



JOHNS HOPKINS  
MEDICINE

# Getting started in musculoskeletal research

## Accessing the data that you need to answer the important questions

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# Objectives

- Identify institutional resources for clinical and health services research
- Describe access to musculoskeletal datasets and analytics support
- Highlight real-world examples



# Institutional Landscape

## Data Sources

- Department
  - *Division-level registries*
  - *Secondary analysis of trial data*
- Health System
  - *Epic*
  - *TriNetX*
- Administrative Data
  - MarketScan

## Resources

- Research Electronic Data Capture
- Qualtrics
- AI Lab



# Department-level Resources

- Spine
  - Surgical Outcomes Research Center
    - Prospective registry of patient-reported outcome (PRO) measures
    - Linked to socio-demographic, clinical, surgical, and radiographic data
- Joints
  - American Joint Replacement Registry (AJRR)
- MSK Tumor
  - Musculoskeletal Tumor Registry (MsTR)
- Shoulder
  - McFarland's prospective registry of shoulder patients



# Example

> J Neurosurg Spine. 2019 Jan 18;30(4):524-531. doi: 10.3171/2018.9.SPINE18521.  
Print 2019 Apr 1.

## Comparison of PROMIS Anxiety and Depression, PHQ-8, and GAD-7 to screen for anxiety and depression among patients presenting for spine surgery

Taylor E Purvis, Brian J Neuman, Lee H Riley, Richard L Skolasky

PMID: 30660113 DOI: 10.3171/2018.9.SPINE18521

### Abstract

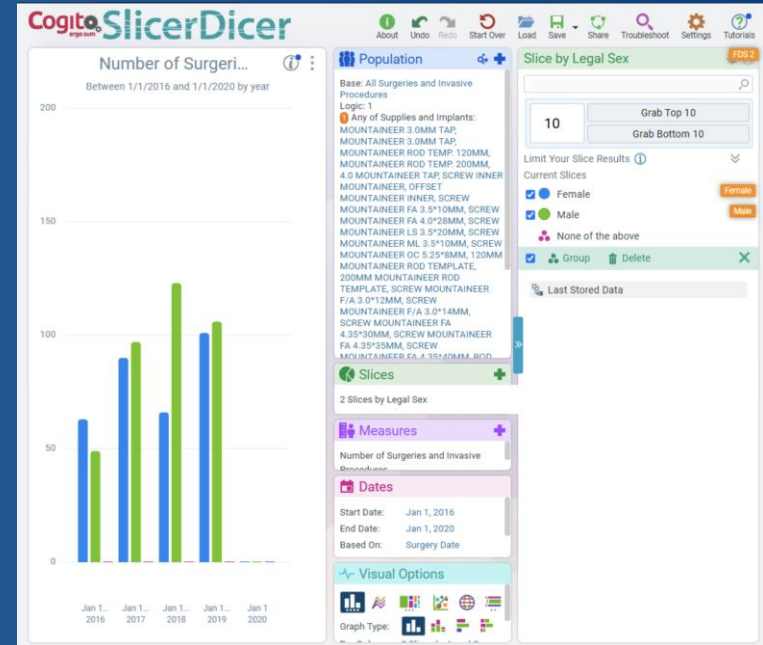
**Objective:** In this paper, the authors demonstrate to spine surgeons the prevalence and severity of anxiety and depression among patients presenting for surgery and explore the relationships between different legacy and Patient-Reported Outcomes Measurement Information System (PROMIS) screening measures.

- Spine registry
  - 512 adult spine surgery patients
  - GAD-7, PHQ-9, PROMIS
  - Correlation
  - Cross-walk tables
  - ROC curves



# Health System-level Resources

- Epic
  - Slicer-Dicer – data exploration tool in HER
  - Analyze data – demographics, medications, and procedures
  - Create reports
  - Identify trends
- Patient level data with CCDA approval



# Example

> Seizure. 2024 Nov;122:172-178. doi: 10.1016/j.seizure.2024.09.018. Epub 2024 Oct 3.

