of the US Centers of Excellence as a Best Practice. The Centers of Excellence program is supported by the Office of Minority Health. It was designed to encourage the recruitment and retention of minority students in health professions. This type of Best Practice provides information, opportunity, and outreach. Other Members of the Work Group pointed to the "Opening Doors" program funded by Robert Wood Johnson as a Best Practice. It funds primary care programs that use both Western and traditional medicine in health care delivery.

Federal agencies in the US government are now compiling Best Practices related to cultural competence. OMH has a number of internal committees addressing cultural competence research projects, and HRSA has a compendium of cultural competency projects. OMH's study of managed care [noted above in the section on *"Monitoring, Evaluating, and Linking Cultural Competence to Outcomes"*] is focusing on translation/interpreter services, the provider/staff pool, supportive plans and policies at the institutional level, and training (including sensitivity to culture and values).

In a summary discussion, the Members of the Work Group posed several important questions for future joint projects. They asked:
$	How do you determine what a Best Practice is? What are the guidelines?
$	What are medical schools and organizations of health professionals doing to incorporate Best Practices into their curriculums and short courses?
$	What occurs in practice settings to provide a more integrated approach to traditional and Western medicine? How can examples of Best Practices be collected?
All Members agreed that a great deal of work must be done to establish standards and terminologies to identify Best Practices, to gather information from exemplary projects, and then to disseminate information on Best Practices to those who need them most.

Opportunity: Assessing Minority Programs According to Broad Standards. In an effort to develop meaningful yardsticks for the health care of racial and ethnic minorities, the Members of the Work Group explored the meaning of "access to good health care" by defining what "good health care" is more broadly. The goal of the Work Group was to set a vision of what constitutes health for everyone and then apply that definition to different populations.

The Members agreed that assessing health care depends on the analysis of data on health outcomes and on the perceptions of communities and individuals. However, it also depends on meeting certain basic, minimum standards. For guidance, the Work Group referred to the definitions of "health," "access," and "quality" in *Healthy People 2000* and *Healthy People 2010 Objectives: Draft for Public Comment*: "From an individual perspective healthy life means a full range of functional capacity at each life stage from infancy through old age, allowing one the ability to enter into satisfying relationships with others to work and to play. From a national perspective healthy life means a vital creative, and productive citizenry contributing to thriving communities and a thriving nation... Access has been defined by the Institute of Medicine [IOM] as the 'the timely use of personal health services to achieve the best possible health outcomes...' IOM defines quality as 'the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.' "

The Members of the Work Group developed parameters for four, basic health care packages that they believed sufficiently broad to satisfy the *Healthy People 2000/2010* definitions. They agreed that these packages would provide an excellent benchmark for assessing health care programs for racial and ethnic minorities. Essentially, they constitute a comprehensive planning tool that defines basic health care services regardless of the ability to pay. The Members emphasized that local communities must be involved in tailoring the health care packages for their populations.

$ Ages 0-18. Comprehensive physical examinations (including eyes, teeth, ears, and postnatal checkup); immediate access to care; assessments (including diet, exercise, housing, education, parental employment, and mental health); immunizations; health education (specifically sex education and violence prevention as part of school curriculums); and services to avoid unwanted pregnancies.

$ Ages 19-45. Comprehensive, regular physical examinations; prenatal care; health promotion and education for the reduction of risk for chronic diseases; work site health promotion; women's health; strategies to limit occupational stress exposures; and violence prevention.

$ Ages 46 and upCYearly screening, health promotion and education, diet and exercise, assessment and limits on occupational health exposure, and immediate access to health care.

$ ElderlyCHealth promotion and education; diet and exercise; assessment and limits on occupational health exposure; immediate access to health care; regular checkups; comprehensive assessments (transportation, housing, medical equipment needs, social,and physical); rehabilitative services and facilities; facilities for continuing care; health education; and pre-retirement education.

Opportunity: Addressing Barriers to Access at Every Level. The Members of the Work Group discussed the meaning of "access to health care" by addressing known barriers to access. They agreed that there are different types of barriers that function at different levels and in different ways: *cultural barriers* (differences between female patients and male doctors, the roles of nutrition and exercise, traditional medicine in health maintenance, and understanding the predictors of health problems); *financial barriers* (poverty, lack of health insurance, high costs of health care, distance to treatment, and the exclusion of minority providers); and *political barriers* (for example, the US has Federal, State, and county policies; and the issue of immigration). The Work Group Members agreed that a close partnership with governmental bodies is required to overcome all of these barriers to good health care. They agreed that the principles underlying the barriers to access are the same in the US and UK, although the mechanisms of action may differ. The Members believed strongly in cooperation between the two Nations with the goal of better understanding how and why barriers operate to prevent racial and ethnic minorities from obtaining the best health care possible.

It is important to note that culture, socioeconomic status, and targeted program initiatives C which can all impact access to health care C vary independently and exert both separate and combined effects on the health status of racial and ethnic minority groups. Hayes-Bautista, in his paper presented at the 1997 meeting of the Collaborative Initiative, pointed out that low education and low income (variables signaling low socioeconomic status) do not automatically lead to poor health in a minority group. He describes the "Latino epidemiological paradox" in which US Hispanics, who have, in general, low income and educational levels, also have the low hospital utilization and low death rates. He notes that the health profile of US Hispanics cannot be explained by the major, theoretical health models used since the 1960s: racial group genetics, culture of poverty, urban underclass, and traditional culture models. Hayes-Bautista believes that new theoretical models are needed that better capture the dynamics of minority health. Trevino, in his 1997 presentation, agrees. He reports that "An explanatory model of health care access for minority populations has not been proposed in the literature." The models called for by these authors will hopefully take into account the full complexity of the effects that socioeconomic status and culture have on health.   (See Appendix B for the full references to these papers.)

Opportunity: Changing National Health Care Cultures. The Members of the Work Group agreed that it is important to change certain aspects of the national health care cultures in the US and UK, so that there is a shared commitment to providing adequate health care for all citizens. The Members acknowledged that the systems in the US and UK are different in their approach to health care as a finite resource. Nevertheless, changes in attitudes (for example, about "maintaining wellness" as opposed to "treating disease"), politics, and law are necessary to ensure an equitable distribution of the responsibility for the health care of racial and ethnic minorities. Their health problems are not isolated; they impact both the physical well being and the financial resources of all individuals through the presence or absence of government action, the effectiveness or ineffectiveness of community prevention programs, and the level of mobilization of volunteers and other local resources. There was a strong

sense among Members of the Work Group that "moral arguments don't work in the US," and that it is necessary to point out to government, to private health care providers and insurance companies, and to medical schools exactly how they stand to benefit from the improved health care and health profiles of racial and ethnic minorities.

Opportunity: Potential Joint US/UK Projects for the Coming Year. The Members of the Work Group identified two potential projects to sustain the US/UK Collaborative Initiative, and decided to submit them to the Steering Committee for their consideration. The two projects involve (1) assisting the ministers of health in both countries in promoting their long-term agendas, and (2) developing a learning network for sharing Best Practices.

C   *Assisting the Ministers of Health in Both Countries in Promoting Their Long-Term Agendas*. The Work Group recommended that (1) the Steering Committee identify one or two objectives from the US's *Healthy People 2000/2010* and the UK's *Our Healthy Nation* that are focused on improving racial and ethnic minority health, and (2) the Initiative work with respective governments to develop collaborative demonstration projects to reduce disparities in the health profiles of their minority populations. The health problems of minority sub-populations pose a risk to society at large. Both countries have planning documents that address inequalities in health. This is an opportunity to identify priority issues in both countries and coordinate projects. The Work Group recommended that each government allocate resources for a comparative study of the systems for fostering desired health outcomes.

