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# Roadmap for Limb Loss Prevention and Amputee Care Improvement

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A Report of the Limb Loss Task Force

Amputee Coalition

National Limb Loss Information Center

January 27, 2011

## Roadmap for Limb Loss Prevention and Amputee Care Improvement

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## Foreword

The Amputee Coalition is a nonprofit organization representing individuals with limb loss and empowering them to achieve their full potential through education, support and advocacy, and promoting limb loss prevention across the United States.

The Limb Loss Task Force was convened through funding for the National Limb Loss Information Center from the Centers for Disease Control and Prevention (CDC) partially supported by cooperative agreement #5U59DD000347 from the National Center on Birth Defects and Developmental Disabilities. The contents of this report are solely the responsibility of the authors and do not necessarily represent the official views of the CDC. The findings and recommendations of this report represent a combined effort of leading researchers, clinicians and consumers working in collaboration with the Amputee Coalition.



*A national action plan is necessary, as no comprehensive, integrated blueprint exists on the national or state level to guide amputee care within the civilian population; further, no coordinated plan exists for limb loss prevention.*

## Executive Summary

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### Background

On average, 507 people experience amputation every day in the United States. There are currently 1.9 million people with limb loss living in the U.S., and this number is expected to almost double by 2050. A national action plan is necessary, as no comprehensive, integrated blueprint exists on the national or state level to guide amputee care within the civilian population; further, no coordinated plan exists for limb loss prevention. The inaugural Limb Loss Task Force meeting was convened by the Amputee Coalition in Washington, D.C., on April 16-18, 2010, to develop recommendations for quality care and limb loss prevention. The Amputee Coalition is a nonprofit organization representing individuals with limb loss and empowering them to achieve their full potential through education, support and advocacy, and promoting limb loss prevention across the United States. This panel of limb loss experts, consisting of practitioners (e.g., physicians, podiatrists, nurses, physical therapists, prosthetists and

psychologists), researchers from the public and private sectors, the military and the federal government, and consumer advocates, developed a plan that addresses this growing national health problem. This report summarizes the observations of the Task Force and presents a roadmap for limb loss prevention and improved care for amputees across the country.

The Task Force highlighted the facts and figures that demonstrate urgent demand for a strategic approach to limb loss prevention and improved amputee care.

- Approximately, 185,000 amputations occur each year.
- The main causes of limb loss are dysvascular disease (54%), trauma (45%) and cancer (less than 2%).
- 60% of all amputations are preventable.
- Diabetes and vascular disease are the leading causes of limb loss and major drivers of increased limb loss incidence in the U.S.
- Healthcare costs for people with lower-limb amputations alone account for more than \$6.5 billion each year.
- 75% of acquired pediatric amputations are from trauma – most notable is that, on average, 600 children lose a limb from a lawnmower injury each year.
- Significant health disparities exist, as African Americans are four times more likely to experience lower-limb amputation than non-Hispanic white persons of similar age and gender.
- Amputee care is often fragmented and preventive care is insufficient.
- Access to rehabilitation and prosthetic care is not consistent throughout the United States. Although studies show inpatient rehabilitation care following amputation significantly reduces re-amputation and mortality, less than 10% of amputees are admitted to inpatient rehabilitation centers.

## Four-Point Action Plan

Based on the current scientific literature, practice standards, care models and statistics on incidence of limb loss, the Task Force recommends a four-point action plan.

### 1. Develop and Implement a Blueprint for Limb Loss Prevention

The Task Force recommends developing a strategic blueprint to partner with other groups on a multifaceted approach to limb loss prevention.

#### Develop a Strategic Communications Plan

The Task Force stressed the vital importance of having clear messages and targeted audiences. They also recognized the complexity of the prevention communications in regard to managing the messages to ensure balance between prevention and when an amputation is the best healthcare and quality of life decision. Task Force members recommended coordination with the initiatives of the Centers for Disease Control and Prevention (CDC) related to smoking cessation, obesity and diabetes and focusing on at-risk populations.

