Transforming Cardiovascular Care Through Discoveries in Imaging

SCMR 23RD ANNUAL SCIENTIFIC SESSIONS

How can I Participate in the SCMR Registry?

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Chair, SCMR Registry Committee
The Ohio State University

Friday, 14 February 2020

History

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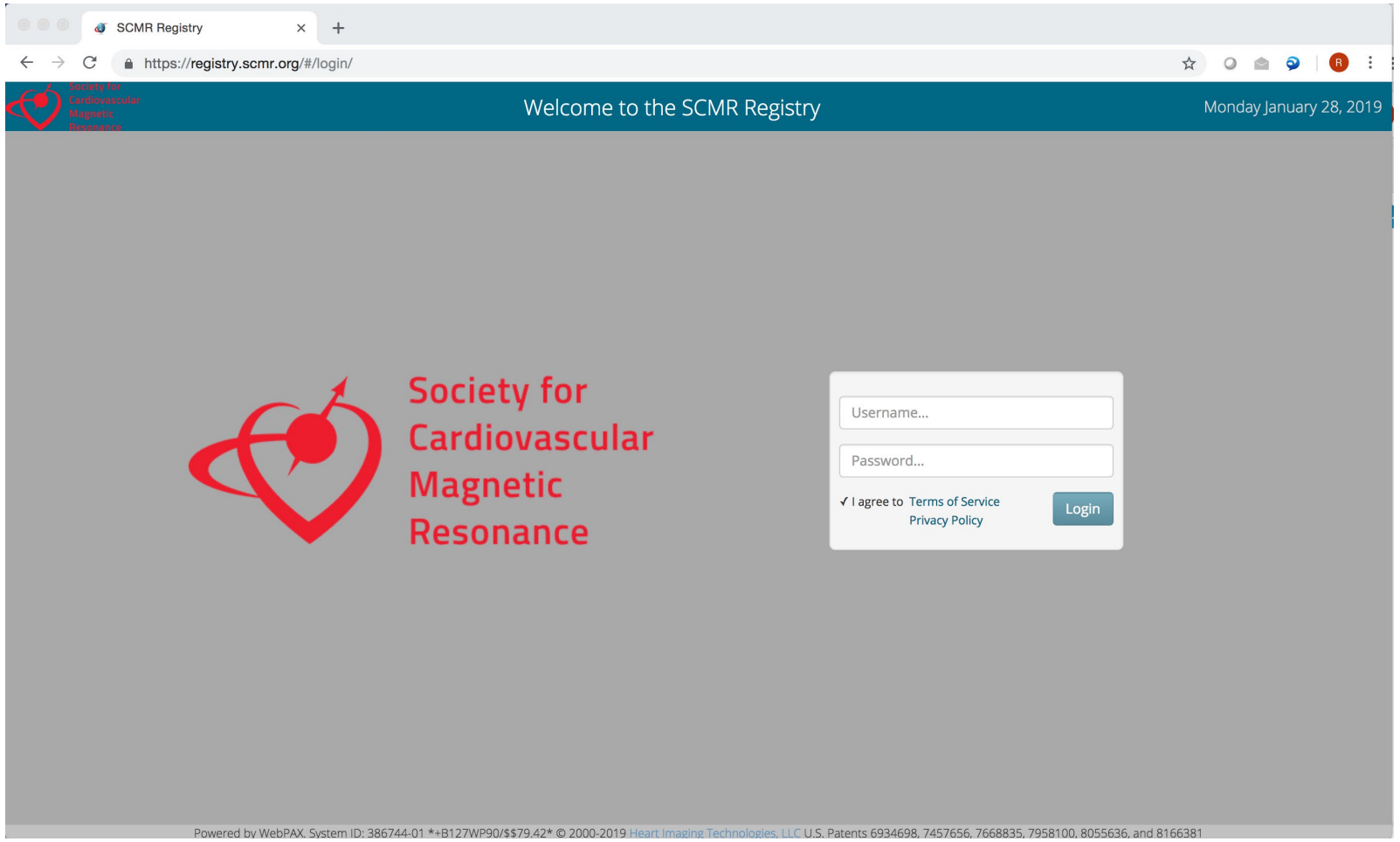
- The SCMR Board invested resources to start a Global CMR registry in 2014.
- The main goals of the Registry are to:
  - Support the SCMR mission: **To improve cardiovascular health by advancing the field of CMR**
  - Provide a web mechanism for CMR centers to upload de-identified patient data, CMR reports, and images to share for purposes of **research, education, and quality control**
  - Support data access globally by making registry data available to the wider CMR research community
- SPINS trial led by Raymond Kwong demonstrates the power and potential of SCMR Registry research efforts.

