



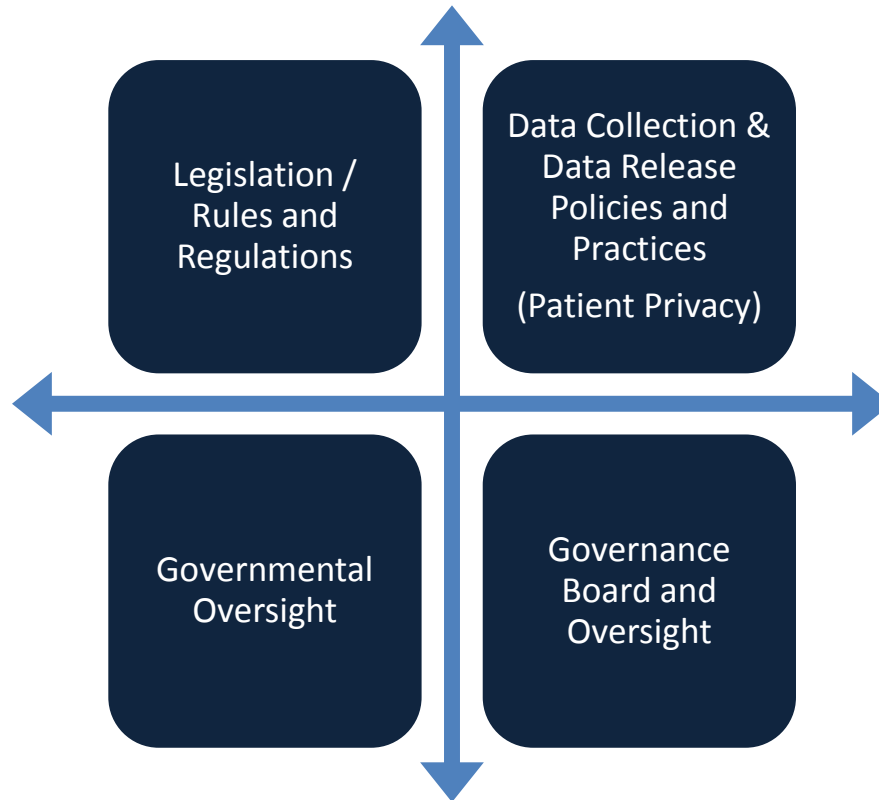
**Department  
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# Data Release and Sharing

## De-Identification from a Public Health Standpoint

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# Governance Framework



# Decision Points

- What information, if any, is shared
- With whom data reports are shared
- When and how data and reports are shared
- Restrictions on public release and access
- In what formats data are released

