



# Data, Analytics and Workflow: Meeting Urgent—and Growing—Need for Security, Interoperability and Analytics July 2020

Thought Leadership & Innovation Foundation draws on public health, military health and pandemic preparedness experience to provide powerful analytics for a secure, interactive healthcare data repository and clinical workflow

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"Better Data for Better Care," a book authored by Thought Leadership & Innovation Foundation Chairman Bill Oldham more than 10 years ago, outlined a principle that resonates to this day: we must use technology more effectively to unleash its power in a way that transforms the delivery of health care. The COVID-19 pandemic has demonstrated yet again the critical role data plays in health—and how poorly this has been handled.

While much of healthcare information has gone digital, such as a patient's medical history, the challenge of interoperability and, more importantly, analytics has stymied healthcare leaders, policy makers and the entire nation. The staggering array of articles promulgating the latest pandemic health "data" has left many of us numb—or scared.

Whether it's in the form of more efficient medical data management, collecting patient reported outcomes or improvements to drug discovery programs for complex diseases, healthcare information technology (HIT) must make the next major transition to improve data quality, reduce cost and lead to better patient outcomes.

TLI's experience integrates the human dimension of building trusted data systems with an indepth understanding of the technologies needed and how they can be made to work cooperatively—with the understanding that data does not equate with having solid information that can be readily put into practice.

### **Turning Raw Data into Meaningful Information**

While technology makes it possible to generate and collect unprecedented amounts of data, managing, analyzing and aggregating that data in a systematic way that informs decision-making remains a challenge for many healthcare organizations. These complex computations require the development and implementation of artificially intelligent (AI) algorithms and machine learning methods to achieve accurate, automated decision-making at a speed which manual human analysis is incapable of achieving.

When armed with high quality information, today's decision-makers can quickly extract insights from and understand extremely complicated problems. In fact, big data analysis has the potential to reduce healthcare costs by over 25% in the coming years.1

TLI has many years of experience developing solutions that advance the quality of healthcare data and improve outcomes, with an understanding that improving "how we work" requires the acquisition, management and integration of data, along with the knowledge of how to turn that data into meaningful information that can improve performance.

We have hands-on experience designing and building systems on a high-performing scalable cloud architecture that enables a flow of data from systems, web-based platforms and mobile apps. This includes validation, quality checking and ingestion of the data to ensure that it is transformed into accessible and useable information.

TLI uses a proven, disciplined, agile approach that allows us to work collaboratively with the community to validate our analysis, assumptions and comprehension of the requirements. This enables us to design and build a solution tailored to the customers' unique needs in a way that ensures we are building systems and deploying technology that people trust – a deep need in today's current crisis.

This approach is critical to developing a secure, reliable, sustainable and integrated dataset that adds value to the organization. Our fluency with developing data-driven solutions comes from many years of experience building analytical capabilities for the Centers for Medicare & Medicaid Services (CMS), the U.S. Department of Defense (DoD), the U.S. Department of Veterans Affairs (VA) and commercial healthcare clients.

This white paper features three case studies of organizations facing difficult health data challenges—and the enormous difference TLI's approach made for them—as well as an overview of our capabilities.

### Eunice Kennedy Shriver National Institute for Child Health and Human Development Limb Loss and Preservation Registry – Mayo Clinic and TLI

As a subcontractor to the Mayo Clinic, TLI currently supports the National Institute of Health (NIH) National Institute of Child Health and Human Development (NICHD) in the development and launch of a Limb Loss and Preservation Registry (LLPR). For the past three years, TLI has worked with the Mayo Clinic, the American Joint Replacement Registry (AJRR), and the American Orthotic & Prosthetic Association (AOPA) to advance rehabilitation of individuals who have undergone limb loss and limb preservation surgeries.

TLI's scientific experts have worked for many years with civilian and military experts in limb loss and limb preservation to standardize, measure and report patient outcomes data, support evidence-based decision making, enhance healthcare delivery, and establish and disseminate best practices to further reintegration strategies following neuro-musculoskeletal injury.