The New SCMR Registry Platform

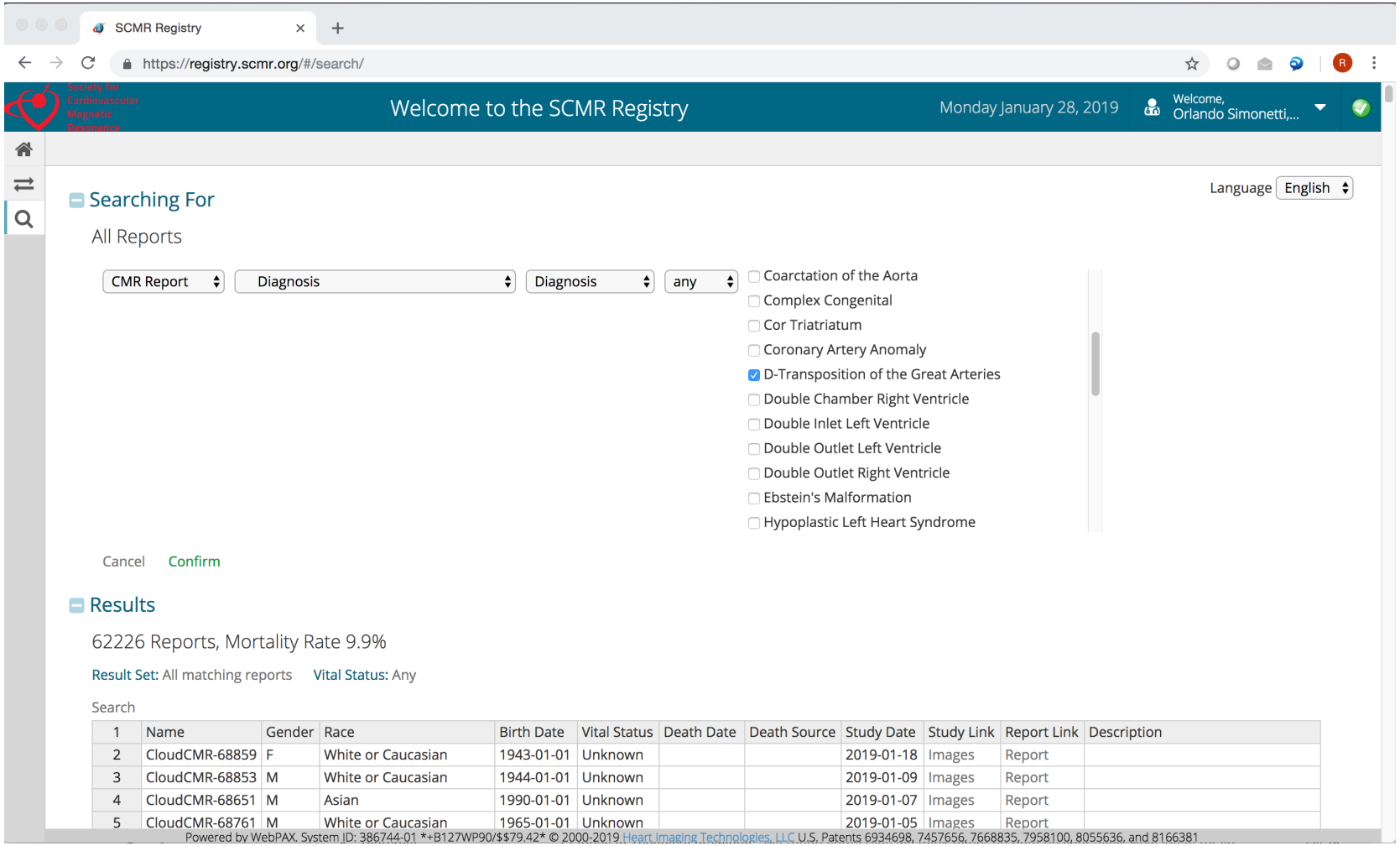


Launched February 2019
https://registry.scmr.org

HeartIT CloudCMR infrastructure

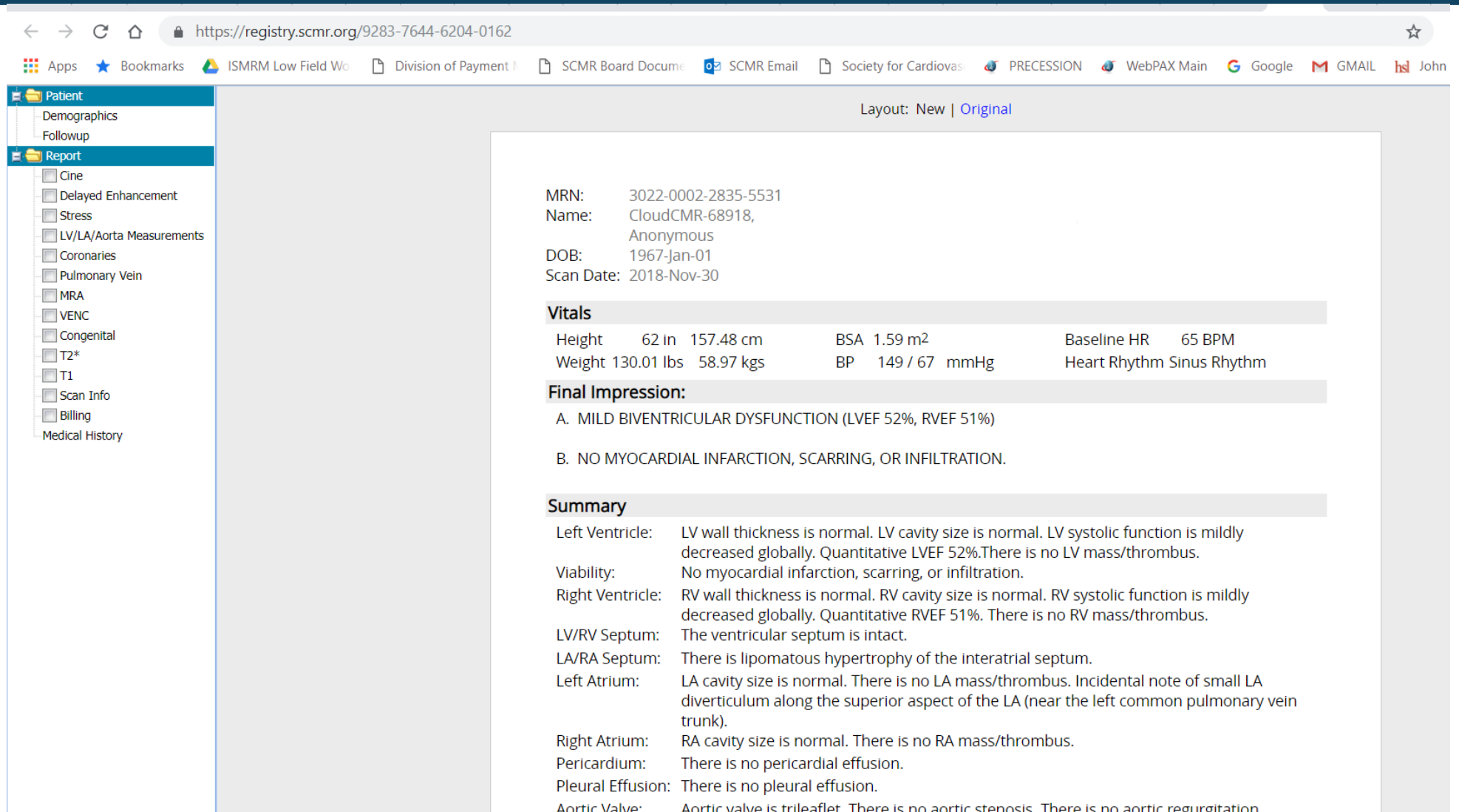
SCMR Registry Committee and SCMRHQ manage the registry

What data are in the Registry?



- **Searchable Database currently includes >74,000 cases.**
- **Additional sites with contracts pending will soon bring the total to 100,000**

What data are in the Registry?