C   *Developing a Learning Network for Sharing Best Practices*. The Work Group recommended that the Steering Committee support the goal of developing a learning network for sharing Best Practices. Objectives would include identifying experts for a US/UK collaborative group of health disparities; linking groups with common interests; developing and disseminating Lessons Learned and Best Practices; and building a communications infrastructure (e-mail, web page, satellite, video conference). The Work Group recommended a set of milestones for accomplishment of these activities in the ensuing year. The resources to build the communication system would come from the US and UK administrative budgets.

The Work Group developed a timetable focused on these two efforts, and presented it to the Steering Committee.

Section 6
Issues and Opportunities for Developing Consumer-Grass Roots
Voice/Voluntary Sectors in the US and UK: Findings of Work Group B

The second meeting of the US/UK Collaborative Initiative on Racial and Ethnic Health, held September 23-25, 1998, involved the separate meeting of two Work Groups composed of Members from both the United States and the United Kingdom. Section 6 provides a summary of the findings of the Work Group on Developing Consumer-Grass Roots Voices and the Voluntary Sectors in the US and UK. Findings of the Work Group on Developing Culturally Sensitive Access to Health Care, are summarized in Section 5 of this report. Members of both groups came from various offices and agencies of their respective governments. Full rosters of the Work Groups are in Appendix D.

Both Work Groups met to address the central purpose of the meeting**C**to establish a framework for the US/UK collaborative process and to identify joint projects. In their own ways, both Work Groups addressed important aspects of the health care of racial and ethnic minorities. The findings of the Work Group on Developing Consumer-Grass Roots Voices and Voluntary Sectors are organized with the same components as the findings of the Work Group on Developing Culturally Sensitive Access to Health Care: Framework, Issues, and Opportunities. As in the Work Group on Developing Culturally Sensitive Access to Health Care, ideas ranged widely on the most appropriate framework for the US/UK Collaborative Initiative, the central issues, and potential joint projects for the future. It is important to note that not all of the ideas that developed in the Work Group on Developing Consumer-Grass Roots Voice/Voluntary Sectors in the US and UK were presented to the Steering Committee. However, the findings of the Work Group provide a good overview of the broad strategies and mechanisms for community and organizational development that facilitate the improvement of health care for local groups and sub-populations. The following material summarizes the framework, issues, and opportunities available for increasing the role and voice of racial and ethnic minorities in policy discussions at every level of government.

Framework
Asking the Right Questions. The Members of the Work Group on Consumer-Grass Roots Voices and Voluntary Sectors began to develop their Framework by first reviewing a focused set the questions to guide their work. They asked:
C   What is meant by developing a consumer-grass roots voice? How is it related to community development and to organizational development?
C   What are some of the factors that enable and encourage a community to have a voice in deciding how health care will be delivered to them? What are the barriers?
C   What roles do the grass roots and community organizations play now and how can they be built upon to improve minority health care?
C   Who is in the voluntary sectors? What kind of people and organizations?

C   Where do local communities seek position? Where do they want to be and how can we help them get there? To what extent is government is committed to creating a voice that will challenge it?

C   What can the US and UK collaborate upon so that racial and ethnic minorities will better draw upon the strengths inherent in grass roots groups and voluntary organizations, and thereby improve the health profiles of their communities?

Establishing Core Values. The Members of the Work Group acknowledged that the questions they asked can be answered in a variety of ways. Therefore, they agreed that it was important to establish certain core values to guide the development of answers to the questions they posed. The core values that they decided upon are the following:

C   *Being inclusive*: Making sure that all voices in each community are recognized and heard, including the groups that the Collaborative Initiative now knows of and those groups that are currently unknown.

C   *Assisting people with their agendas*: Helping groups pursue their own agendas, not setting agendas for them or even defining "health" for them. Avoiding a "top-down" mentality and engendering a "grass roots" approach to problem solving.

C   *Developing skills and resources*: Providing information, training, technical assistance, technology transfer, materials development, and organizational management that help groups gain or use their voice in setting their own standards for health care delivery.

C   *Fighting stereotypes and exclusion*: Helping groups to avoid stereotypes of other groups and helping them to resist others' stereotypes and exclusive policies so that they can receive the best possible health care.

C   *Working with groups from an assets-based perspective, not a problem-based perspective*: Appreciating the skills that groups already have and starting with those, rather than focusing on presumed deficiencies. Working with groups to help them avoid being scapegoated, i.e., a "blaming the victim" mentality in which their "shortcomings" are oversimplified, overgeneralized, and overblown.

C   *Resolving conflict*: Helping groups to avoid the assumption of "limited good" and to adopt a perspective in which they work together for the greater good of the community. Helping groups to avoid competition for limited resources and to value working together to gain greater resources and opportunities.

C   *Protecting local cultures*: Making sure that community values remain intact during intervention efforts, and effectively using the skills, capacities, leadership, and organization that already exist in the community.

C   *Keeping an "eye on the ball"*: Helping groups to focus on the ultimate outcomes of their effortsCimproving health in the communities in which they reside.

Developing a Model. The Work Group developed a diagram illustrating the two-directional influences that organizational development, community development, and individual development have on each other. The Members agreed that technical assistance to local and national groups required a full

understanding of the routes of communication, influence, and action that were inherent in their model. They also agreed that these routes of information and action had both similarities and differences in the US and UK. Therefore, the Members sought to establish some common ground by stating clearly how they would work with the model in their respective countries. They agreed to identify Lessons Learned and Best Practices from each country. They agreed to work with groups that naturally emerge, rather than trying to encourage development of new groups. They agreed that they would work toward replicating Best Practices in the future, primarily through technical assistance to racial and ethnic minority groups that would assist them in gaining a position "at the table" where health service issues are discussed and giving them voice in public policy debates on health care issues.

Issues

The Members of the Work Group Developing Consumer-Grass Roots Voices and Voluntary Sectors addressed four issues on which there are widely varying points of view in the US and UK: (1) nomenclatures for addressing and collecting data on racial and ethnic minority groups; (2) the concept of mainstreaming; (3) the nature of the voluntary sector; and (4) institutionalizing advocacy training. All of these issues impact directly any and all efforts to develop consumer-grass roots voices among racial and ethnic minorities. The resolution of these issues has implications for program development at the national and local levels. In addition, the Members of the Work Group recognized a fifth issue area that in many ways determines the course of that resolution: (5) research. Their interest in research wove its way into all of their discussions and reflected their general interest in determining "what is known" and "what is not known" about the relationships among race, ethnicity, health, and the delivery of health care services. Research issues are somewhat different from general policy issues because their political and scientific components can be separated more clearly and the scientific components can be investigated with replicable, objective, empirical methods.

Issue: Nomenclatures for Racial and Ethnic Minority Groups. The Members of the Work Group discussed the terms that are in common usage to describe racial and ethnic minority groups, and which could be used to identify groups that need technical assistance in developing grass roots voices. The Members acknowledged that while the issue of nomenclatures might seem to be simple on the surface, it is extremely complex because the names that groups use to describe themselves are not always the names that government programs use. The reconciliation of self-identification and program-identification is now an important area of work in both the US and the UK. The terms used are important in program implementation because laws frequently refer to types of individuals and often define their right to health care very specifically. And, both the names and the laws often change.