## Antiseizure medication-induced hypersensitivity reactions: Data from a large healthcare system

Benjamin Cadle <sup>1</sup>, Feride Un Candan <sup>2</sup>, Zulfi Haneef <sup>3</sup>, Christopher Ryan Barton <sup>4</sup>, Dylan Brock <sup>4</sup>, Irfan Ali <sup>5</sup>, Jaime Shoup <sup>4</sup>, Cemal Karakas <sup>4</sup>

Affiliations + expand

PMID: 39454220 DOI: 10.1016/j.seizure.2024.09.018

### Abstract

**Background and objectives:** Data on hypersensitivity reactions (HR) to individual anti-seizure medications (ASMs), and reactions to additional ASMs, is often limited by sample size. This data is vital in helping clinicians identify initial and subsequent ASMs to use in treating persons with epilepsy (PWE). Using a very large dataset, our study attempts to quantify the occurrence of HR across 31 different ASMs. We also attempt to investigate whether certain pairs of ASMs are associated with a higher frequency of HR.

- EHR Slicer-Dicer
  - 573,571 patients with exposure to anti-seizure medication
  - Rate of hypersensitivity reaction by medication



# Health System-level Resources

- TriNetX
  - Aggregate de-identified patient information from EHRs nationally and internationally
  - 250+ millions patients
  - Access through CCDA





Multicenter Study > [Spine](#) (Phila Pa 1976). 2025 Jul 1;50(13):871-880.  
doi: 10.1097/BRS.0000000000005283. Epub 2025 Feb 3.

### Glucagon-Like Peptide-1 Receptor Agonist Medications Alter Outcomes of [Spine](#) Surgery: A Study Among Over 15,000 Patients

Joshua M Wiener <sup>1 2</sup>, Parshva A Sanghvi <sup>1 2</sup>, Katelyn Vlastaris <sup>1 2</sup>, Thomas Mroz <sup>2</sup>, Jonathan Belding <sup>1 3</sup>, David C Kaelber <sup>4</sup>, Thomas Olson <sup>5</sup>, Kevin P Francis <sup>5</sup>, John S Adams <sup>5</sup>, Nicholas Bernthal <sup>5</sup>, William L Sheppard <sup>5</sup>

Affiliations + expand  
PMID: 39895110 DOI: [10.1097/BRS.0000000000005283](#)

#### Abstract

**Study design:** Retrospective cohort study.

**Objective:** To investigate the relationship between perioperative glucagon-like peptide-1 receptor agonists (GLP-1 RAs) and postoperative outcomes after spinal fusion in obese and diabetic patient populations.

**Background:** GLP-1 RAs have been shown to be beneficial when used perioperatively in clinical orthopedic arthroplasty literature. Minimal evidence exists showing efficacy with respect to spinal fusion.

- TriNetX

- 2,263 spine surgery patients with diabetes stratified by obesity
- Post-operative outcomes (infection, revisions, readmission)



# Health System-level Resources

- Marketscan
  - Commercial claims and encounter database
  - Medical and drug data from employers and health plans
  - 6+ million individuals
  - Accessed through JHPCE



Contact us about databases available via CHSOR and its collaborators for health services and outcomes research.

Read about PRO tools [here](#) .

Stay updated about [data and other resources](#) that might be appropriate for HS&OR related to COVID-19

## **National Health and Aging Trends Study (NHATS)**

NHATS is a longitudinal, nationally-representative study of Medicare beneficiaries aged 65 and older. The survey focuses on health and functioning and collects data on the physical, social, technological and service environment, physical and cognitive capacity, use of assistive devices and rehabilitation, help received with daily activities, and wellbeing. It also includes information on quality of end of life care, as well as the role of family caregivers. It began in 2011 and currently has five rounds of longitudinal data publicly available to analyze. It also has the capacity to be linked with Medicare claims data. For more information, please email [nhatsdata@westat.com](mailto:nhatsdata@westat.com).