Integrated Report data

What data are in the Registry?

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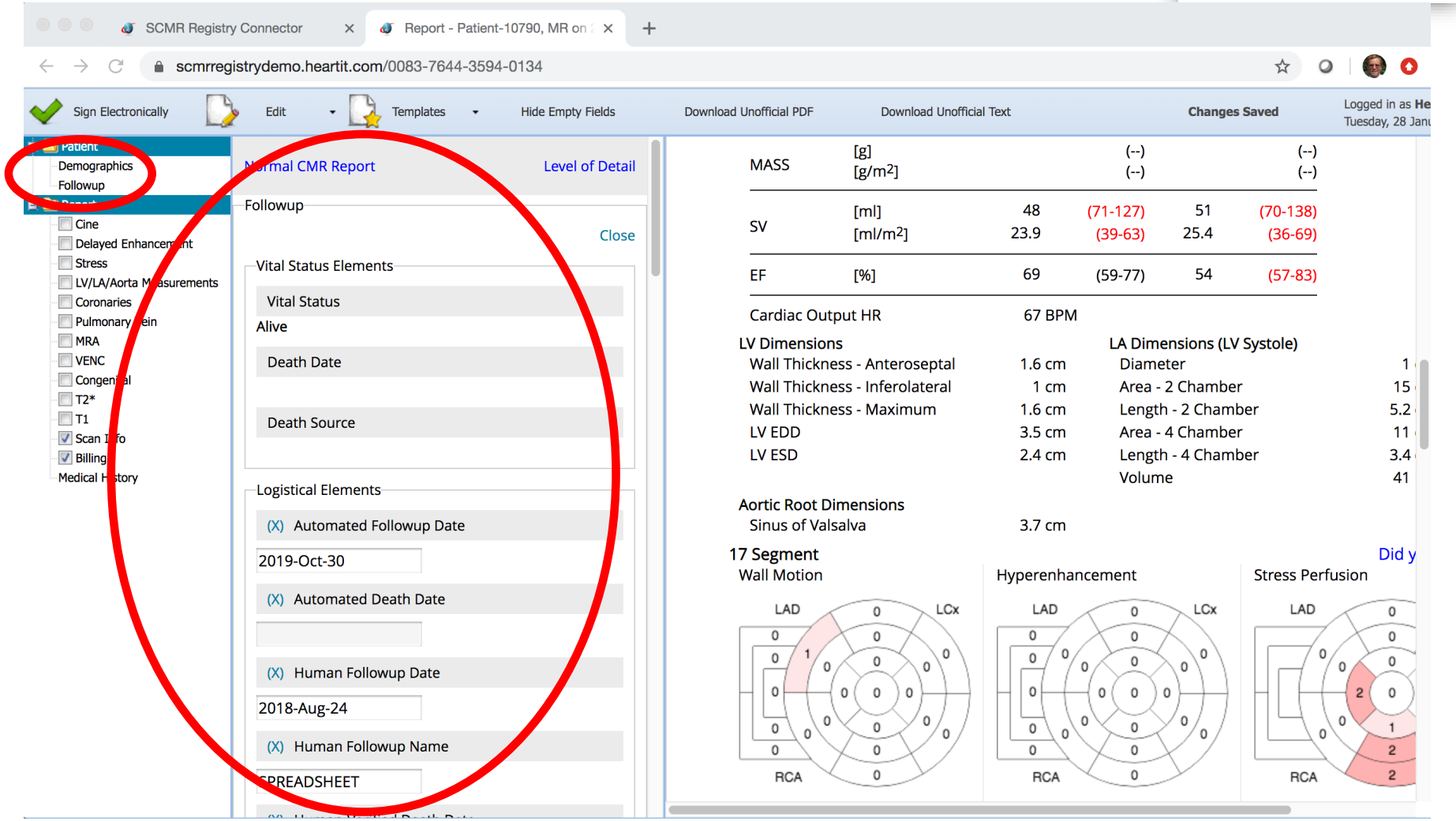
Follow-up data

Linked to Social Security Death Index to track all-cause mortality



What data are in the Registry?