Members from the UK listed terms such as "black and minority groups, immigrants, ethnic groups, refugees, and asylum seekers." They noted that the term Ablack@ in the UK has been used as a generic term for all minority groups, but the more accepted phrase now is Ablack and minority ethnic groups,@ which encompasses everyone from Greek to Chinese people. AImmigrants@ are assumed to be returning to their home countries at some point. "Refugees and asylum seekers" have rights of abode in Britain. "Immigrants" and "Asylum seekers" must pay for health care services. In the UK, there is now

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a movement away from the use of the term Ablack@ because it has negative connotations concerning socioeconomic status. Members of the Work Group from the UK also pointed out that some black people in the UK are defined politically as white and that the framework needs to be able to accommodate self-definition.

Members from the US reported that at least three class strata exist within the four major ethnic groups (i.e., black, Latino, Asian, and white). They noted that issues of access to health care often cut across classes. They pointed out important differences between the US and UK systems. In the US, "Asian" can refer to a number of different groups, including people from Southeast Asia (Vietnam, Cambodia, Thailand, etc.) or South Asia (India, Pakistan, etc.), although in the UK, the term AAsian@ refers most often to people from India, Pakistan, Bangladesh, Sri Lanka, and Nepal. The system of nomenclature in the US, as in the UK, has historical roots and is constantly changing. The Members of the Work Group from the US pointed out that throughout many part of the South, Midwest, and Northeast, access to health care is limited in part because of notions left over from slavery. In the US, migrant workers of all ethnicities are treated as "minorities."

The Work Group Members agreed that nomenclatures for racial and ethnic minority groups should rely primarily on self-designation. The designation of group names remains an important issue that the Work Group should focus upon, because of the implications for access to health care in both the US and UK.

Issue: The Concept of Mainstreaming. The Members of the Work Group acknowledged that the concept of "mainstreaming" has different connotations in the US and the UK. In the UK, it means folding into the National Health Service itself the services for minority populations that duplicate those of the NHS. The goal in the UK is not to have special services for various populations but to have services for specific populations included in the regular package of health care. The Members of the Work Group from the UK pointed out that a fundamental right to health care exists in the UK that does not exist in the US.

In the US, the parallel issue of "mainstreaming" is not about access but about how services are delivered; it is more a matter of cultural competence. For example, the HIV/AIDS community in the US focuses on Aparity, inclusion, and representation@ rather than on Amainstreaming,@ but the terms basically refer to the same underlying concept.   In the US, Amainstreaming@ has negative connotations among minorities because standard services will not take into account their special needs. For racial and ethnic minorities in the US, "mainstreaming" means losing their special identity and their claim to culturally sensitive services.

Issue: The Nature of the Voluntary Sector.   An important part of the Work Group's task was to address the potential roles of the voluntary sector in improving health care for racial and ethnic minorities. However, it was first necessary for the Work Group to consider the exact nature of the voluntary sectors in the US and UK, and their relationships to local communities and national governments. Without a full understanding of the relative positions of the voluntary sectors in the US

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and UK, it was not possible to make recommendations concerning their role in improving minority health. The relative power positions of the voluntary sectors in the two Nations impact strongly their ability to advocate for change.

There are major differences between the UK and the US in the functioning of their voluntary sectors. In the UK, the relationship between the voluntary sector and national, government agencies is not one of partnership. In fact, it is often extremely unequal. In UK, the voluntary sector is not freestanding. It cannot advocate because it is constantly seeking financial support from the government agencies that fund it. Voluntary agencies are in a position of competition, not collaboration, so it is difficult for them to engage in collaborative initiatives. In the UK, large businesses that are owned by ethnic minorities are using money to leverage access to politicians, but the grass roots groups do not currently have much influence. The Work Group Members agreed that helping people understand the established bureaucratic system in the UK can help get them to the table and help them establish a voice in national policy making.

In summary, a strong minority group structure does not exist in the UK. Therefore, before groups can influence decision makers they must build a role so that they can have a voice. Toward that end, the Work Group recommended bringing health professionals into the voluntary sector and providing support for them so that they can better understand how communities work. The Members agreed that integrating health professionals into the voluntary sector was an important strategy to empower racial and ethnic minorities to advocate for themselves.

Issue: Institutionalizing Advocacy Training. The Members of the Work Group from the US and the UK addressed an important issue for both government and higher education in their respective NationsCthe institutionalization of advocacy. At the present, there is disagreement over exactly how much government and higher education (especially medical schools) should support advocacy training. From the perspective of racial and ethnic minorities, it is beneficial to have government leaders and managers, as well as highly skilled health care professionals, well trained in the techniques of advocacyCespecially if they are members of racial and ethnic groups. Because this is the subject of current debate, the Work Group agreed that there is a need: (1) to examine health care advocacy roles in the community and at the national level, (2) to examine the role of law schools and lawyers (who have a stronger tradition of advocacy in the US than the UK), (3) to examine university and institutional models (especially in medical schools) to train people in advocacy, and (4) to create a university or other institutional training course for health care advocates. At the national level, professionals would learn the techniques of advocacy to effect change in government policy making. At the community level, local leaders would get training and certification so that they could better run advocacy organizations.

The institutionalization of advocacy training occurs to some extent as a normal part of the training of minority physicians and other health care providers. By virtue of their advanced education, minority health care professionals increase to some extent their ability to access decision makers at the national and local levels. In his presentation at the 1997 meeting of the Collaborative Initiative, Baines describes

a number of Federal agencies and programs that have been instrumental in increasing the number of minority individuals going into the health professions, among them the National Institutes of Health, the Health Careers Opportunity Program, and the National Health Service Corp. He notes, "As minorities are more likely to provide care for the poor and minority populations and be more culturally sensitive, a number of programs have tried to increase the number of minorities going into health professions... affirmative action went a long way in increasing the number of minority health professionals. Many fear that without it, ground will be lost." (See Appendix B for the full reference to his paper.)

Issue: Research. The Work Group Members agreed on three immediate action steps that reflect their interest in research on race, ethnicity, health, and health care services. They agreed that they should support:

1.   *Establishing "what is known"*: Gathering and disseminating information on the health profiles of racial and ethnic minority communities and sub-populations.
2.   *Influencing research on "what is not known"*: Helping community groups to gain a greater voice in setting research priorities on racial and ethnic health.
3.   *Supporting work force training*: Fostering the empowerment of community groups and sub-populations by emphasizing the need to train sufficient numbers of health professionals from racial and ethnic minority groups, and encouraging their leadership in the community.

Actions steps 1 and 2 are clearly related to the goals of research. Action step 3 is also related, because the training of minority scientists to conduct research on race, ethnicity, and health will influence how the research is conducted and which research questions are asked. There is a strong and important connection between work force training and the development of research.

The interest of the Work Group Members in research followed directly from several presentations at the first meeting of the Collaborative Initiative in 1997 (see Appendix B for the full references to these presentations.) While there was no specific Work Group assigned to research issues in 1998, both Work Groups A and B explored a variety of research issues, and research remains an important, potential focus of a work group at some future meeting of the Collaborative Initiative. David Hayes-Bautista, in his 1997 presentation on "Research and Development Issues in Minority Health," provided a good summary of the advantageous and disadvantageous aspects of American research on race and ethnicity. Hayes-Bautista pointed out that the "United States is one of the few industrialized countries to maintain detailed records by racial category. This practice was begun in the very first census (1970)..." The United Kingdom did not begin collection of data on ethnicity until the 1991 Census of England and on ethnicity and health until the 1991 Health Survey of England (Williams 1998b:5).

