LIMB LOSS *and* PRESERVATION REGISTRY

Activity is health.

There is no national data available through the Centers for Disease Control, the Agency for Healthcare Research and Quality, or no existing registry that provides credible data on limb loss, limb preservation, or limb difference in the United States. The lack of data for this specific population of individuals with physical disability hampers prevention, treatment, and rehabilitation efforts. No recent data are available to provide information on incidence, prevalence, cost, and quality of life for those who experience limb loss. There is no feasible method to gather this data through existing national surveys or existing health interviews due to the size of the population. This is a significant public health gap and inhibits policy initiation to address the potential causes or effective post-amputation rehabilitation and recovery efforts to optimize the health and wellness of those who suffer limb loss.

The National Center for Medical Rehabilitation Research, within the National Institutes of Health, is partnering with the Department of Defense (DoD) to fund the creation of a clinical registry for amputation and amputation prevention, the Limb Loss and Preservation Registry (LLPR). Mayo Clinic has received the competitive contract to create the LLPR. The goal is to collect data so this growing field of research and treatment can be based on reliable evidence to make informed analytical decisions.

WHAT

The Limb Loss and Preservation Registry (LLPR) is a national program to improve the quality, safety, effectiveness and cost of limb loss treatment and limb preservation. The LLPR is a centralized data warehouse designed to collect relevant patient data and perform analysis to improve the quality of care and patient outcomes.

WHO

The Registry is a multi-stakeholder model. This means that it includes a broad group of participants such as care providers (OT, PT, physicians, prosthetists etc.), care sites (hospitals, clinics wound centers), insurance payors, device manufacturers, suppliers, and regulatory agencies.

HOW

To participate in the LLPR, a Participation Agreement needs to be signed. Please request a Participation Agreement at info@llpregistry.org. Enrollment is a simple, one-time process.

WHY

The main objective of the Limb Loss and Preservation Registry is to address a substantial public health knowledge gap. The information housed in this database will help to integrate limb loss care into clinical practice guidelines, refine rehabilitation approaches, and guide development of more functional devices for people with limb loss.

DATA VISUALIZATION

These data sets will be made available to researchers studying medical conditions that contribute to limb loss, such as diabetes and vascular disease. In addition, the research community will be able to analyze the data by age, gender, and type of limb loss or preservation surgery. Clinicians will improve treatment plans for long-term care of these patients that will enhance their functionality and quality of life.

SECURITY

The LLPR data is encrypted as it resides in our database, and access to de-identified LLPR data is controlled by strict account permissions and restrictions. No end user ever has access to raw personally identifiable data. The LLPR system is accredited to meet FedRAMP and NIST 800-53 security standards, and the data is secured and controlled for HIPAA compliance. Data queries are de-identified and filtered for compliance before any data is reported to the end user.

MISSION

To improve functional outcomes for patients treated with limb difference, preservation, and/ or loss by establishing a baseline care level and improving centralized data warehouse designed to collect relevant patient data and perform analysis to improve the quality of care and patient outcomes available to these patients.

VISION

To provide a framework for data analysis and to guide public policy for care for patients with prosthetics.

VALUES

Our success is built on innovation, respect, integrity and transparency. These values shape our daily work, the way we meet challenges and our interactions with our customers, partners and colleagues.

INNOVATION

—requires trust in one's own abilities
—leads to a healthy challenge to the status quo
—requires the courage and resourcefulness to spark change

RESPECT

—is the foundation of any relationship
—generates an atmosphere of esteem, fairness and recognition
—requires open and honest communication

INTEGRITY

—is the cornerstone of what makes us credible
—ensures our credibility
—enables us to do what we say

TRANSPARENCY

—makes mutual trust possible
—makes our actions understandable
—supports goal-oriented behavior throughout the organization

CLINICIANS

The Limb Loss and Preservation Registry (LLPR) meets the needs of various stakeholder groups in the limb loss and limb difference community by collecting data into one database for capturing insights which have never been accessible before. Prior to the LLPR, no national database existed for measuring quality outcomes for patients with a limb loss or limb difference. The data visualization provided by the LLPR offers unique value for clinicians, hospitals, and manufacturers. As the LLPR develops, it will also derive value for patients, payors, researchers, and policy makers. Currently, the LLPR data comprises over thirty-five thousand patients and seven million patient encounters. The data are rapidly expanding as the number of participants (hospitals and O&P clinics) increase.

