



## **MIDRC Data Contribution Pathways**

### **MIDRC Town Hall**

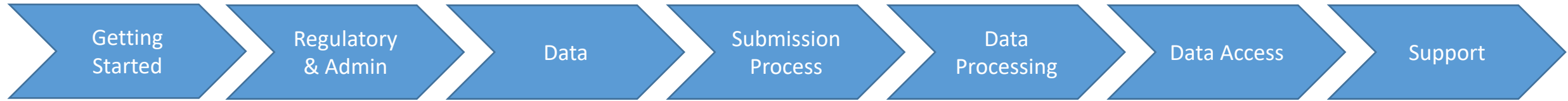
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July 22, 2021

# MIDRC Team is Experienced With...

- Management and curation of DICOM/clinical data through clinical trials, registries and data science challenges.
- De-identification of PHI and HIPAA regs.
- Secure transfer of large volumes of medical image data.
- Securing appropriate permissions with leadership at donating sites.
  - IRB
  - Compliance, privacy, regulatory officers
  - Preparing appropriate documentation
    - Data Use Agreements
    - Data Sharing Agreements

# What is the Pathway to Contribution?



How do I get started?

What are the regulatory and legal requirements?

What Imaging and other Data are Needed?

How do I submit cases?

How is data de-identified and processed?

When is the data made accessible?

How does the MIDRC team support this process?

# What is the Pathway to Contribution?



- Attend Town Hall (you're already here!)
- Sign up through MIDRC portal (<https://www.midrc.org/donate>)
  - Tell us about yourself
- Identify a champion for the project (if it's not already you)
- Identify key personal at your organization (varies by site)
  - Compliance/privacy officer
  - Institutional review board (IRB)
  - Department leadership
  - IT leadership