Both Hayes-Bautista and David Williams, in his 1997 presentation on "The Monitoring of Racial/Ethnic Status in the United States: Data Quality Issues," described the enormous problems inherent to categorizations of race and ethnicity in the US, including the following: incomplete data, especially for Hispanics; sources of bias in the recording race in vital statistics records; undercounting racial groups and the consequent inflation of rates of disease conditions; unrepresentative small studies that are

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generalized to entire populations; and the reliability of self-reports on race, which tend to change for individual respondents even over short periods of time.

In their 1997 presentations, Hayes-Bautista and Williams went on to describe problems with previously used models of the relationship between race and ethnicity, and health. They critiqued the following:

C   *race-specific disease models*, which apply to a very small number of disease conditions (like sickle cell anemia) and which tend to obscure the fact that most diseases are the product of behavior and familial genetics;

C   *structural risk factor models (SES or socioeconomic status models)*Cin which education, income and access to care are the main determinants of health statusCbut, which fail to completely explain health status when these variables are controlled and suggest an independent for variables of "racism" or "discrimination"; Williams believes that "racism is causally prior to SES and exerts its most profound impact by transforming SES such that an equivalent value on a traditional SES measure represents important differences in social and economic circumstances for persons belonging to different racial groups" (see also Williams, Lavizzo-Mourey, and Warren 1994).

C   *folk culture models* and *urban underclass models*, which are related to socioeconomic models, but focus on socio-psychological factors in "health-harming behavior," and which fail to hold up in the analysis of all types of rural and urban populationsCnot surprisingly since they are based on isolated, local studies of small numbers of people; and

C   *models of "traditional" and "modern" cultures*, in which fatalism, parochialism, and passivity are seen to be related to poor health and lack of modern health-seeking behavior among "traditional" people when they are contrasted in an overly simplistic way to active, rational, and scientific "modern" people.

All of the presentations at the first meeting of the Collaborative Initiative in 1997 (by Baines, Chen, Hayes-Bautista, Smith, Trevino, and Williams) acknowledged difficulties in past research efforts, and they all helped to define a future research agenda and a new approach for research on race and ethnicity, and health. Among the most important points they made about future research studies were the following:

C   An "Anglo" profile is no longer the norm, primarily because of the increasing variety of racial and ethnic groups in the United States, because of accelerating rates of intermarriage of these individuals, and because by around 2055 whites will no longer be the "majority," but a minority.

C   If "basic demographic data" are to be collected on race and ethnicityCand there are many problems with the rationale for this activity because of the inexact nature of both "race" and "ethnicity" as biological and social constructsCthen there is a great need to implement OMB Directive 15 fully and uniformly throughout the US government; at the present time different agencies are collecting different data and most of them do not all collect needed data on sub-groups within Asian and Hispanic populations;

C   There is no single "minority" norm. None of the models and theories used to date to explain the relationship between race and health and/or ethnicity and health hold up under broad-based

scrutiny of "minority" vs. "majority" populations. Minority groups are highly varied and the relationships between their racial and ethnic identities and health are very complex, and they can change rapidly over time. Singular indicators like infant mortality rate, crude death rate, and hospital utilization rate are not consistently related to minority status.

C   It is worthwhile for governments to support the training of minority researchers because they ask new questions and they ask old questions in new ways. Minority researchers are not as constrained by worn out theoretical models and are most likely to investigate the possible nature and functioning of a concept such as "racism" or "discrimination." However, most minority researchers are not senior academicians at the present time and are not very competitive in obtaining research grant money. So, there may be a delay before their influence is felt.

C   Future research topics include the demographic and health profiles of individuals of mixed racial and ethnic heritage; the quality of data on race and ethnicity; the undercount of all types of racial and ethnic minorities, not just American blacks, and the effects of the undercount on reported rates of disease conditions; variation within racial and ethnic groups, not just between different groups; alternative medicine and "informal care" among racial and ethnic minorities; the treatment of racial and ethnic minorities in managed care systems, including Medicaid managed care; the role of primary care; and comparative, international analyses of race and ethnicity between the US and UK, and among all modern industrialized nations.

Opportunities

The opportunities identified by the Work Group on Developing Consumer-Grass Roots Voices and Voluntary Sectors focused on "capacity building," i.e., a special type of technical assistance through which minorities and local groups learn how to develop their roles as advocates and their voice in national debates. The Work Group identified four areas for capacity building: funding, information sharing (especially Lessons Learned and Best Practices), staff and management training, and materials development. People are the main resource in all capacity building models. Once they have skills, they cannot be taken away. The Work Group Members agreed that it is important to build on existing strengths and not to impose new paradigms on people, but to discover theirs. Once a target population is identified, people within that population who are most effectively placed to do advocacy work should be identified and trained.

The Work Group Members pointed out that building grass roots groups is an inherently self-limiting concept. It is important to have both internal (local) and external (national) activists. If, for example, individuals from the community are trained in advocacy and then go into government, they can still be effective advocates. Developing both a local and a national voice must include the concept of "sustainability." Advocacy must become institutionalized so that skills can be passed along to new members of groups. Advocacy for health care reform must develop as part of the natural fabric of a community and must be transferable to other sectors, as individuals move from location to location and from job to job.

Finally, the Work Group Members agreed that there was a need for an infrastructure to build capacity. Without an infrastructure, training people in advocacy and other skills will not have the desired effect of moving an agenda forward. The Members agreed that there is much to be learned from existing organizations who help each other rather than winning at each other=s expense. They agreed that helping to build an infrastructure to advocate for health care reform was a worthwhile task for the Collaborative Initiative on Racial and Ethnic Health.

Opportunity: Technical Assistance to Foster Engagement, Ownership, and Voice. The Work Group Members agreed that an important opportunity to advance the goal of improving minority health lay in the area of community development, more specifically, in engaging local leaders and creating a sense of ownership within a local minority group. That engagement and sense of ownership could then be used to move a local health care agenda forward. Members agreed that in both the US and the UK, local communities do not now have much of a voiceCa fact that led to the presidential initiative on eliminating racial disparity in health care in the US. The Work Group Members agreed that they should seek to understand the common threads in the advocacy experiences of local groups in both Nations, and to encourage community development focused on ownership and voice in local health care policy discussions.

Opportunity: Technical Assistance in the Formation of Partnerships and Collaboratives. In the past decade, several agencies of the US government have offered grants to support the formation of partnerships and collaboratives focused on local and regional health problems, especially substance abuse. These projects are designed to bring organizations together so that they can conduct research on local problems and create a larger voice in solving them. The UK has funded approximately 100 projects on developing community voices in the past several years. Therefore, there is now a compendium of local demonstration projects that offer useful Lessons Learned and Best Practices in the formation of partnerships and collaboratives. This information could be gathered and shared to assist local racial and ethnic minority groups in coalescing their community voice and thereby influencing local platforms and programs that serve their communities.

The Work Group Members agreed that, while it is true that the power of groups derives partly from their numbers, it is also true that joint action creates a larger voice irrespective of the numbers of individuals involved. People should be trained to work together to gain larger concessions from powerful health care organizations and health care agencies. However, along with the development of greater voice and power comes greater responsibility. Partnerships and collaboratives must naturally account for how they spend resources and monitor their efforts to determine if they are achieving desired outcomes. It is also important to involve local research organizations that can conduct epidemiological studies of diverse groups and to use their findings in advocating for change.