Most recently, NHATS is conducting a mail follow-back for its participants to ascertain COVID-19 symptoms, social distancing behaviors, and changes compared to before the outbreak in living arrangements, contact with family and friends, activities, health care, finances, wellbeing and care. NHATS has also added an open-ended question to its telephone interview on how the COVID-19 pandemic has affected participants' lives.

## **Marketscan Commercial Claims and Encounters Database**

The MarketScan Commercial Claims and Encounters Database (Commercial Database) consists of medical and drug data from employers and health plans. It contains data for several million individuals annually, encompassing employees, their spouses, and dependents who are covered by employer-sponsored private health insurance. Healthcare for these individuals is provided under a variety of fee-for-service (FFS), fully capitated, and partially capitated health plans. These include PPOs and exclusive provider organizations (EPOs), POS plans, indemnity plans, HMOs, and consumer-directed health plans. Medical claims are linked to outpatient prescription drug claims and person-level enrollment information. These data are managed by the staff of the Center for Drug Safety and Effectiveness and can be contacted at [cdse@jhsp.edu](mailto:cdse@jhsp.edu).

## **Annual Hospital Survey Database**

Several faculty members have extensive experience working with the American Hospital Association's Annual Hospital Survey Database. Johns Hopkins University's Welch Library provides access to the Survey Database. The database encompasses topics including: Organizational structure; Facilities and services; Beds and utilization; Staffing; Expenses; Physician arrangements; System affiliation; Geographic indicators; Accreditations and approval codes by credentialing organizations. Access to these data can be initiated here: <https://databases.library.jhu.edu/databases/database/JHU04715>. For more information on collaborating with CHSOR faculty to use the Survey, please contact Jill Marsteller at [jmarste2@jhu.edu](mailto:jmarste2@jhu.edu) and Yea-Jen Hsu [yhsu2@jhu.edu](mailto:yhsu2@jhu.edu).

## **Medicare Current Beneficiary Survey (MCBS)**

The MCBS is a nationally-representative, panel survey of Medicare beneficiaries that collects information on health status, access to care, satisfaction with care, utilization, and cost through a survey linked to Medicare claims data. These files are now being made available as a publicly use file (certain parts of the access and satisfaction file not linked to the cost and utilization data), and the full limited data set that contains all the survey questions and claims data. Currently the 2013 data files are available from CMS. For more information, please contact Amber Willink at [awillink2@jhu.edu](mailto:awillink2@jhu.edu).

# Example

> J Neurosurg Spine. 2018 Aug;29(2):169-175. doi: 10.3171/2018.1.SPINE17964.  
Epub 2018 May 25.

## **Trends in isolated lumbar spinal stenosis surgery among working US adults aged 40–64 years, 2010–2014**

Micheal Raad <sup>1</sup>, Callum J Donaldson <sup>2</sup>, Mostafa H El Dafrawy <sup>1</sup>, Daniel M Sciubba <sup>1</sup>,  
Lee H Riley <sup>1</sup>, Brian J Neuman <sup>1</sup>, Khaled M Kebaish <sup>1</sup>, Richard L Skolasky <sup>1</sup>

Affiliations + expand

PMID: 29799337 DOI: 10.3171/2018.1.SPINE17964

### **Abstract**

**OBJECTIVE** Recommendations for the surgical treatment of isolated lumbar spinal stenosis (LSS) (i.e., in the absence of concomitant scoliosis or spondylolisthesis) are unclear. The aims of this study were to investigate trends in the surgical treatment of isolated LSS in US adults and determine implications for outcomes. **METHODS** The authors analyzed inpatient and outpatient

- **Marketscan**

- 20,279 patients undergoing lumbar spinal stenosis surgery
- Trend over time for decompression vs. fusion
- Post-operative complications, length of stay, etc.