*The MIDRC team is here to help!*

# What is the Pathway to Contribution?

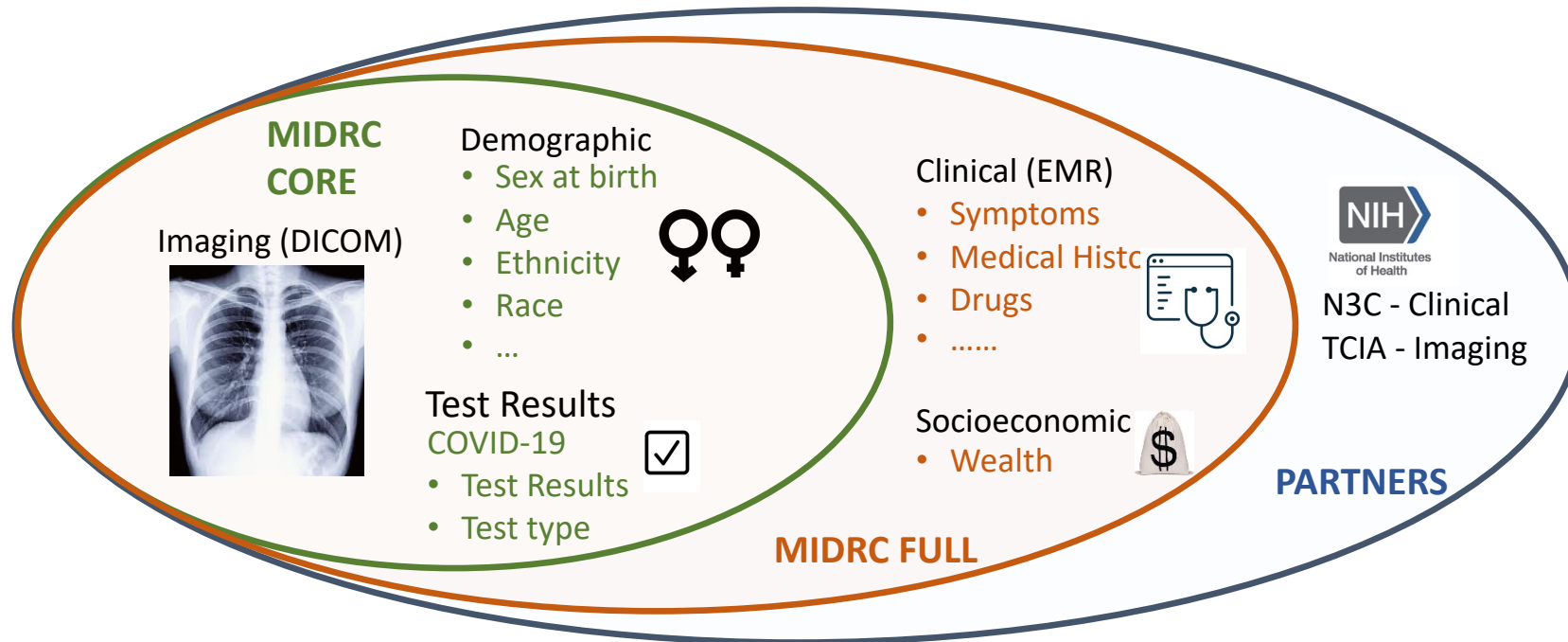


- Work with a MIDRC Liaison
- Standard Data Transfer Agreements
- MIDRC guides sites through:
  - ✓ Obtaining IRB determination.
  - ✓ Obtaining Privacy Office Approval
  - ✓ Executing data contribution agreements

Sites can work on technical set-up and data identification and extraction alongside legal and regulatory steps.

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# What is the Pathway to Contribution?



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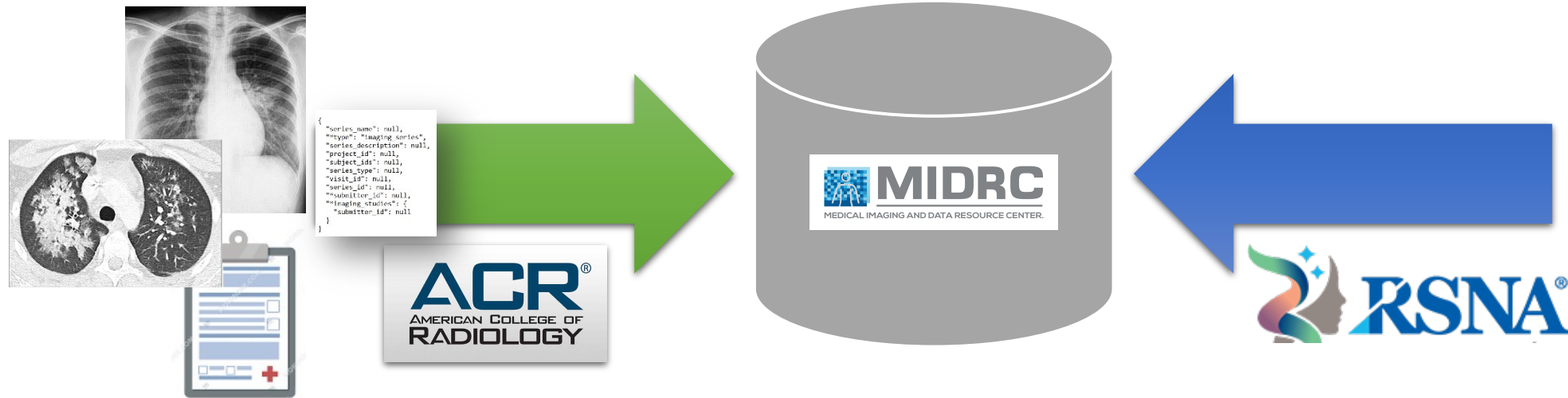
# What is the Pathway to Contribution?



- MIDRC supports sites in identifying the most efficient approach to extracting clinical and image data from their local systems.
- Flexibility in approach to accommodate site needs and minimize site burden.
- Mature technologies to facilitate the process

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# What is the Pathway to Contribution?