Opportunity: Discovering Best Practices. The Work Group Members agreed that future efforts to assist racial and ethnic minorities in gaining a greater voice in health care reform should rely on Lessons Learned in previous efforts of local groups and sub-populations. The examples provided by other groups constitute in many cases Best Practices that can serve as useful models for future action. The Group identified and discussed two examples of Best Practices in the area of community development and advocacy for health care reform:
1.   The Gay Men=s Health Crisis in New York City at the beginning of the AIDS epidemic, and
2.   A group of women from Pakistan communities who were paid to speak on behalf of those communities and advocate for change in health care.

The Members attributed the organizations= success to the same characteristics, which constitute, themselves, important Lessons Learned. They found that the following themes were important in each case:
$ *Maintaining cohesion and mutual support*; the organizations first advocated among themselves, then to others;
$ *Maximizing the use of the people in the community* and empowering people in the community to do the job;
$ *Effective packaging of the cause* and selling it to policy makers;
$ *Investing in building skills*; bringing people up to the same level to start everyone off as equal partners; and
$ *Giving power away to become more powerful*, along with effective selection of partners to engage the broader group.

The Work Group Members concluded that these five themes constitute a Best Practice model to guide the planning of new efforts by racial and ethnic minority groups to gain a greater voice in health care reform, both locally and nationally. It is important to note that Best Practices are not always or necessarily wedded to standard western medical practice. Empowering local groups may rely on effective use of combinations of western and traditional, "informal" care. In his 1997 presentation in London, Moon Chen defined informal care as "the practice of alleviating distressful physiological and psychological dysfunctions through all others (e.g., traditional healers, family members, self, etc.) using measures that do not require a physician's prescription or intervention (e.g., lifestyle modifications) typically outside of formal, institutionally based care mechanisms (e.g., homes and communities.)" He emphasized that "An enormous potential exists to better utilize informal care because informal care is culturally more compatible, relatively low cost, and

flexible." Chen made the important point that coping effectively is, itself, empowering, so reliance on alternative medicine may not always be counterproductive if it is integrated into an overall care regimen for members of racial and ethnic minority groups. He pointed out that "Empowerment of these communities is important both demographically and historically... minority populations are increasing at higher rates than the majority population in the U.S.A. and hence, the health status of minorities will become the health status of the nation in the next half century." The National Institutes of Health has recently recognized these trends by establishing an Office devoted to alternative medicine. The 1989 National Health Interview Survey, in spite of its under-representation of minorities in the sampling structure, suggested that the use of alternative medicine has been underestimated. Empowerment of racial and ethnic minority communities to advocate for the improved delivery of services has also been pursued vigorously in some settings in the UK. Chen's co-presenter at the 1997 meeting, Pui-Ling Li, reported on how she has empowered a Chinese community in London to help to meet their own health care needs. (See both sections of Appendix B for full references to Chen's papers. See also Department of Health, United Kingdom, 1998: 56-57, for a summary of Chen's and Li's workshop.)

Opportunity: Potential Joint US/UK Projects for the Coming Year. The Work Group Members agreed upon a theme for the coming year's work: AThe right of the consumer voice to be heard.@ The Members agreed that the framework for the US/UK collaborative should be based on the right of citizens to reduce the burden of illness and disease and their impact on the community. The work flowing from this theme would take the form of capacity building and infrastructure development. The Work Group agreed on recommending to the Steering Committee the following joint US/UK efforts for the coming year.

1. *Focusing on the community level* to enable grass roots voices to be heard in health policy making and health care reform; ensuring that health care advocacy does not alter the nature of the organizations' basic work.

2. *Identifying and sharing the baseline of community organizations in each country;* gathering and distributing information on epidemiological profiles of local and national groups and sub-populations.

3. *Designing a model on the intersection of community and service delivery;* using the linkages identified in the model to plan for action, while at the same time taking into account differences between the US and UK.

4. *Training groups to advocate in the public sector;* learning how to impart communication, lobbying, and advocacy skills; providing a demonstration training session at the next meeting in September 1999.

5. *Integrating of health professionals in the voluntary sector*; seeking their assistance in leading efforts to gain a greater voice in health care advocacy.

6. *Evaluating the effectiveness of community-based projects* and developing methods to measure success of advocacy and capacity-building technical assistance.

Section 7
Issues and Opportunities for Resource Development in the US and UK:
Findings of the Steering Committee

The role of the Steering Committee was to provide oversight and advice for the two Work Groups. Members of the Steering Committee attended meetings of the Work Groups and reviewed their recommendations. The Committee also served to facilitate relationships between the Collaborative Initiative and the government hierarchies in the US and UK, and to assist in helping to find resources and develop partnerships. This section summarizes their discussions and findings on resources.

Expanding the Collaborative Initiative to Include Other Nations
The Steering Committee discussed the possibility of expanding the Initiative beyond the United States and United Kingdom. The Members agreed that the health of racial and ethnic groups was a global issue, and that the public health policies and programs which concerned them most were not circumscribed by national borders. The Members noted that expanding the Initiative to other countries could expand the resources available to the Initiative and increase its sphere of influence. A possible intermediate step might be to invite other countries to the meetings of the Collaborative Initiative, so that leaders in other countries could gain from the insights of the representatives from the US and the UK. However, the Members agreed that the Initiative still needed to "prove itself binationally." Therefore, they reached no consensus on efforts to expand the Collaborative Initiative at the present. They agreed that the expansion of the Initiative might be a worthwhile long-term goal that could be discussed in future meetings.

Resources from Administrative Budgets
The Members of the Steering Committee agreed that some support for the Collaborative Initiative could come from their respective agencies' general administrative budgets. They agreed to seek support for telephone calls, a small amount of administrative support, and possibly
teleconferencing. These modest resources could be obtained without the need to designate funds specifically for the Collaborative Initiative.

Seeking Resources within Two Government Systems
The Members of the Steering Committee acknowledged the systems of national government in the US and UK each had their own distinctive culture, politics, and processes for setting priorities and budgeting. The Members agreed to seek funding for the Collaborative Initiative in those ways that are most appropriate for their respective governmental systems.

Communicating about Existing Programs
The Members of the Steering Committee agreed that communication was essential to developing resources to support the Initiative. Simply by sharing information on existing programs, the Members can go far in identifying sources of funds that might not be readily apparent or specifically targeted to minority health. Programs exist in both the US and UK that address many of the disorders and disease

conditions that afflict racial and minority groups disproportionately. By creating a knowledge base on those programs and disseminating knowledge about them, the Members can go far in identifying resources that could support the Initiative's efforts.

Partnerships with the Private and Voluntary Sectors
Members of the Steering Committee agreed that a worthwhile goal is to develop partnerships with foundations and existing programs in the voluntary sector. For example, the Robert Wood Johnson Foundation now supports a variety of projects that address minority health issues. The Red Cross and Salvation Army could also be approached and brought into the Initiative's activities. The myriad programs addressing the needs of the homeless form another interest group that could be beneficially engaged in the Initiative's work. The Members also mentioned the potential role of pharmaceutical companies in helping to address the inequities in access to health care that racial and ethnic minority groups face.