#### Develop a Limb Loss Risk Index

This Web-based tool would be easily accessible and would support positive lifestyle choices and behavioral changes, such as better nutrition, increased exercise and smoking cessation through a personal index score that would automatically calculate individually rated risk for limb loss. Messaging would communicate the seriousness and risk of limb loss and the need for appropriate screening.

#### Establish Prevention Partnerships

Partner with other organizations to develop and promote a series of initiatives to prevent both dysvascular and traumatic amputation.

*Create a Consequence Campaign.* The Task Force recommends an initiative focused on youth using private/public partnerships with like-minded nonprofit organizations (e.g., Amputee Coalition, PAD Coalition, American Diabetes Association), schools, professional associations (e.g., Society of Vascular Nursing) and for-profit businesses and ongoing youth-based programs such as First Lady Michelle Obama's *Let's Move* campaign. The Task Force also recommended a campaign to include

“limb loss” as a potential outcome as part of the Surgeon General’s tobacco warning program.

*Prevent Subsequent Amputations.* The Task Force recommended a close relationship with the prosthetic profession and using the Amputee Coalition database to identify those most at risk for subsequent amputations. The Task Force recommended inclusion of fitness and nutrition education in healthcare treatment plans and a concerted effort to engage this most-at-risk population in risk-reduction activities.

*Prevent Traumatic Amputations.* The Task Force emphasized that significant numbers of traumatic amputations can be prevented through increased education and support of safe product design and use. The Task Force urges the creation of partnerships with, and support from, the manufacturers of products commonly associated with amputation injuries (e.g., lawnmowers) for a public awareness campaign.

## **2. Partner With Professional Organizations to Develop Practice Guidelines for the Care of People With Limb Loss**

The Task Force recommends convening a Consensus Conference to review current practice guidelines and address questions relevant to efforts to advance and promote specialized care that improves and extends the lives of people living with limb loss. The conference would expand upon the significant work the Amputee Coalition accomplished in 2007 with the development of the first-ever standards of care for the rehabilitation of amputees. These Commission on Accreditation for Rehabilitation Facilities (CARF) standards are now used throughout the veteran and civilian healthcare systems as well as internationally. The Consensus Conference should bring together committees of subject-matter experts, including doctors, nurses, physical therapists, prosthetists, podiatrists, nutritionists, chiropractors and amputees and family members, to review current guidelines and to write new guidelines where needed, to imprint a pathway of recovery after limb loss.

### **3. Develop a National Research Agenda on Limb Loss Prevention and Amputation Care**

The Task Force recommends the development of a two-pronged research agenda on:

- Limb Loss Prevention Research. This agenda would be developed to implement interventional strategies for limb loss prevention. A conference would be convened to bring together researchers, clinical and educational experts, national organizations and policy makers to focus on decreasing primary and subsequent amputations by incorporating limb loss prevention strategies in early onset care pathways for at-risk conditions and focusing on disparity populations.
  - Amputee Care Research. This agenda would focus on key initiatives to quantify limb loss in America through a prevalence study and to define the burden of living with limb loss. These research initiatives would be inclusive of comparative effectiveness research, surgical amputation guidelines, quality of life influences and community reintegration. The Task Force recommended exploring the value of developing a limb loss registry. A conference of experts should be convened to address these initiatives.
- ### **4. Create and Demonstrate a Model System of Care Ranging From Prevention Through Amputee Rehabilitation and Community Integration That Can Be Emulated by Health Systems Throughout the Country**

The Task Force recommends pursuit of a demonstration project that would develop and evaluate a model system of amputee care. Similar model systems were developed and served as a stimulus for progressive research leading to standards of care in other disabling conditions such as spinal cord injury, traumatic brain injury and burns. A similar demonstration project is needed for amputee care. The Department of Defense and the Department of Veterans Affairs are poised to serve as key partners in developing the framework of the model system due to their extensive efforts in limb loss prevention and establishing Amputee Care Centers of Excellence.

