



A NATIONAL ACTION PLAN
FOR CANCER SURVIVORSHIP:
African American Priorities

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ACKNOWLEDGEMENT

This project is indebted to the support of the National Black Leadership Initiative on Cancer and its national network of offices and coalitions. We would also like to thank all the members of the project workgroup as well as its leadership, Funmi Apantaku Onayemi and Sandra Hamilton.

We would like to thank all of the cancer survivors whose participation made this report possible. Special thanks to those survivors who shared their photographs with us:

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COSPONSORS

Centers for Disease Control and Prevention
Lance Armstrong Foundation

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This report was supported by Cooperative Agreement Number U58/CCU623066-02 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

INTRODUCTION

There are currently more than 10 million people living with, through or beyond cancer in the United States today.¹ One in three people will be diagnosed with cancer during their lifetime, and three in four families will care for a family member with cancer.¹ More people diagnosed with cancer are surviving each year as a result of improvements in screening, early detection and treatment for many cancers. However, survivors often face numerous physical, psychological, social, spiritual and financial issues during their diagnosis and treatment and throughout their lives.

Cancer survivors are defined as those who have been diagnosed with cancer as well as the people in their lives who are affected by the diagnosis, including family members, friends and caregivers. Survivorship begins at the moment of diagnosis and continues through the balance of life.²

While cancer affects all segments of the population, there are wide disparities in cancer survival rates and quality of life issues by race, ethnicity and geography. Healthy People 2010 reports that African Americans are about 34% more likely to die of cancer than are whites and more than twice as likely to die of cancer than Asian Pacific Islanders, American Indians and Hispanics.³ Furthermore, cancers among African Americans are more frequently diagnosed after the cancer has metastasized and spread to regional or distant sites.⁴ Cancer health disparities are also found in relation to quality-of-life issues. Minorities with cancer often suffer more pain due to under-medication. Nearly 62 percent of patients at institutions serving predominately African American patients were not prescribed adequate analgesics.⁵

There are currently more than 800,000 African American cancer survivors in the United States today.⁶ *A National Action Plan for Cancer Survivorship: African American Priorities* provides a framework for actively addressing the survivorship needs of this growing population.

BACKGROUND

In 2002, the Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation (LAF) collaborated to chart a course for comprehensively addressing cancer survivorship. This collaboration involved a series of meetings among key partners and experts, including numerous organizations, health advocates, cancer survivors and researchers from a variety of ethnic and racial backgrounds across the United States. The goal was to identify public health issues that would serve as a framework from which to mobilize cancer survivorship. The needs of cancer survivorship were prioritized across four core areas:

- Surveillance and applied research
- Communication, education and training
- Programs, policies and infrastructure
- Access to quality care and services

In addition, five other issues or needs were identified that cut across the four issues above. These were a need to support:

- Infrastructure for a comprehensive database on cancer survivorship
- Patient navigation systems that facilitate optimum care for cancer survivors
- Clinical practice guidelines for each stage of cancer survivorship
- Public education programs that promote informed decisions
- Comprehensive evaluation programs to measure outcomes and ensure service quality

The result of these efforts is [*A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*](#). This national action plan provides a framework for addressing the problems faced by cancer survivors in our nation.

PURPOSE

A National Action Plan for Cancer Survivorship: African American Priorities prioritizes the cancer survivorship needs of the African American community to ultimately lead to improved quality of life and survival rates for survivors. State agencies, organizations and individuals can use the identified priorities to increase awareness among the general public, policy makers, researchers, advocates, survivors and others of the needs of African American cancer survivors and to stimulate organizations to take direct and focused action to meet those needs.

Using *A National Action Plan for Cancer Survivorship*, a number of African American stakeholders in cancer survivorship participated in prioritizing the needs and topics contained in the original action plan. Through an Internet-based survey process, 75 respondents ranked each need in five topic areas of cancer survivorship. Respondents also provided comments on the process and cancer survivorship in general.

Access to services was identified as the top issue, but many respondents admitted that it was difficult to prioritize when there is so much that needs to be done. Culturally competent patient and provider education was a priority for many respondents, and patient navigation was the top crosscutting issue across all areas of need. The following report summarizes the ranked priorities as identified by African Americans regarding cancer survivorship issues.

PRIORITIZED RANKING AND COMMENTS

Stakeholders in the African American community prioritized the survivorship needs identified in *A National Action Plan for Cancer Survivorship* across the various topic areas. Each section below contains a description of the survivorship topics prioritized, a list of the needs in the order they were ranked (one being the most important and five being the least), and finally, a summary of the comments made by participants on that particular topic area.

OVERVIEW

MAIN CANCER SURVIVORSHIP TOPICS:

These are listed in the order of importance.