Appendix A

Text of the 1997
JOINT STATEMENT OF INTENT OF THE DEPARTMENT OF
HEALTH OF THE UNITED KINGDOM AND THE DEPARTMENT OF
HEALTH AND HUMAN SERVICES OF THE UNITED STATES OF AMERICA
COLLABORATION IN MINORITY ETHNIC HEALTH

The Secretary of State for Health on behalf of the UK, the Rt Hon Frank Dobson and the USA Deputy Secretary of Health and Human Services, the Honorable Kevin Thurm.

Having expressed their commitment to collaborate in public health by hosting of a binational meeting of governmental and non-governmental representatives to address black and minority ethnic communities' public health issues specific to their two countries:

Welcome the opportunity to receive recommendations and advice developed by the UK/USA Health Gain for Black and Minority Ethnic Communities Conference held on 16-18 September 1997 in the UK.

Reaffirm their countries' active support for minority ethnic health, particularly through the establishment of a joint agenda that addresses the challenges both countries face in meeting the health needs of minority ethnic population groups.

Agree to seek opportunities for their respective countries to work collaboratively in minority health, especially in the areas of sharing experiences and information on good practices, research, access to and quality of health services, health status, inequalities in health, partnerships and coalition building.

Further agree, in support of this objective, to pursue joint efforts for cooperation in minority health, with an emphasis on sharing the UK/USA experience in meeting the health needs of minority ethnic population groups, and developing links between UK and USA health professionals, managers and others who have a commitment to addressing ethnic and minority ethnic health needs.

Signed on 16th day of September in London

Rt Hon Frank Dobson
Secretary of State for
Health United Kingdom

The Honorable Kevin Thurm
Deputy Secretary of Health
and Human Services
United States of America

Appendix B
Selected References

Papers Commissioned by the Office of Minority Health and Presented at the First Meeting of the Collaborative Initiative in September 1997, in London, England

Baines, David R., MD, "Obstacles to Equality; Issues for Purchaser and Provider." Dr. Baines is Chief of Staff, Benewah Community Hospital, and Clinical Faculty, University of Washington School of Medicine, and Past President, Association of American Indian Physicians.

Chen, Moon S., Jr., PhD, MPH, "Informal Care and the Empowerment of Minority Communities: Comparisons between the U.S.A. and the United Kingdom." Dr. Chen is Professor and Chair, Division of Health Behavior and Health Promotion, School of Public Health, College of Medicine and Public Health, The Ohio State University, Columbus.

Hayes-Bautista, David E., PhD, "Research and Development Issues in Minority Health." Dr. Hayes-Bautista is Professor of Medicine and Director of the Center for the Study of Latino Health, School of Medicine, University of California at Los Angeles.

Smith, Marcia Bayne, DSW, "Primary Care: Choices and Opportunities for Racial/Ethnic Minority Populations in the U.S. and U.K.: A Comparative Analysis." Dr. Smith is Assistant Professor, Urban Studies Department, Queens College of the City University of New York.

Trevino, Fernando M., PhD, MPH, "Quality of Health Care for Ethnic/Racial Minority Populations." Dr. Trevino is Professor and Chairman, Department of Public Health and Preventive Medicine, University of North Texas Health Science Center, Fort Worth.

Williams David R., PhD, MPH, "The Monitoring of Racial/Ethnic Status in the United States: Data Quality Issues." Dr. Williams is Sr. Associate Research Scientist with the Institute for Social Research, University of Michigan, Ann Arbor.

Journal Articles and Reports

Alvarado, M., and Smolenski, M. C. 1996. Community panel discussions: From research to community action. *Pub Health Rep* 111(Supp 2): 74-6.

Benzeval, M., Judge, K., and Smaje, C. 1995. Beyond class, race, and ethnicity: Deprivation and health in Britain. *Health Serv Res* 30(1 Pt 2): 163-77.

Bhopal, R. 1997. Is research into ethnicity and health racist, unsound, or important science? *BMJ* 314(7096): 1751-6.

Bhopal, R., Kohli, H., and Ranking, J. 1997. Editors' practice and views on terminology in ethnicity and health research. *Ethn Health* 2(3):223-7.

Chen, M. 1998. Cultural Competency. In: *Closing the Gap* (March): 6. Published by the Office of Minority Health, DHHS.

Department of Health, United Kingdom. *Saving Lives: Our Healthier Nation*. Executive Summary.

Department of Health, United Kingdom. 1998. *Health Gain for Black and Minority Ethnic Communities*. Report of an International Conference between the UK and the USA, held 16/18 September 1997.

Free, C., and McKee, M. 1998. The new NHS: From specialist services to special groups. Meeting the needs of black and minority ethnic groups. *BMJ* 316(7128): 380.

Georges, C. A. 1998. President Clinton's new racial and ethnic health disparities initiative. *Ethn Dis* 8(2): 257-8.

Hahn, R. A., and Stroup, D. F. 1994. Race and ethnicity in public health surveillance: Criteria for the scientific use of social categories. *Public Health Rep* 109(1): 7-15.

Holman, P. B., Jenkins, W. C., Gayle, J. A., Duncan, C., and Lindsey, B. K. 1991. Increasing the involvement of national and regional racial and ethnic minority organizations in HIV information and education. *Pub Health Rep* 106(6): 687-94.

Hu, T. W., Snowden, L. R., Jerrell, J. M., and Nguyen, T. D. 1991. Ethnic populations in public mental health: Services choice and level of use. *Am J Public Health* 81(11): 1429-34.

King, G. 1996. Institutional racism and the medical/health complex: A conceptual analysis. *Ethn Dis* 6(1-2):30-46.

Lawrenson, R., Leydon, G., Freeman, G., Fuller, J., and Ineichen, B. 1998. Are we providing for ethnic diversity in accident and emergency (A&E) departments? *Ethn Health* 3(1-2):117-23.

Laws, S., and Cuninghame, C. 1994. Ethnicity in epidemiological research. Similar methodological problems exist in health services. *BMJ* 309(6959): 958-9.

Lieu, T. A., Newacheck, P. W., and McManus, M.A. 1993. Race, ethnicity, and access to ambulatory care among US adolescents. *Am J Public Health* 83(7): 960-5.

Lillie-Blanton, M., and Hoffman, S. C. 1995. Conducting an assessment of health needs and resources in a racial/ethnic minority community. *Health Serv Res* 30(1 Pt 2): 225-36.

Loudon, R., and Greenfield, S. 1998. Undergraduate education must include improving health of minority ethnic communities. *BMJ* 317(7173): 1660.

Maiese, D. R., and Fox, C. E. 1998. Laying the Foundation for Healthy People 2010. *Pub Health Rep* 113:92-5.

Mondragon, D. 1993. No more "Let them eat admonitions": The Clinton Administration's emerging approach to minority health. *J Health Care Poor Underserved* 4(2): 77-82.

Mueller, K. J., Ortega, S. T., Parker, K., Patil, K. and Askenasi, A. 1999. Health status and access to care among rural minorities. *J Health Care Poor Underserved* 10(2): 230-49.

Mueller, K. J., Patil, K., and Boilesen, E. 1998. The role of uninsurance and race in healthcare utilization by rural minorities. *Health Serv Res* 33(3 Pt 1): 597-610.

Naish, J., Brown, J., and Denton, B. 1994. Intercultural consultations: Investigation of factors that deter non-English speaking women from attending their general practitioners for cervical screening. *BMJ* 309(6962): 1126-8.

Nickens, H. W. 1995. The role of race/ethnicity and social class in minority health status. *Health Serv Res* 30(1 Pt 2): 151-62.