## Introduction

The incidence of limb loss is increasing in the United States, and costs to our society are significant. A national action plan is necessary, as no comprehensive, integrated blueprint exists on the national or state level to guide amputee care within the civilian population; further, no coordinated plan exists for limb loss prevention. The inaugural Limb Loss Task Force meeting was convened in Washington, D.C., on April 16-18, 2010, to develop recommendations for quality care and limb loss prevention. This panel of limb loss experts consisting of practitioners (physicians, podiatrists, nurses, physical therapists, prosthetists and psychologists), researchers from the public and private sectors, the military and the federal government, and consumer advocates developed a plan that addresses this growing national health problem. This report summarizes the observations of the Task Force and presents a roadmap for limb loss prevention and improved care for amputees across the country.

## Background

### Impact of Limb Loss

Limb loss has significant impact on the health and quality of life of our country. In the U.S., it is estimated that, on average, 507 people lose a limb every day. There are currently 1.9 million people with limb loss living in the U.S. and this number is expected to almost double by 2050 (1). This growing level of incidence is primarily driven by the increasing prevalence of diabetes and vascular disease in the U.S. (1).

As the incidence of limb loss increases, so do costs to society. Direct healthcare expenditures, while significant, pale in comparison to the indirect costs of lost productivity of people with amputation and their families. These individuals experience significant emotional and quality of life ramifications. There are significant health disparities with regard to limb loss in America. African Americans, particularly those over the age of 35, are

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generally at a significantly higher risk of amputation than non-African Americans (2).

This review is not intended to be comprehensive but to provide highlights regarding the background literature underlying the Task Force recommendations.

## Individual and Societal Costs and Burdens

### Direct Health-Related Costs

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*In 2007, hospital charges for lower-limb amputation procedures accounted for more than \$6.5 billion.*

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- In 2007, hospital charges for lower-limb amputation procedures accounted for more than \$6.5 billion (3).
- In 2004, the total hospital costs associated with diabetes-related lower-limb amputations alone totaled more than \$1.5 billion (4).
- Professional nursing care at home after losing a limb due to dysvascular disease costs a person with limb loss an estimated \$100,000 per year (5).
- A below-knee amputation costs Medicare an average of \$81,051 per person (6).
- Trauma patients who undergo attempts at limb salvage over the course of 18-24 months following their injury averaged 53.4 days in the hospital at a cost of \$53,462 in hospital charges and, on average, underwent 6.9 surgical procedures with attendant personal and financial costs (7).

### Employment and Social

- Less than half of those who experience amputation return to work. For those who return to work, the average time to return is approximately 14 months (8).
- People with limb loss perceive that they are participating less in recreational activities, are more dissatisfied at work, and are more impaired in community mobility relative to their premorbid status (9).

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*African-Americans are up to four times more likely to undergo an amputation than white Americans.*

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- Factors positively influencing amputees' return to work include prosthetic use, access to vocational services and age at the time of amputation. Factors negatively related to successful employment included residual and phantom limb pain, multiple limb amputations and significant psychological distress (10).

### **Disparity**

- African-Americans are up to four times more likely to undergo an amputation than white Americans (11).
- Hispanic/Latino Americans are one-and-a-half times more likely than white Americans to undergo amputations (12).
- Poverty is an important risk factor for amputations (13).
- Amputees with a household income at or near the poverty line were two to three-and-a-half times more likely to perceive barriers to participation in work and community life than those who were not poor (9).

### **Morbidity and Mortality**

- Survival rates after amputation vary based on a variety of factors. Those who have amputations from trauma tend to have good long-term survival, but those from vascular etiology (inclusive of peripheral arterial disease and diabetes) face a 30-day mortality rate reported to be from 9-15% and long-term survival rate of 60% at 1 year, 42% at 3 years, and 35-45% at 5 years (14).
- Nearly half of the people who lose a limb to dysvascular disease will die within 5 years. This is higher than the 5-year mortality rate experienced by people with colorectal, breast and prostate cancer (15)-(16).
- Of people with diabetes who have a lower-limb amputation, up to 55% will require amputation of the second leg within 2 to 3 years (17).