Supported by the National Institutes of Health (NIH) and the DoD, the database will be the first national registry in the United States of its kind to include adults and children. The goal is to collect data which could lead to prevention of limb loss and improve pre- and post-surgical treatment and rehabilitation efforts for this population.

The LLPR, which is projected to be operational in 2020, 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 to support decision making for long-term care of these patients that will enhance their functionality and quality of life.

The development of the LLPR will demographically and geographically represent the U.S. population. The DoD is partnering with NIH on the database to help improve the quality of care for active military personnel and veterans, highlighting the ongoing coordination and collaboration among federal partners in rehabilitation research.

### TLI Approach

TLI worked with stakeholders to determine pertinent research questions and design and is in the process of launching the pilot for this state-of-the-art registry. The registry will collect data from multiple hospital electronic health record (EHR) systems and clinical care provider EHRs and provide a means of collecting patient reported outcomes (PROs) data. This disparate data will follow industry standard data integration, data transformation and patient identity management processes that will result in a unique data set. This data is representative of individuals with limb loss and preservation across all ages and will provide a user interface that allows diverse stakeholders to access standard reports and data visualization tools.

TLI has an extensive track record of working with DoD, Veterans Health Administration (VHA) and Health and Human Services (HHS) to find innovative ways to deal with complex and important clinical questions. We partner with AJRR, which has successfully implemented the most extensive orthopedic registry in the United States and has experience in data collection from over 1,100-member hospitals, clinics and individual providers. Their techniques of data curation, storage, report generation and portal development will be invaluable in implementation and sustainment planning. Our solution draws data from hospitals, clinicians and individuals with limb loss and preservation.

#### Extensive Experience

TLI has extensive experience in convening expert scientific advisory boards and developing comprehensive research guestions and implementable research strategies. Working with AJRR, AOPA, American Academy of Orthotics and Prosthetics (AAOP), American Academy of Physical Medicine and Rehabilitation (AAPMR), American Physical Therapy Association (APTA), academia and industry, we are developing a LLPR to make data available to gualified academic, military, VHA and clinical researchers.

What's more, the LLPR will be secure, HIPAA-compliant and meet all applicable DoD, VHA, HHS and industry standards. The interface with researchers is designed to not only be intuitive and user-friendly, but also control data access through rigorous transfer protocols.

The enabled research is far-reaching to encompass processes of care and outcomes research and support investigation of when limb preservation is appropriate and when amputation enhances functionality. Assistive device usage and availability of advanced technology is another major area of interest to individuals with limb loss and preservation, their care providers, and the industry. This LLPR will also be critical for developing new practice guidelines and reimbursement strategies to achieve optimal outcomes.

## Uniformed Services University through Henry M. Jackson Foundation (HJF) for the Advancement of Military Medicine Building Health Military Communities (BHMC) / Operation Live Well

TLI experts provided strategic insights to shape the Operation Live Well (OLW) portfolio, linked OLW to the 100 Million Healthier Lives Campaign, translated the Total Force Fitness (TFF) academic framework into a measurable, actionable behavior change model and created the action domain structure for Technology Enhanced Mobile Platform for Performance Optimization (TEMPPO) that translates to multiple populations. TLI also developed and tested TEMPPO on a mobile platform.

TEMPPO goals were to: 1) develop an app that provides individuals with engaging virtual fitness coaching across the TFF multiple domains, and 2) conduct human subject research to determine the effectiveness of smartphones, apps and other internet resources, as components of mobile health engagement, for improving behaviors necessary to achieve higher levels of fitness, readiness and wellness in military populations.

TLI provided scientific expertise and research support to the multiple activities of the OLW portfolio by developing the rapid needs assessment (RNA) interview guides and data management plan and supported the interviews and data management for three of the seven BHMC pilot states.

## Uniformed Services University of the Health Sciences through the Henry M. Jackson Foundation for the Advancement of Military Medicine Preservation of the Force and Family (POTFF) Toolbox

TLI hosted and facilitated a series of workshops to develop a toolbox for POTFF program leaders. The toolbox provided the basis for programmatic measures of effectiveness and

performance consistent with the core principles of human performance, the Special Operations Forces (SOF) mission, which we mapped back to the four key domains of the POTFF program.