Specific examples of the value added by the LLPR to providers in the industry include:

EVIDENCE-BASED CARE

With the data from the LLPR, clinicians are able to use data to evaluate treatment options and care plans to maximize their patient's function. Clinicians can answer questions such as:

- How long is the patient wearing the prosthesis/orthosis?
- When I change components, does the patient improve their function?

SERVICE DELIVERY

With the data from the LLPR, clinicians are able to set realistic goals and objectives with patients. Clinicians can answer questions such as:
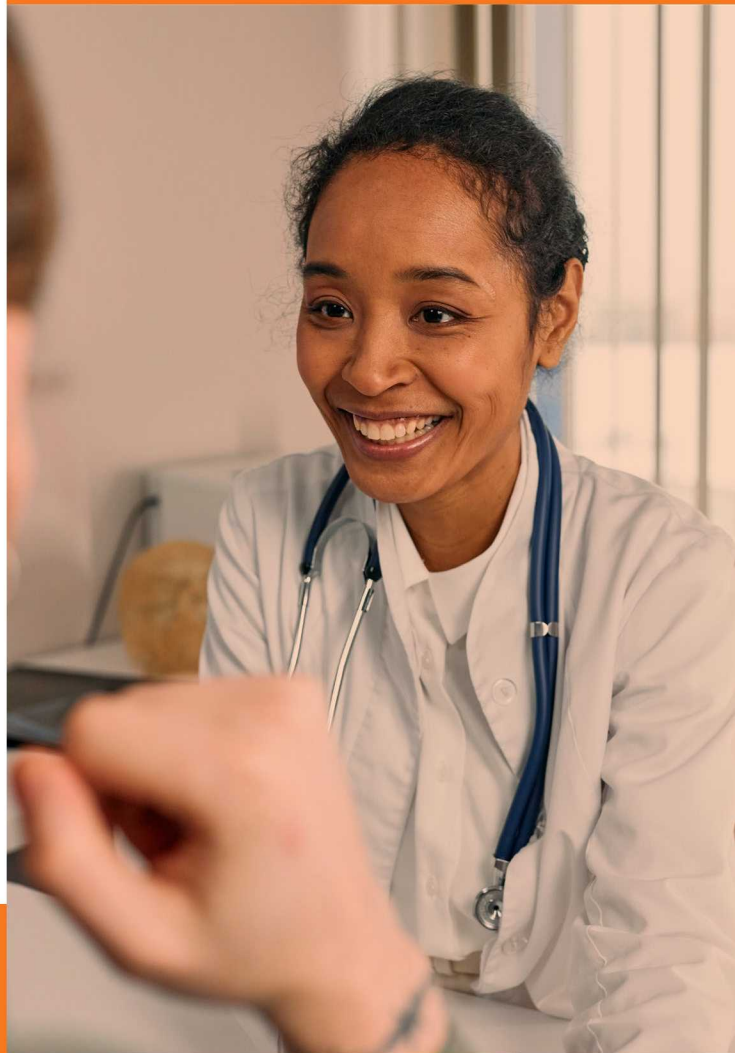
- How can I provide excellent patient care in a meaningful and consistent manner?
- How does patient outcome correlate with frequency of visits?

DIFFERENTIATION

With the data from the LLPR, clinicians are able to critically evaluate the care they provide to their patients compared to regional and national benchmarks. Clinicians can answer the question:

- What are my colleagues achieving and how can I be more consistent in my patient outcomes?

BETTER DATA. BETTER *CARE.*