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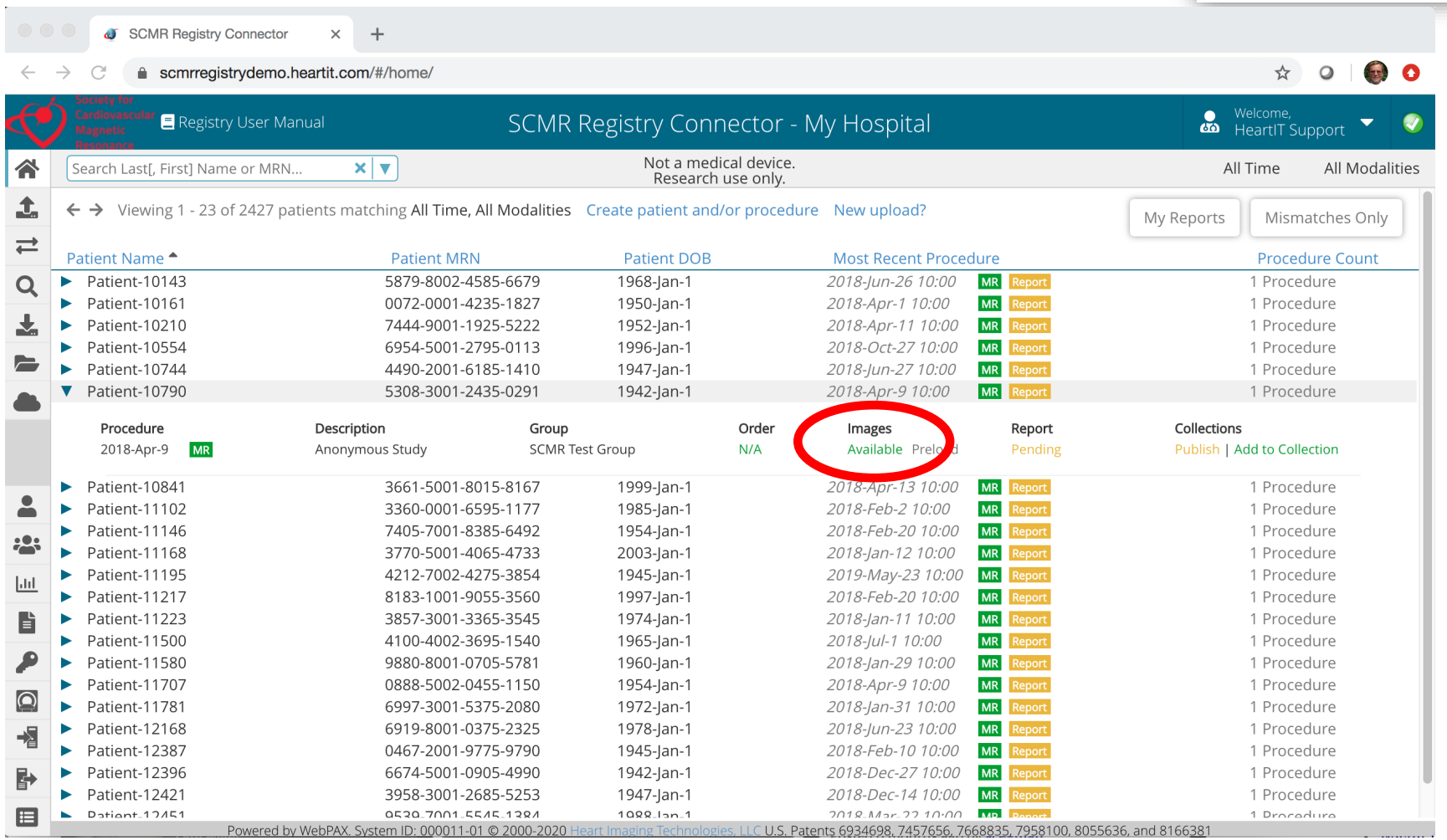
Images



What data are in the Registry?