Orlandi, M. Ed. 1992. *Cultural Competence for Evaluators*. DHHS Pub. No. (ADM)92-1884.

Raleigh, V. S. 1997. Diabetes and hypertension in Britain's ethnic minorities: Implications for the future of renal services. *BMJ* 314(7075): 209-13.

Raleigh, V. S. 1996. Suicide patterns and trends in people of Indian subcontinent and Caribbean origin in England and Wales. *Ethn Health* 1(1): 55-63.

Russell, K. M. 1997. Public policy analysis of Indiana's minority health initiatives. *Ethn Health* 2(1-2): 105-16.

Satcher, D. 1999. Meeting health challenges and setting priorities: An interview with US Surgeon General, David Satcher, MD, PhD. *J Natl Med Assoc* 91(4): 191-2.

Savage, P. J., and Harlan, W. R. 1991. Racial and ethnic diversity in obesity and other risk factors for cardiovascular disease: Implications for studies and treatment. *Ethn Dis* 1(2):200-11.

Simpson, C. E. 1998. The U.S. and U.K. Collaborate on Minority Health. In: *Closing the Gap* (March): 1. Published by the Office of Minority Health, DHHS.

US DHHS. 1998. Eliminating racial and ethnic disparities in health. *Pub Health Rep* 113(4): 372-5.

US DHHS. 1991. Forum on youth violence in minority communities: Setting the agenda for prevention. December 100-12, 1990, Atlanta, Georgia. Proceedings. *Pub Health Rep* 106(3): 225-79.

Williams, D. R. 1998a. The Quality of Racial Data. In: *Closing the Gap* (March): 4. Published by the Office of Minority Health, DHHS.

Williams, D. R. 1998b. Racial Data in the United Kingdom. In: *Closing the Gap* (March):5. Published by the Office of Minority Health, DHHS.

Williams, D. R., Lavizzo-Mourey, R., and Warren, R. C. 1994. The concept of race and health status in America. *Pub Health Rep* 109(1): 26-41.

Appendix C
Agenda for the US/UK Collaborative Meeting
On Racial & Ethnic Health
September 23-25, 1998

Meeting Purpose:	Establish a framework for the US/UK collaborative process and identify future joint projects.

DAY 1

7:45 a.m.   WALK TO DHHS, HUBERT H. HUMPHREY BUILDING (2ND & Independence Ave.)

8:30 a.m. - 9:15 a.m.   WELCOME AND INTRODUCTIONS
Dr. Clay E. Simpson, Jr., Deputy Assistant Secretary for Minority Health, Office of Minority Health
Room 800

OVERVIEW OF MEETING AGENDA
Captain Tuei Doong, Deputy Director, Office of Minority Health

9:15 a.m. - 10:00 a.m.   UK ACTIVITY UPDATE
Veena Bahl, Departmental Advisor, Ethnic Minority Health
Wellington House
Bryan Harrison, Chief Executive, Forest Health Care NHS Trust
Pul-Ling Li, Public Health Consultant, South Thames Regional Office

REPORTS FROM
Scotland - Hector Mackenzie, Scottish Office Health Gain Division
Wales - Neil Woodling, NHS Wales Equality Unit

10:00 a.m. - 10:15 a.m.   BREAK

10:15 a.m. - 12:00 p.m.   STEERING COMMITTEE & CORE WORK GROUP BREAKOUTS

Work Group A - Develop Culturally Sensitive Access to Health Services Core Group - Room 705A (Joined by Steering Committee Group I)

Guadalupe Pacheco, Special Assistant to the Director, Office of Minority Health
Bryan Harrison, Chief Executive, Forest Healthcare NHS Trust

Work Group B - Develop Consumer-Grass Roots Voice/Voluntary Sectors Core Group - Room 440-D (Joined by Steering Committee Group 2)

Gerrie Maccannon, Special Assistant to the Director, Office of Minority Health
Pul-Ling Li, Public Health Consultant, South Thames Regional Office

12:00 p.m. - 1:00 p.m.   WORKING LUNCH

1:00 p.m. - 3:30 p.m.   STEERING COMMITTEE & CORE WORK GROUP BREAKOUTS CONTINUE

3:30 p.m. - 4:00 p.m.   WORK GROUP CO-CHAIRS MEETING

3:30 p.m. - 4:30 p.m.   BREAK

4:30 p.m. - 6:00 p.m.   RECEPTION

AGENDA

Meeting Purpose:	Establish a framework for the US/UK collaborative process and identify future joint projects.

DAY 2

8:30 a.m. - 11:00 a.m.   STEERING COMMITTEE & CORE WORK GROUPS CONTINUE DELIBERATION

> *Work Group A -* Develop Culturally Sensitive Access to Health Services Core
> Group - ODPHP Room 736G
> (Joined by Steering Committee Group 1)
> *Work Group B -* Develop Consumer-Grass Roots Voice/Voluntary Sectors
> Core Group - Room 705A (Joined by Steering Committee Group 2)

10: 00 a.m. - 11:00 a.m.   STEERING COMMITTEE DISCUSSION
> *Dr. Simpson/Veena Bahl, Co-Chairs*
> Ç *Advisory/Oversight Roles*
> Ç *Resource Support*
> *Room 800*

11:00 a.m. - 11:45 a.m.   PRELIMINARY REPORTS *- Work Group A and Work Group B Co-Chairs*,
> *Steering Committee Co-chairs*
> *Room 800*

11:45a.m. - 12:00 p.m.   CLOSING REMARKS
> *Dr. Clay Simpson/Veena Bahl*

12:00 p.m. - 1:30 p.m.   WORKING LUNCH
> *Room 800*

1:30 p.m. - 2:15 p.m.   UK PARTICIPANTS MEET WITH THE OFFICE ON WOMEN=S HEALTH
> *Frances Page*, **Senior Public Health Advisor**

2:30 p.m. - 3:00 p.m.   ORIENTATION - UK MEMBERS TRAVEL TO OMH RESOURCE CENTER, SILVER
SPRING, MARYLAND
> *Bus will pick members up in front of the DHHS, Hubert H. Humphrey Building*
> *at 2:30 p.m. sharp.*

3:00 p.m. - 4:30 p.m.   MEET WITH OMH RESOURCE CENTER STAFF AND
TOUR RESOURCE CENTER

4:30 p.m. - 5:00 p.m.   TRAVEL BACK TO HOLIDAY INN CAPITOL HOTEL

US/UK COLLABORATIVE MEETING
ON RACIAL & ETHNIC HEALTH
SEPTEMBER 23-25, 1998

AGENDA

Meeting Purpose:	Establish a framework for the US/UK collaborative process and identify future joint projects.

DAY 3 (SITE VISITS)

8:00 a.m. - 12:30 p.m.   MEET WITH COMMUNITY BASED ORGANIZATION/COMMUNITY HEALTH CENTER

8:30 a.m. - 9:00 a.m.	*Travel to Site Visit - Bus will pick members up at Holiday Inn Capitol - 8:30 a.m. sharp.*
9:00 a.m. - 10:00 a.m.	*Visit the Mary=s Health Center*
10:00 a.m. - 10:30 a.m.	*Travel to NMAC*
10:30 a.m. - 11:30 a.m.	*Visit The National Minority Aids Council*

11:30 a.m. - 12:30 p.m.   TRAVEL TO PHILLIPS FLAGSHIP

12:30 p.m. - 2:00 p.m.   LUNCH
Phillips Flagship - The Waterfront, SW Washington, D.C.