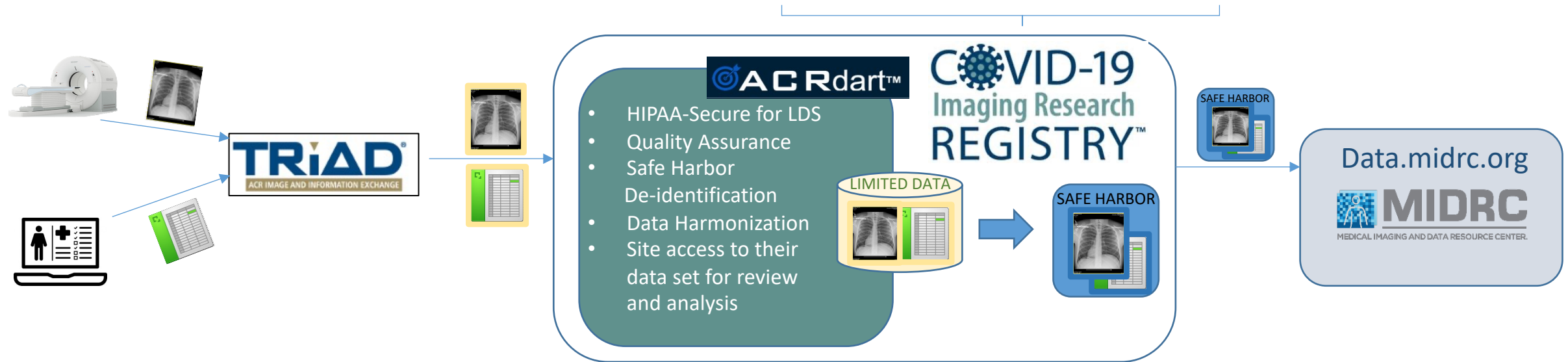


**Multiple Pathways for Contribution**

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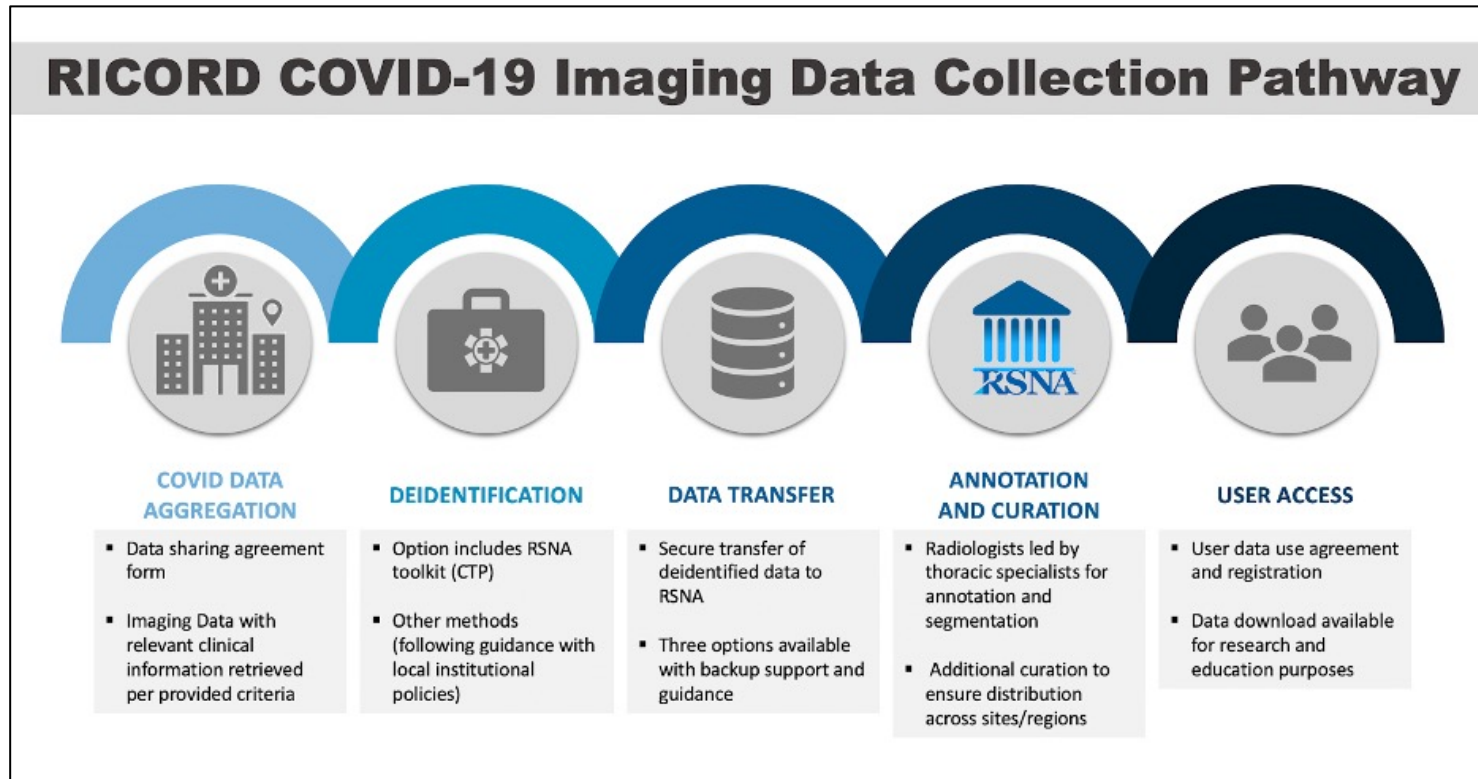