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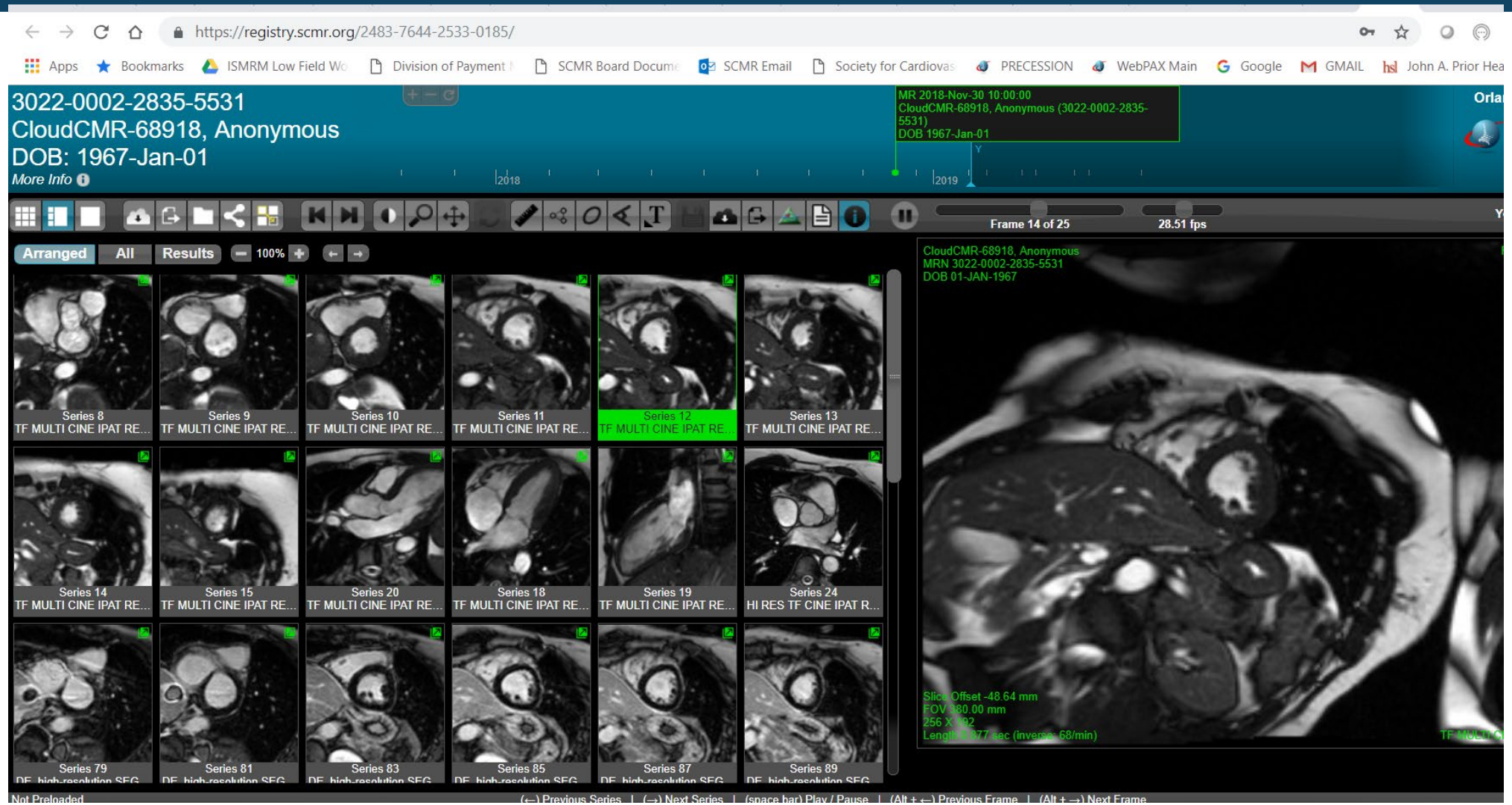

Integrated DICOM data

Steps to Registry Participation

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1. Download the SCMR Registry Participation Agreement:

   from https://scmr.org/page/Registry

2. Secure Institutional signature

3. IRB Review

   Note that Registry participation is not considered to be human subjects research in the USA according to HHS Guidelines, and therefore does not require IRB oversight.

4. Data Security Review by your hospital IT department

Steps to Registry Participation

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Registry Connector System Installation

The Registry Connector will:

1. Extract, de-identify, and upload images and report data to the Registry from existing PACS and CMR reporting systems.
2. Provide a local, searchable database of CMR images and reports for research and quality control.
3. Enable participation in SCMR Quality Control Program.