## Risk Factors for Limb Loss

Estimates show that 49-85% of amputations are preventable (18)-(19), clearly highlighting the importance of prevention of both dysvascular and traumatic amputation. The large number of preventable amputations is due to the increasing incidence of diabetes and peripheral arterial disease (PAD), and the related problems of obesity and smoking (20)-(21).

### Dysvascular Amputation

- 54% of amputations are related to dysvascular disease (1).

### Diabetes

- In 1997, nearly 70% of all amputations were performed on people with diabetes (22)-(23).
- It is estimated that by 2025, there will be 250 million people with diabetes worldwide, compared to 120 million in 1996 (24).
- As many as one in four people with diabetes will develop a foot ulcer in their lifetime (25) and those who develop foot ulcers are at high risk for amputation within the subsequent year.
- 75% of nontraumatic amputations in people with diabetes would have been prevented by early identification and education of those at risk of ulceration (24).

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### Peripheral Arterial Disease

- A study from the National Health and Nutrition Examination Survey 1999-2000 data found that PAD affects approximately 5 million adults. Prevalence increases dramatically with age and disproportionately affects African-Americans (26).
- PAD is a common cause of amputation; 1-2% of all people with PAD will progress to major amputation (2).

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*Over two-thirds of amputations due to trauma occur among adolescents and adults below the age of 45 with many years of productive life ahead of them.*

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### **Obesity and Smoking**

- Subjects who had ever smoked were twice as likely to have a lower-limb amputation as those who never smoked (27).
- Among people with a lower-limb amputation, smoking cigarettes has been associated with a re-amputation risk 25 times higher than that of nonsmokers (28).
- People with lower-limb amputation had a higher baseline Body Mass Index (BMI) than those without a lower-limb amputation (27).

### **Traumatic Amputations**

- Limb loss secondary to trauma accounts for 45% of all amputations in the U.S. (1).
- Over two-thirds of amputations due to trauma occur among adolescents and adults below the age of 45 with many years of productive life ahead of them.
- The most common causes of pediatric acquired amputations are lawnmower accidents, with an average of 600 children losing a limb to a lawnmower each year (29)-(30).

### **Prevention Opportunities**

- In a 2001 study, only 49% of those receiving amputations related to dysvascular disease had any diagnostic vascular evaluation prior to amputation (31).
- The Ankle-Brachial Index (ABI) is a simple, reliable means to predict the severity of PAD (32).
- Limb-preservation experts report a significant number of the 80,000-plus toe, foot and lower-limb amputations related to diabetes would be preventable if only patients received proper foot care and had improved diabetes control (33).
- Self-management education activities and programs can improve foot care behaviors, resulting in decreased lower-limb complications (34).

- The three most important contributors to amputation reduction in people with diabetes are: 1) education, 2) regular clinical visits and 3) proper shoe wear (35)-(36) (37) (38).

### Improving Care for People With Limb Loss

In spite of the significant healthcare burden related to limb loss, the quality of and access to care are variable. There is a growing consensus and developing evidence base regarding what is appropriate care for people with limb loss to guide both practitioners and policy makers. The Institute of Medicine (IOM), in its landmark 2001 report, *Crossing the Quality Chasm*, indicated that “patient-centered care” is one of the six fundamental aims of the U.S. healthcare system (39). The IOM defines patient-centered care as: “Healthcare that establishes a partnership among practitioners, patients and their families (when appropriate) to ensure that decisions respect patients’ wants, needs and preferences and that patients have the education and support they need to make decisions and participate in their own care (40).” This type of care is critical for the management of people with limb loss and other chronic conditions.

- Transdisciplinary teamwork has shown to improve short- and long-term outcomes for people with limb loss (41).
- Family members of amputees play a critical role in the entire treatment process, including the establishment of short- and long-term goals (41).
- Peer support should be included throughout the course of amputation and rehabilitation (42).
- Receiving inpatient rehabilitation immediately after acute care improves survival rates, reduces subsequent amputations and correlates with greater acquisition of prosthetic devices and greater medical stability than for patients who were sent home or to a skilled nursing facility (43).