Various and diverse stakeholders' viewpoints and positions were gathered during facilitated workshops designed to allow for answers that respected service-specific and joint equities, leaders at many levels and family members. Stakeholders were asked to identify their most important goals for achieving and maintaining optimal human performance. Their responses were measured with respect to the prime question of "what does successful human performance look like across the four POTFF domains for both deployment and redeployment?"

TLI served as a third-party host and facilitator of the workshops, as well as the integrator of the data collected through the workshops and information revealed through data analysis. We also analyzed the information and drafted recommendations for a toolbox of POTFF outcome metrics for use in various evaluation efforts before and after exposure to POTFF-related interventions.

TLI used a transparent, methodological process to achieve the aims and ensure that clear, comprehensive and unbiased information was available to the POTFF leaders and community seeking to make informed decisions for the construction of a toolbox for outcome measures and metrics. These metrics were used in various evaluation efforts before and after exposure to POTFF-related interventions.

### **Snapshot of TLI Capabilities**

Program and Project Management and Integration

TLI has a mature Program Management Office (PMO) and internal controls and processes for program/project management to include financial management of the project budget, which are modeled to the Project Management Body of Knowledge (PMBOK) and industry best practices. This enables TLI to work from a task and milestone-oriented schedule for delivery of contract deliverables and a forecasted budget as we execute a program. Our PMO is a permanent integrated structure supporting all TLI programs. It performs tool management, financial planning and tracking, quality control, process and financial audits, communication planning and employee training.

Furthermore, TLI uses a robust change management framework to ensure quality. Our framework uses quality control procedures and enables continuous monitoring of data in order to determine whether it is compliant with relevant quality standards and identify methods by

which invalid or incomplete data occurrences can be mitigated. This is accomplished through data versioning and preservation strategy, data collecting and recording, data storage and retrieval and data validation, transformation and integration.

### Strategic Communications and Implementation

TLI participates in all strategic communications and serves in a technical design and implementation role. We are also responsible for communications with other team partners and management of project schedule and deliverables. In this role we:

- Meet with funders, clinicians, research scientists and policy makers
- Assist with leading meetings
- Create a governance model to ensure high standards
- Develop data requirements and identify the analytical tools required to answer a wide range of research questions with scientific rigor and evidence-based methods
- Identify data sources and strategy of data acquisition and integration
- Evaluate feasibility of various data acquisition strategies and pilot data acquisition processes to ensure viability
- Architect the system to harmonize and securely store data in a way that meets all privacy and security requirements
- Create a role-based access control matrix for users to request and access data based on their needs

#### **Financial Management**

Through our PMO, TLI has procedures, processes and tools in place that bring together planning, budgeting, accounting, financial reporting, internal control, auditing, procurement and the execution of a project with the goal of managing project resources properly and achieving project objectives. Every TLI project is engaged with our PMO to ensure compliance to budgetary, regulatory and audit standards. Our PMO provides meaningful financial data that can be used to manage each program's budget and resources.

### Work with Us

The possibilities of technology continue to evolve and challenge us all to work smarter and better together. We strongly believe that *better data* leads to *better care* – but it takes a lot of work.

TLI is currently seeking new clients and partners who need our help with health data and analytics challenges. Recently, we began partnerships in genomic analytics, rehabilitative medicine, pharmacogenomics and telehealth.

Please reach out to us at info@thoughtfoundation.org to start a conversation on how we can collaborate to make healthcare work better!

<sup>&</sup>lt;sup>1</sup> Dash, S., Shakyawar, S.K., Sharma, M. et al; Big data in healthcare: management, analysis and future prospects; J Big Data 6, 54 (2019); https://doi.org/10.1186/s40537-019-0217-0; https://link.springer.com/article/10.1186/s40537-019-0217-0; accessed July 20, 2020.