There is a nominal charge to setup and maintain the Registry Connector

Why should I contribute data?
i.e., what's in it for me?!

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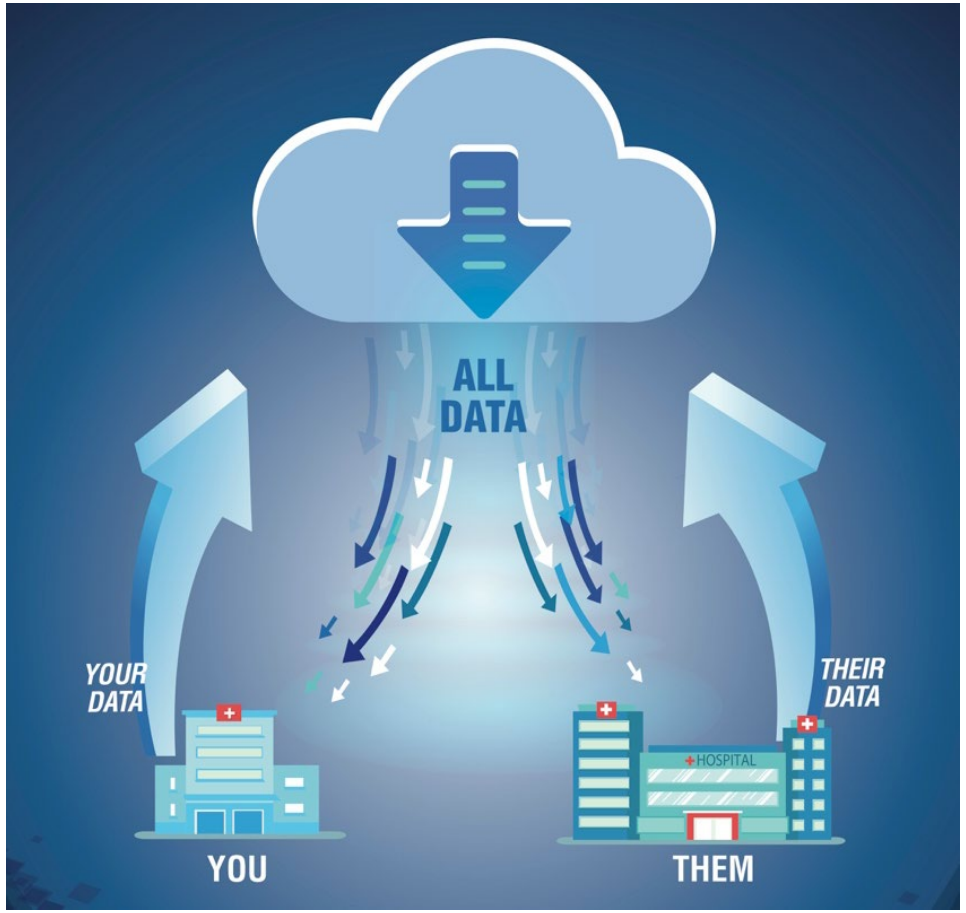
- Opportunities for research, collaboration, and publication.
- Registry Connector is a powerful local research database.
- Quality assessment features (under development) will improve your CMR service.
- "VIP access" through the Registry Portal
  - Self-service searching of the entire Registry
  - Real-time access to multi-center images, clinical data, and follow-up data

Data Sharing Principles



- **<u>Registry data are accessible to all SCMR Members</u>** for research without preferential or exclusive access for any person or organization.
- **<u>Registry data remains in control of each contributing center</u>**. Each contributor has the option to allow or restrict the use of their data on a project specific basis.
- All researchers will be subject to the same application process and approval criteria.
- All users will be required to publish their findings and return their results to the Registry

Registry Data Access Policy

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- **Any SCMR member may request access to Registry data** for the purposes of research and publication, and for the development of grant proposals that will potentially lead to external funding. **Contribution of data is not a prerequisite for access** to Registry data.

- **Registry data access will follow a two-step process**:
  1. **A search** of the Registry data will determine the number and contributor of cases meeting the specific search criteria.
  2. **A proposal** for access to the data resulting from the search is submitted to the Registry Committee for approval.