## Roadmap for Limb Loss Prevention and Amputee Care Improvement

- Self-management programs can improve the outcomes of people with limb loss beyond the benefits of traditional support groups (44).
- Patients understand the importance of diabetic foot care better when it is demonstrated by a provider who examines the feet carefully at least annually and asks about foot problems at every visit (34).
- Functional outcome can be improved by appropriately addressing the psychosocial factors related to limb loss. Loss of ability to relate to previous vocational, leisure and social activities may have more impact of post-amputation quality of life than the loss of the limb itself (45).

## Four-Point Action Plan

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1. *Develop and implement a blueprint for limb loss prevention*
  2. *Partner with professional organizations to develop practice guidelines for the care of people with limb loss*
  3. *Develop a national research agenda on limb loss prevention and amputation care*
  4. *Create a model system of care for people with limb loss that can be emulated by health systems throughout the country*
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### 1. Develop and Implement a Blueprint for Limb Loss Prevention

The Task Force recommended developing a strategic blueprint with a multifaceted approach to limb loss prevention. Prevention permeated each avenue of discussion for the Task Force, with critical recommendations being: developing a strategic communications plan, creating limb loss risk assessment tools for the public, including limb loss as a consequence of high-risk behavior, creating an education campaign for amputees about subsequent amputations, and addressing high-incidence preventable traumatic limb loss. The Task Force also identified the need to tune messages to disparity populations, target those most at risk, approach youth to set positive behaviors, and create sophisticated messaging around making the choice of amputation.

#### *Develop a Strategic Communications Plan*

The Task Force stressed the vital importance of having clear messages and targeted audiences. They also recognized the complexity of the prevention communications in regard to managing the messages to ensure balance between prevention and when an amputation is the best healthcare and quality of life decision. Task Force members recommended coordination with the CDC initiatives related to smoking cessation, obesity and diabetes and focusing on the following key populations:

- African Americans
- Hispanic/Latinos
- American Indians
- Children.

#### *Develop a Limb Loss Risk Index*

This Web-based tool would be easily accessible and support positive lifestyle choices and behavioral changes, such as better nutrition, increased exercise and smoking cessation, through a personal index score that would automatically calculate

individually rated risk for limb loss. Messaging would communicate the seriousness and risk of limb loss and the need for appropriate screening and follow-through. The Amputee Coalition's Web site and resource center could be a key vehicle to provide consistent, accurate, relevant, accessible and timely information to the public. This screening tool would guide at-risk individuals to engage in a series of health behaviors including discussion with the primary care doctor, blood glucose monitoring, Ankle-Brachial Index screening, healthy living and fitness communications and education. The Task Force recommended the creation of specific outreach mechanisms to reach under-served communities.

### **Prevention Partnerships**

Partner with other organizations to develop and promote a series of initiatives to prevent both dysvascular and traumatic amputation.

*Create a Consequence Campaign.* The Task Force recommends an initiative focused on youth using private/public partnerships with like-minded nonprofit organizations (e.g., Amputee Coalition, PAD Coalition, American Diabetes Association), schools, professional associations (e.g., Society for Vascular Nursing) and for-profit businesses and ongoing youth-based programs such as First Lady Michelle Obama's *Let's Move* campaign. The Task Force also recommended a campaign to include "limb loss" as a potential outcome as part of the Surgeon General's tobacco warning program.

*Prevent Subsequent Amputations.* The Task Force recommended a close relationship with the prosthetic profession and using the Amputee Coalition's database to identify those most at risk for subsequent amputations. The Task Force recommended inclusion of fitness and nutrition education in healthcare treatment plans and a concerted effort to engage this most-at-risk population in risk-reduction activities.

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product design and use. The Task Force urges the creation of partnerships with, and support from, the manufacturers of products frequently involved in amputation injuries (e.g., lawnmowers) for a public awareness campaign.

## **2. Partner With Professional Organizations to Develop Care Guidelines for People With Limb Loss**

The Task Force recommends convening a Consensus Conference to review current practice guidelines. This Consensus Conference will identify gaps within existing practice guidelines. The overall goal is to advance and disseminate standardized care guidelines that improve and extend the lives of people living with limb loss. The Amputee Coalition is in a unique position to partner with professional organizations and facilitate the development of practice guidelines. Collaboration among consumers – represented by the Amputee Coalition, professional organizations and leading health services researchers will lead to evidence-based guidelines that serve the public.