1. **Access to quality care and services** means ensuring that survivors are able to obtain high-quality treatment and services in a timely, competent manner. This approach must also promote good, culturally appropriate communication and shared decision making between the cancer survivor and healthcare providers.
2. **Education, training and communication** include efforts to communicate with the general public as well as policy and decision makers, to educate survivors and their families and to train healthcare providers to meet informational needs of all those affected by cancer survivorship.
3. **Infrastructure, programs and policies** are the means by which change can be made in public health.
4. **Applied research and surveillance** are the scientific tools of public health and can be used to establish a solid, systematic knowledge base in cancer survivorship.



CROSSCUTTING ISSUES:

A set of five core issues 'cut across', or affected, all of the main topic areas. These were prioritized and are listed below.

1. **Develop and promote patient navigation systems for cancer survivors.** Patient navigation can be used to ensure that survivors understand their care and to enhance the delivery of optimum care. Navigators can ensure timely delivery of care, connect survivors with appropriate resources, provide educational information on cancer survivorship and provide general oversight to the delivery and payment of services for each survivor.
2. **Develop and disseminate public education programs on informed decision making for cancer survivors.** Cancer survivors are faced with extremely difficult medical decisions at each stage of living with, through and beyond cancer. Survivors need to thoroughly understand their options for care. When patients are well-informed and participate in deciding how to manage their health, the results are more positive and survivors are more likely to follow their providers' recommendations.
3. **Develop and disseminate clinical practice guidelines for each stage of cancer survivorship.** Clinical practice guidelines summarize research on outcomes pertaining to one specific disease. Physicians select guideline recommendations according to the individual's healthcare needs. Guidelines have been developed for the treatment of particular cancers, but not enough for cancer survivors at each stage of cancer survivorship (e.g., monitoring survivors after treatment is completed, monitoring long-term health care and end-of-life care).
4. **Develop a comprehensive database on cancer survivorship.** Increasing the capacity of surveillance systems to capture information on health topics can lead to a better understanding of diseases and the people affected by them. A comprehensive database system could provide information on the ongoing health and other issues facing survivors.
5. **Develop comprehensive evaluation systems that monitor cancer survivorship issues and services.** The goal of evaluation is to increase program efficiency and its impact over time. Effective evaluation requires high quality indicators that are comprehensively monitored during all steps in program implementation.

COMMENTS: CROSSCUTTING NEEDS

- Cancer survivors need improved access to healthcare services.
- More culturally appropriate, multi-channel patient education is needed.
- More patient navigation programs are needed.
- Providers need education that is culturally competent.

DETAIL

MAIN CANCER SURVIVORSHIP TOPICS:

ACCESS TO QUALITY CARE AND SERVICES:

Access to quality care and services means ensuring that survivors have the ability to obtain high quality treatment and services delivered in a timely, competent manner. This approach must also promote good, culturally appropriate communication and shared decision making between the cancer survivor and healthcare providers.

1. **Access to quality treatment:** Cancer treatment is complex and differs for each individual based on his or her specific situation and needs. All cancer patients should have timely access to the latest and most effective treatments available, including clinical trials.
2. **Pain and symptom management:** The goal of pain and symptom management is to provide relief so that survivors can tolerate the diagnostic and therapeutic procedures needed to treat their cancer and live comfortably throughout each stage of cancer survivorship.
3. **End-of-life care:** Appropriate end-of-life care affirms life and regards dying as a natural process, neither hastening nor postponing death. The goal of end-of-life care is to achieve the best possible quality-of-life for cancer survivors.

“Access to equitable, quality care for African American cancer survivors should be a priority. There is far too great a disparity in health care, even when controlling for education, insurance and income.”⁷

NEEDS:

The following access to quality care and services needs are ranked in their order of importance.

1. Develop and promote a patient navigation system for cancer survivors.
2. Develop and disseminate guidelines that promote quality and timely service provision to cancer survivors.
3. Educate decision makers about economic healthcare barriers related to cancer survivors.
4. Establish integrated multidisciplinary teams of healthcare providers that support cancer survivors.
5. Assess and enhance palliative services for cancer survivors.

COMMENTS: ACCESS TO QUALITY CARE AND SERVICE

- The public health community needs to create and support more multi-disciplinary patient navigation systems to serve African American cancer survivors.

EDUCATION, TRAINING AND COMMUNICATION:

Education, training and communication include efforts to educate survivors and their families as well as to train healthcare providers to meet informational needs of all those affected by cancer. This category also includes communication with the general public as well as policy and decision makers.