Requesting a Registry Search

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- **Active contributors** of Registry data are permitted to view and search the Registry database themselves at any time via the Registry portal.
- SCMR Members who are **not active contributors** of Registry data may submit a **search request** to the SCMR Registry Committee.
  - A Registry Committee Member will work with you interactively to optimize and execute your search.
- The outcome of an effective search will result in a tally of the number of cases meeting the search criteria, a list of which sites contributed these data, and the number of cases contributed by each site.
- This information (number of cases and contributing sites) will be incorporated into an application for access to these data.

Proposing a Registry Project

- An application to access Registry data for a specific project will be submitted to the SCMR Registry Committee
- The application will incorporate key elements including:
  - the purpose of the study,
  - a projected timeline and milestones,
  - and expected outcomes (publications and/or funding proposals).
- A publication plan is required detailing:
  - hypotheses,
  - proposed authorship,
  - pre-existing intellectual property (if any),
- The SCMR Registry Committee will review and render a decision on each proposal

Proposing a Registry Project

- The SCMR Registry Committee will contact the Contributors of data required for the project, present the research proposal together with the researcher, and request data access.
- Those Contributors who permit their data to be used may be granted co-authorship, co-investigator status, or other acknowledgement commensurate with their contribution to the project.
- Once contributing sites have agreed to participate, the relevant data will be aggregated into an SCMR Registry folder.
- Access by researchers to the aggregate data is granted only for the purposes of the specific research project detailed in the approved proposal.

Steps to Registry Research

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SEARCH THE REGISTRY DATABASE

- Data Contributors search on their own
- Non-contributors submit a search request

SUBMIT A PROJECT PROPOSAL

- Application reviewed and approved by Registry Committee

REQUEST DATA ACCESS FROM CONTRIBUTORS

- Researcher and Registry Committee pitch the project to contributors

AGGREGATE PROJECT DATA FOLDER CREATED BY SCMR

- Data contributors access in real-time
- Non-contributors receive periodic data dumps

Does this data sharing model work?

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Research

JAMA Cardiology | Original Investigation

Prognostic Value of Vasodilator Stress Cardiac Magnetic Resonance Imaging

A Multicenter Study With 48 000 Patient-Years of Follow-up

John F. Heitner, MD; Raymond J. Kim, MD; Han W. Kim, MD; Igor Klem, MD; Dipan J. Shah, MD; Dany Debs, MD; Afshin Farzaneh-Far, MD, PhD; Venkateshwar Polsani, MD; Jiwon Kim, MD; Jonathan Weinsaft, MD; Chetan Shenoy, MD; Andrew Hughes, BS; Preston Cargile, BS; Jean Ho; Robert O. Bonow, MD; Elizabeth Jenista, PhD; Michele Parker, MS; Robert M. Judd, PhD

> 9,000 patients

Automated all-cause mortality tracking

Does this data sharing model work?

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- > 1,000 patients
- **Access to images for post-hoc analysis**
- Automated all-cause mortality tracking

JACC: CARDIOVASCULAR IMAGING VOL. 11, NO. 10, 2018

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Feature-Tracking Global Longitudinal Strain Predicts Death in a Multicenter Population of Patients With Ischemic and Nonischemic Dilated Cardiomyopathy Incremental to Ejection Fraction and Late Gadolinium Enhancement

Simone Romano, MD,[a,b] Robert M. Judd, PhD,[c] Raymond J. Kim, MD,[c] Han W. Kim, MD,[c] Igor Klem, MD,[c] John F. Heitner, MD,[d] Dipan J. Shah, MD,[e] Jennifer Jue, MD,[a] Brent E. White, MD,[a] Raksha Indorkar, MD,[a] Chetan Shenoy, MD,[c] Afshin Farzaneh-Far, MD, PhD[a]

ABSTRACT

OBJECTIVES The aim of this study was to evaluate the prognostic value of cardiac magnetic resonance (CMR) feature-tracking-derived global longitudinal strain (GLS) in a large multicenter population of patients with ischemic and nonischemic dilated cardiomyopathy.

Support the SCMR Registry!

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- The success of the SCMR Registry depends on your participation!
- You can participate as a researcher even if your site does not contribute data.
- Stop by the SCMR Booth to try out your search with a Registry Committee member
- To find out more go to: https://scmr.org/page/Registry or contact me (Simonetti.9@osu.edu) or Lauren Small (lsmall@scmr.org)