Recent work by the Amputee Coalition and representatives of various professional organizations in 2007 led to the development of standards of care for inpatient rehabilitation of people with limb loss (46). These standards are now used throughout the veteran and civilian healthcare systems, as well as internationally.

The development of care guidelines is critically important given the projected increase in the number of people with limb loss. Also, there is significant fragmentation of care in our current system that has led to disparity across the U.S. in the treatment of those at risk and with limb loss. This is further compounded by the growing concern over the rise in healthcare expenditures.

## **3. Develop a National Research Agenda on Limb Loss Prevention and Amputation Care**

The Task Force recommends the development of a two-pronged research agenda on limb loss prevention and amputee care.

### **Limb Loss Prevention Research**

There is a need to identify and implement effective intervention strategies for limb loss prevention. A conference would be convened to bring together researchers, clinical and educational experts, national organizations and policy makers to identify gaps in the knowledge and encourage research to achieve this goal. Potential fruitful areas of research are decreasing primary and subsequent amputations by incorporating limb loss prevention strategies in early onset care pathways for individuals at risk and focusing on overcoming health disparities.

### **Amputee Care Research**

There is a need to develop the evidence base to guide care of people with limb loss. A conference would be convened to bring together researchers, clinical and educational experts, national organizations and policy makers to identify gaps in the knowledge and encourage research to achieve this goal. This research agenda could focus on: 1) quantifying the prevalence of limb loss in America and the burden of living with limb loss; 2) pursuing comparative effectiveness research on medical, surgical, prosthetic and rehabilitative care options; and 3) identifying determinants of quality of life and community reintegration.

The Task Force recommends that the following entities be included, among others, as part of the agenda-setting processes and recommends integration of the report recommendations into the agendas and funding initiatives of the following federal agencies (listed in alphabetical order):

- Agency for Healthcare Research and Quality
- Centers for Disease Control and Prevention
- Department of Defense
- Department of Veterans Affairs
- Institute of Medicine
- National Institute on Disability and Rehabilitation Research
- National Institutes of Health.

#### 4. Create and Demonstrate Model Systems of Care Ranging From Prevention Through Amputee Rehabilitation and Community Integration That Can Be Emulated by Health Systems Throughout the Country

The Task Force recommends pursuit of a demonstration project that would develop and evaluate model systems of amputee care. Similar model systems were developed and served as a stimulus for important research and improved quality of care in other disabling conditions such as spinal cord injury, traumatic brain injury and burns. A demonstration model system project would provide for innovation in a similar manner for individuals with amputation.

The Department of Defense and the Department of Veterans Affairs are poised to serve as key partners in developing the model system due to their extensive efforts in limb loss prevention and establishing Amputee Care Centers of Excellence.

The Task Force recommended an exploratory discussion with the National Institute on Disability and Rehabilitation Research, which has pioneered the development of model system projects to enhance the lives of people with disability.

#### Funding

The Limb Loss Task Force realizes the Four-Point Action Plan is bold and will require additional resources for execution.

Implementing this plan will require development of collaborative and strategic alliances between nonprofit, commercial and governmental organizations to obtain the necessary resources. Members of the Task Force are committed to supporting and working to build these relationships, raise awareness and increase funding for implementing this landmark plan.

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## Conclusion

The Limb Loss Task Force was convened to bring together leading researchers, clinicians and consumers to work in collaboration to define a broad action plan based on existing data and current gaps in our knowledge and clinical care. The Task Force believes the work has only just begun and continued efforts by the Task Force are needed. With this inaugural meeting, important steps were taken to address the burden of limb loss in America.

## Limb Loss Task Force

The Amputee Coalition of America is grateful to the many organizations and individuals that have contributed to this work. The following individuals served on the Task Force and are authors of this report:

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## Roadmap for Limb Loss Prevention and Amputee Care Improvement

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