1. **Survivor education:** Education of cancer survivors includes information tailored to each particular stage of survivorship. Educational interventions may be most appropriate during the first five years after diagnosis as this is the time when many of the challenges associated with the adjustment to survivorship occur.
2. **Provider training:** Healthcare provider training aims to ensure that providers are aware of the medical and other needs of cancer survivors. Training should cover all services necessary to enhance quality of life throughout survivorship
3. **Public communication:** Communication about the issues surrounding cancer survivorship aims to create a societal understanding and acceptance of the growing population of cancer survivors and the issues they face. Communication strategies will need to target the general public as well as policy or decision makers.

NEEDS:

The following education, training and communication needs are ranked in their order of importance.

1. Develop and promote patient navigation systems for cancer survivors.
2. Educate healthcare providers about cancer survivorship issues.
3. Educate decision makers on the value of follow-up care and clinical trials.

4. Teach survivors to access and evaluate cancer survivorship information.

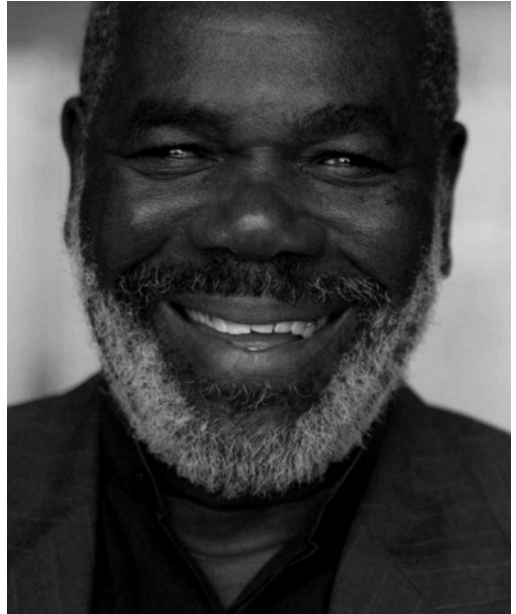
5. Train survivors in advocacy skills.

“Increasing the value of culturally specific education, clinical research and reaching out to high-risk populations may be the key to reducing cancer disparities.”⁷

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6. Educate the public about cancer survivorship.

COMMENTS: EDUCATION, TRAINING AND COMMUNICATION

- More patient education that is culturally specific to African Americans, especially on early detection of cancer, is needed.
- Healthcare providers need cultural-competency training and education on survivorship.



INFRASTRUCTURE, PROGRAMS AND POLICIES:

Infrastructure, programs and policies are the means by which change can be made in public health.

1. **Infrastructure:** Infrastructure refers to basic resources and facilities to address survivorship, such as healthcare and public health systems at state and local health departments. Effective infrastructure and good relationships with public and private sectors are required to operate and manage effective programs.
2. **Programs:** Programs are specific activities that aim to improve the quality of life of cancer survivors. These programs may address medical, psycho-social, legal and financial issues associated with cancer survivorship.
3. **Policies:** Policies include legislation, regulations, ordinances, guidelines and norms that establish an environment conducive to program implementation and other changes specific to survivorship. Policies may be implemented at the national, state, organizational and community levels in an effort to advance public health.

NEEDS:

The following infrastructure, programs and policies needs are ranked in their order of importance.

1. Develop and promote patient navigation programs that facilitate optimum care.
 2. Identify and implement programs proven to be effective.
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3. Develop and disseminate education programs that empower survivors to make informed decisions.
4. Implement evidence-based cancer plans that include all stages of cancer survivorship.
5. Promote policy changes that support addressing cancer as a chronic disease.
6. Establish clinical practice guidelines for each stage of cancer survivorship.
7. Develop infrastructure to obtain quality data on all cancer management activities.

COMMENTS: INFRASTRUCTURE, PROGRAMS AND POLICIES

- Standards in data systems and collection methods need to be improved.
- Clinical trials need to be evidence-based and more sensitive to African American cancer survivors.

APPLIED RESEARCH AND SURVEILLANCE:

Applied research and surveillance are the scientific tools of public health and can be used to establish a solid, systematic knowledge base in cancer survivorship.

1. **Applied research:** Cancer survivorship research focuses on applying our knowledge of cancer and issues survivors face to the development of solutions and appropriate interventions. Applied research investigates health systems, public policy and effects on individuals to address survivor needs.
 2. **Surveillance:** Cancer surveillance is the collection, analysis and use of cancer data. Surveillance data is critical for directing effective cancer prevention and control programs. Data comes from cancer registries that collect information on each cancer patient. National surveys collect data
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on health attitudes, beliefs and behaviors that are used to help understand issues related to all stages of cancer survivorship.

NEEDS:

The following applied research and surveillance needs are ranked in their order of importance.

1. Identify factors associated with health concerns of cancer survivors.
2. Identify programs/services that best meet cancer survivorship needs.
3. Research preventive interventions to evaluate their impact on survivorship.
4. Translate applied research into practice.
5. Enhance existing surveillance and applied research infrastructure.