# What is the Pathway to Contribution?



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## Data Harmonization

- MIDRC accepts DICOM images and clinical data submitted in various formats
- Data is mapped to standard expressions.
- MIDRC ensures data integrity through harmonized data quality and acquisition processes.

## Data De-identification

- Technology tools installed on-site will aid in de-identification of data prior to leaving institution (Limited Data Set or Fully De-ID)
- Data is further reviewed after submission and taken through an extensive QC process to ensure that data is safe to share
- Only fully deidentified data will be shared in the public MIDRC data commons

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# What is the Pathway to Contribution?



The screenshot shows the MIDRC Explorer interface. At the top, there's a navigation bar with 'About', 'Browse Data', 'Documentation', and 'Login'. Below that, a header indicates 'Work in progress: Beta Phase'. The main content area is divided into several sections:

- Filters:** Includes 'Demographics' and 'Medical History'. Under 'Demographics', there are filters for Gender (no data: 632, Male: 390, Female: 303) and Race (no data: 1,220, Black or African American: 57, White: 40, Other: 6, Asian: 1).
- Charts:** Three pie charts are displayed: 'COVID-19 Positive' (true: 1,208 (91.2%), false: 117 (8.8%)), 'Gender' (Male: 390 (29.4%), Female: 303 (22.9%), no data: 632 (47.7%)), and 'Race' (Black or African American: 57 (4.3%), White: 40 (3%), Other: 6 (0.5%), Asian: 1 (0.1%), Native Hawaiian or Other Pacific Isla...: 1 (0.1%), no data: 1,220 (92.1%).
- Table:** A table showing the first 20 of 1,325 cases. The table has columns for Case ID, Gender, Age, Race, Zip, Covid Test Name, Covid Test Positive, Asplenia, Cancer, Chicken Pox, Chronic Kidney Disease, Current Pregnant, Cytomegalovirus, Diabetes Type 1, and Diabetes Ty.

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# What is the Pathway to Contribution?



The screenshot shows the MIDRC website's FAQ page. At the top is the MIDRC logo and navigation menu. The main content is divided into three sections: 'FAQs' (with a sub-header 'General topics'), 'Data types', and 'Data access and contributions'. Each section contains several questions with plus signs indicating expandable content.

**FAQs**  
Last updated February 22, 2021

**General topics**

- + Are images available for download at the moment?
- + What is the Medical Imaging and Data Resource Center (MIDRC)?
- + Why was the MIDRC founded?
- + Who founded the MIDRC?
- + There are other COVID-19 image data sets being created - what makes MIDRC different?

**Data types**

- + What image format is used?
- + What about data other than medical images?
- + What kinds of images are there?
- + Is there access to treatment and outcomes information?

**Data access and contributions**

- + How do I get the data and is there a fee?
- + Are there any data use restrictions?
- + Can I contribute images and other data from COVID-19 patients?

The screenshot shows the MIDRC website's contact page. It features the MIDRC logo and navigation menu at the top. The main content includes a 'Contact us.' section with a search bar and a contact form. The search bar is labeled 'Please check out our page with answers to frequently asked questions or search the MIDRC site:'. The contact form has fields for Name (First Name and Last Name), Email, Subject, and Message, followed by a 'Submit' button.

**Contact us.**

SAVE THE DATE!  
**Town Hall** MARCH 02, 2021 | 11:00 AM TO 12:00 PM CT

Join us for our first ever MIDRC Town Hall meeting and [register for the event!](#)

Please check out our page with answers to [frequently asked questions](#) or search the MIDRC site:

Search

If you still have unanswered questions or another MIDRC-related inquiry, please contact us through the form below:

Name \*

First Name Last Name

Email \*

Subject \*

Message \*

Submit

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