2:00 p.m. - 3:00 p.m.   TRAVEL TO OMH (VIA NIH)

3:00 p.m. - 3:45 p.m.   OMH ORIENTATION FOR UK PARTICIPANTS (**Division Directors)**
US/UK Co-Chairs Meet (Separately)

3:45 p.m. - 4:00 p.m.   CLOSING REMARKS
Dr. Clay Simpson

4:00 p.m. - 4:20 p.m.   UK PARTICIPANTS TOUR OMH

4:20 p.m.   ADJOURNMENT

4:20 p.m. - 5:00 p.m.   RETURN TO HOTEL

6:30 p.m. - 7:00 p.m.   TRAVEL TO PRIVATE RECEPTION IN POTOMAC, MARYLAND

7:00 p.m. - 9:30 p.m.   PRIVATE RECEPTION

9:30 p.m. - 10:00 p.m.   RETURN TO HOTEL

Appendix D
Rosters of the Steering Committee, the Work Group to Develop Culturally Sensitive Access to Health Care, and the Work Group to Develop Consumer and Other Grass Roots Voices and the Voluntary Sector

<u>Roster of the Steering Committee</u>

Co-Chairperson (US): Clay E. Simpson, Jr., MSPH, PhD, Former Deputy Assistant Secretary for Minority Health, DHHS/OPHS, Office of Minority Health

Co-Chairperson (UK): Veena Bahl, Departmental Advisor, Ethnic Minority Health

US/UK Project Coordinator: Georgia Buggs, RN, MPH, Special Assistant to the Director, DHHS/OPHS, Office of Minority Health

Ross Arnett, Director, Cost and Financing Studies, DHHS/OPHS, Agency for Health Care Policy and Research

Tuei Doong, Cpt., Deputy Director, DHHS/OPHS, Office of Minority Health

Sharon Smith Holston, MPA, Deputy Commissioner for External Affairs, DHHS/OPHS, Food and Drug Administration

M. June Horner, Acting Director, Office of Minority Health, DHHS/OPHS, Health Resources and Services Administration

DeLoris Hunter, PhD, Associate Administrator, Office of Minority Health, DHHS/OPHS, Substance Abuse and Mental Health Services Administration

Mireille (Mimi) Kanda, MD, MPH, Director, Health and Disabilities Services, Head Start Bureau, DHHS/OPHS, Administration on Children and Families

Thomas Kring, MD, MTH, Acting Deputy Director, DHHS/OPHS, Office of Population Affairs

Leo Nolan, MEd, (represented at the conference by Deborah Melton), Acting Associate Administrator, Office of Planning, Evaluation and Legislation, DHHS/OPHS, Indian Health Service

John Ruffin, PhD, Associate Director, Office of Research on Minority Health, DHHS/OPHS, National Institutes of Health

Edwin Walker, Director, Office of Program Operations and Development, DHHS/OPHS, Administration on Aging

Walter W. Williams, MD, MPH, Associate Director for Minority Health, DHHS/OPHS, Centers for Disease Control and Health Prevention

Susan Wood, PhD, Acting Deputy Director for Policy, DHHS/OPHS, Office of Women's Health

Roster of the Work Group to Develop Culturally Sensitive Access to Health Services

Co-Chairperson (US): Guadalupe Pacheco, MSW, Special Assistant to the Director, DHHS/OPHS, Office of Minority Health

Co-Chairperson (UK): Bryan Harrison, Chief Executive, Forest Healthcare NHS Trust

Marcia Bayne-Smith, DSW, ACSW, Assistant Professor for Urban Studies, Urban Studies Department, Queen's College-SUNY

Robert J. Carson, Cpt., ACSW, Special Assistant to the Director, DHHS/OPHS, Office of Minority Health

Gwendolyn Clark, MS, Public Health Analyst, DHHS/OPHS, Health Resources and Services Administration

Carol Creasy, MS, Director, Office of State and Community Programs, DHHS/OPHS, Administration on Aging

June L. Dow, Director of Information and Education, DHHS/OPHS, Office of Research

Matthew Guidry, PhD, Senior Advisor to the Director, Office of Disease Prevention and Health Promotion, DHHS/OPHS, Center for Disease Control and Prevention

R. C. Gupta, Consultant Physician, Chorley and South Ribble District General Hospital

Earl G. Long, PhD, Health Scientist, Office of Minority and Women's Health, National Center for Infectious Diseases, DHHS/OPHS, Centers for Disease Control and Prevention

Hector MacKenzie, The Scottish Office, Health Gain Division

Fran Page, RN, MPH, Senior Public Health Advisor, DHHS/OPHS, Office of Women's Health

Edward Renford, MS, Chief Executive Officer, Grady Health System

John Ruffin, PhD, Associate Director, Office of Research on Minority Health, DHHS/OPHS, National Institutes of Health

Pitambar Somani, MD, PhD, Columbus, Ohio

Kermit Smith, DO, MPH, Chief Medical Officer, DHHS/OPHS, Indian Health Service

Fernando M. Treveno, PhD, MPH, Chairman, Public Health and Preventive Medicine Department, University of North Texas Health Science Center at Fort Worth

David R. Williams, PhD, MPH, Sr. Associate Research Scientist, Institute for Social Research, University of Michigan

Advisor to the Work Group: Mary Lou Valdez, MS, International Health Officer, Office of International and Refugee Health, DHHS/OPHS

Consultant: Blake Crawford, Director, Division of Education and Information, DHHS/OPHS, Office of Minority Health

Roster of the Work Group to Develop Consumer and Other Grass Roots Voices and the Voluntary Sector

Co-Chairperson (US): Gerrie Maccannon, MPA, Special Assistant to the Director, DHHS/OPHS, Office of Minority Health

Co-Chairperson (UK): Pui-Ling Li, Public Health Consultant, South Thames Regional Office

Professor R. Balarajan, National Institute for Ethnic Studies in Health and Social Policy

Douglass Black, Director, Office of Tribal Activities, DHHS/OPHS, Indian Health Service

Nan Carle, PhD, Advisor on Organizational Effectiveness, DHHS/OPHS, Substance Abuse and Mental Health Services Administration

Carmella Castellano, JD, Executive Director, California Primary Health Care Association

Moon S. Chen, PhD, MPH, Co-Director, Department of Preventive Medicine, Ohio State University.

Eugena (Gena) Eckard, MS, Acting Director, DHHS/OPHS, Office of Research

Karen Garthwright, MA, Senior Public Health Analyst, DHHS/OPHS, Office of Minority Health

Cecilia Gutierrez, Special Assistant, DHHS/OPHS, Office of Women≡s Health

Betty Lee Hawks, Special Assistant to the Director, DHHS/OPHS, Office of Minority Health

Morgan Jackson, MD, MPH, Director, Minority Health Program, DHHS/OPHS, Agency for Health Care Policy and Research

Antonio Martin, MS, Network Deputy Executive Director, Kings County Hospital

John Ruffin, PhD, Associate Director, Office of Research on Minority Health, DHHS/OPHS, National Institutes of Health

Samuel Taveras, MEd, Team Leader, Community Assistance, Planning and National Partnership Branch, Division of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention

Mary Wallace, MBA, PA, Director, Minority Health, Office of Consumer Affairs, DHHS/OPHS, Food and Drug Administration

Neil Woodling, NHS Wales Equality Unit, Tal-y-Garn Rehabilitation Centre