COMMENTS: APPLIED RESEARCH AND SURVEILLANCE

- Increase government funding for cancer survivor programs.
- Increase patient education and include African American cancer survivors as educators and other support roles.

COMMENTS: GENERAL SURVEY

- The areas and issues were difficult to rank due to the great needs among cancer survivors and the inter-relationships between the issues and needs.
- More funding is needed for cancer research to improve education and treatment.
- More attention and support needs to be focused on survivors in rural communities.
- Assistance with patient navigation of the healthcare system should be increased.
- The most recent advances in cancer treatment should be better promoted and should be made available to all cancer survivors.
- Respondents were grateful for the opportunity to participate in the survey.

“In all my 38 years as a breast cancer and brain tumor survivor, this is the first time I have been included in a survey of this kind. Thank you so very much.”⁷

IMPLEMENTATION

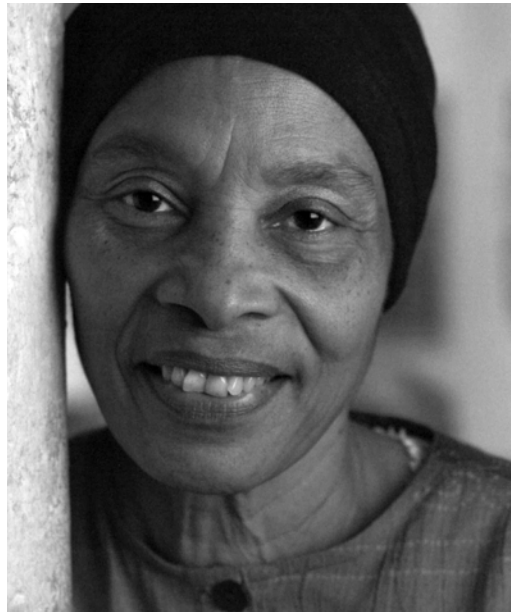
African Americans are now more likely to develop and die from cancer than any other racial or ethnic group.¹ By using *A National Action Plan for Cancer Survivorship: African American Priorities* as a guide, the public health community can better respond to this disparity and effectively address the needs of African American cancer survivors.

This report has identified the areas of access to care, cultural competency training and patient navigation programs as priorities for improving the survivorship infrastructure. Organizations and individuals representing healthcare personnel and the public may use this report to focus their current and future cancer survivorship activities along the lines proposed below:

- Local organizations will find this report useful as a starting point or as a source for strategic planning goals for local activities. This report can also be used as a guide for prioritization or justification of organizational infrastructure development, such as in the determination of which projects to invest in, especially when resources are limited and/or access to local or regional opinion leaders is difficult or not feasible to obtain in a timely manner.
- These recommendations could act as a basis for the design of local programs especially at the early stages of planning when there is a need to prioritize objectives for cancer survivorship.
- Another core event for many organizations is the development of grant applications for organizational support. These recommendations will serve as a credible reference source for establishing needs (i.e., literature review) as well as for describing operational goals and objectives or culturally supported methods, which are clearly delineated in *A National Action Plan for Cancer Survivorship*.
- Foundations, grant-makers and other funding organizations can use this report as a guide when setting funding priorities for this population.
- Comprehensive Cancer Control Coalitions can use this report to establish goals and objectives for meeting the needs of underserved populations when creating or updating their cancer plans. Coalitions with current plans can compare the priorities identified in this report with the goals and objectives in their own cancer plans to determine which strategies to implement. Additionally, cancer plans that identify eliminating health disparities or addressing the needs of underserved survivors as objectives may choose to further focus their efforts through the implementation of the priorities identified in this report.

- Media advocacy is increasingly being used as an effective strategy to motivate local groups and stimulate public media agendas to raise awareness of public health issues. These recommendations can contribute to talking points for cancer survivorship representatives or to augment news media story lines about cancer survivorship issues.
- Similarly, political advocacy could benefit from the credibility of recommendations in the action plan supporting specific policy points to local funding agencies, local government decision makers and even regional and state politicians responsible for healthcare legislation.
- The recommendations could be used as content for public educational purposes, whether through mass media channels (e.g., public affairs or news broadcasting) or via group education to the public.
- Healthcare professionals could also find these recommendations useful in formal or informal presentations on a variety of issues, such as cultural competence training, treatment and palliative care and/or for clinical trial recruitment and retention.

By focusing programmatic and advocacy activities on the identified priorities, organizations and individuals can work collaboratively toward addressing the needs that will ultimately lead to improved quality of life for African American cancer survivors, their families, friends and caregivers.



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7. Quotations are derived from the survey respondents' comments.

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