# Tools to Support Research

- REDCap
  - Secure web-based application to build and manage online surveys and databases
  - Requires IRB approval
  - Accessed through ICTR

**PROMIS 29 Profile V20**

Data Access Group: Johns Hopkins ?

Invitation status:  **Survey options**

[Editing existing Study ID 10347-1.](#)

Event: **Baseline** w00

Study ID 10347-1

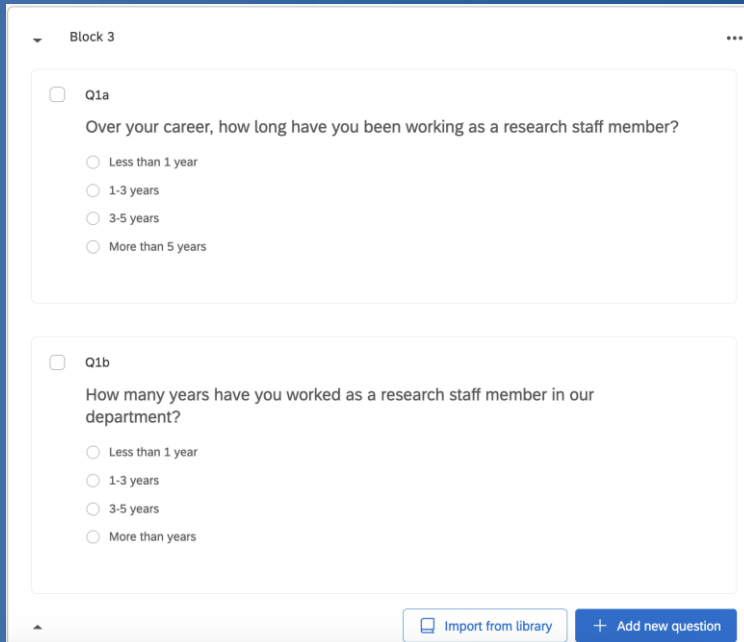
Please respond to each item by choosing one answer per statement.

**Physical Function**

	Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
1. Are you able to do chores such as vacuuming or yard work?.... <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
<a href="#">reset</a>					
2. Are you able to go up and down stairs at a normal pace?.... <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
<a href="#">reset</a>					
3. Are you able to go for a walk of at least 15 minutes?.... <small>* must provide value</small>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<a href="#">reset</a>					
4. Are you able to run errands and shop?.... <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
<a href="#">reset</a>					



# Tools to Support Research



Block 3

☐ Q1a

Over your career, how long have you been working as a research staff member?

☐ Less than 1 year

☐ 1-3 years

☐ 3-5 years

☐ More than 5 years

☐ Q1b

How many years have you worked as a research staff member in our department?

☐ Less than 1 year

☐ 1-3 years

☐ 3-5 years

☐ More than years

[Import from library](#) [+ Add new question](#)

- Qualtrics
  - Cloud-based platform to create, distribute, and analyze surveys
  - Tableau integration for tables and reports
  - JHED ID access



# Tools to Support Research

- GenAI Lab
  - Generative AI tool developed at JH
  - Secure engagement with Claude, Llama, ChatGPT
  - Other resources
    - AI for Research & Scholarship
    - Responsible AI Task Force
    - Gen AI Tool Guidance
    - Prompting tips



## Welcome to GenAI@JH

Generative artificial intelligence (GenAI) has the potential to revolutionize the ways in which we advance research, deliver patient care, perform administrative processes, and achieve academic discovery.

As GenAI rapidly evolves, it unlocks a world of possibilities that can elevate our research, invigorate our teaching, spark groundbreaking academic discoveries, and streamline our administrative processes. We are dedicated to unleashing GenAI's transformative potential across Johns Hopkins while upholding responsible and ethical usage.

[Check out the Hopkins AI Lab!](#)



**GenAI Responsible  
Use Guidance**



**GenAI Resources**