# Data Release Considerations

Identifiable Data  
Files

Limited Use Data  
Files

Public Use / Open  
Data Portals

Suppression/  
Masking /  
Encryption of  
Sensitive Data

Tiered Approach /  
Standard Reports

Custom Reports

Consumer Facing  
Transparency  
Website

Web Query System

Inter-agency  
Intra-agency  
Agreements

Data Use  
Agreements /  
MOUs

Authorized Use /  
Restrictions on  
Access

Legal and Financial  
Penalties

Citation  
Requirements

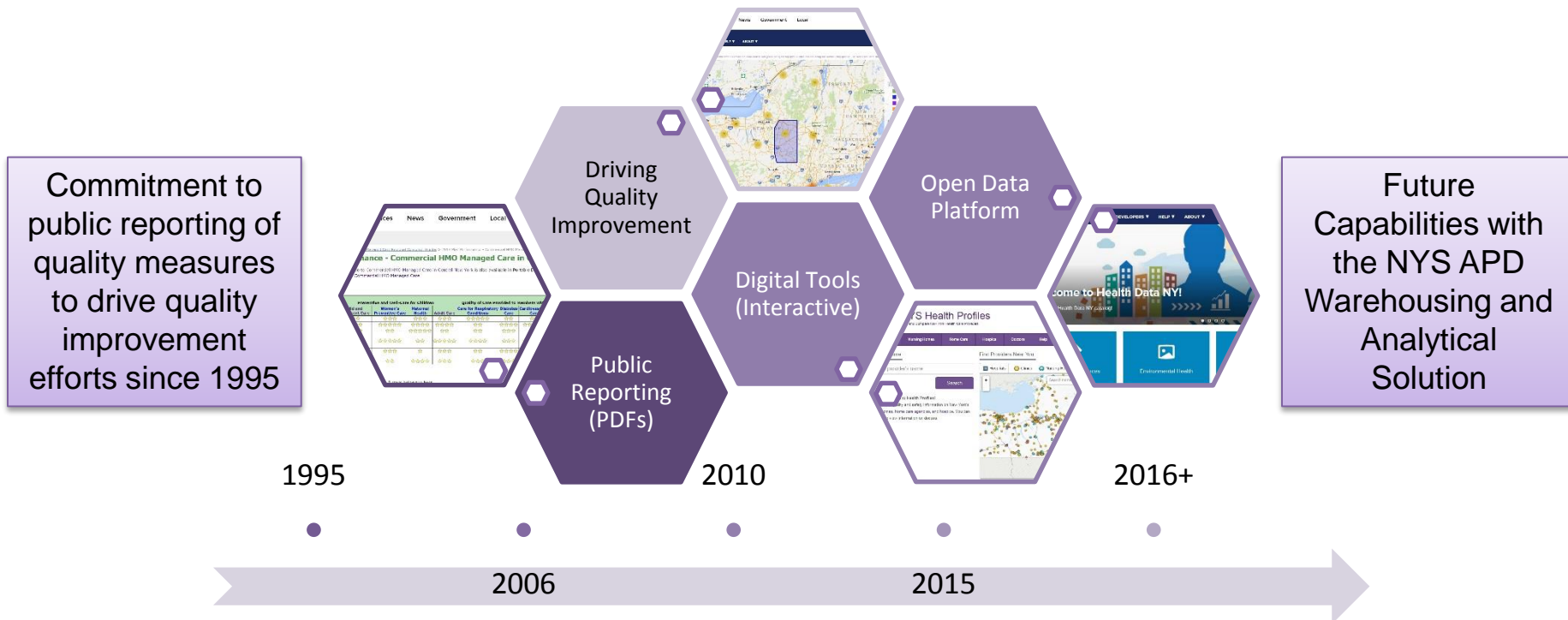
Fee Schedules /  
Licensing

Management of  
Requests /  
Dissemination

# Unique Considerations on Release

- Linkages
- Downstream Sharing
  - Medicaid
  - Medicare
- Sensitive Data
  - Fetal deaths
  - HIV/AIDS
  - Communicable diseases
  - Mental Health Treatment
  - Substance Abuse Treatment
- Expanded Content
  - Non-claims based payments
  - Plan benefit design
  - Premium information
  - Clinical/EHR data
  - Registries
  - Social determinants of health

# Current DOH Transparency Efforts



# SPARCS File Type Descriptions

## Three levels of access by file type:

File type	Contents	SPARCS Application process
Identifying/ Deniable Data Requests	Contains data elements that if disclosed without any restrictions on use or re-disclosure would constitute an unwarranted invasion of personal privacy	<ul style="list-style-type: none"><li>• Must submit application</li><li>• Data Use Agreement(s)</li><li>• Must be approved by the Data Governance Committee and ratified by the Commissioner</li></ul>
Limited	Research-oriented data file that retains some of the direct and indirect identifiers (e.g., service date, DOB) for qualified researchers with appropriate DUAs in place and appropriate restrictions.	<ul style="list-style-type: none"><li>• Must submit application</li><li>• Data Use Agreement(s)</li><li>• Must be approved by program staff as legitimate use</li></ul>
Public Use Files	Contain de-identified data consisting of basic record-level detail. Public use files do not contain protected health information (PHI) under HIPAA	<ul style="list-style-type: none"><li>• No application required</li><li>• Available on public websites (Health Data NY)</li></ul>

Additional  
Considerations  
for Custom  
Reports



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# Vital Statistics

- Aggregated reports of Vital Statistics data made available on public website and the open data portal
- Separate governance structure for birth, pregnancy and mortality data between NYC and outside of NYC
- No identifiable birth or fetal death data are released external to the DOH
- Data requests for custom data reports are handled on a per request basis for protecting patient privacy (i.e. sufficient population / denominator)

Live Births

Deaths

Pregnancies

Marriages /  
Dissolutions

Population

NYC Link: <http://www.nyc.gov/html/doh/html/home/home.shtml>

Annual Reports: [http://www.health.ny.gov/statistics/vital\\_statistics/](http://www.health.ny.gov/statistics/vital_statistics/)

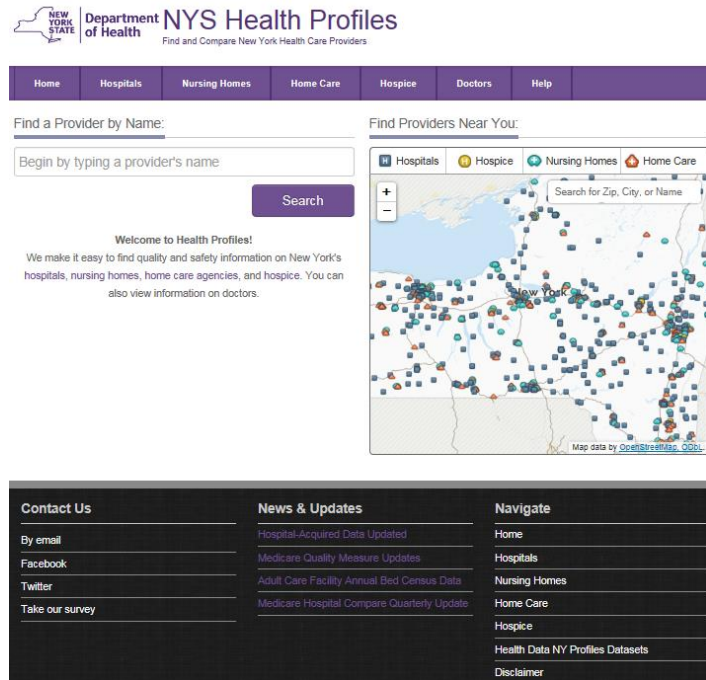


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# New York State Health Profiles

- Consumer facing DOH website for hospital, nursing home, home care, hospice and physician performance
  - Includes measures on quality, utilization, surveillance and services provided
  - Includes both NYS and national measures of provider quality
  - Ability to compare facilities and quality measures



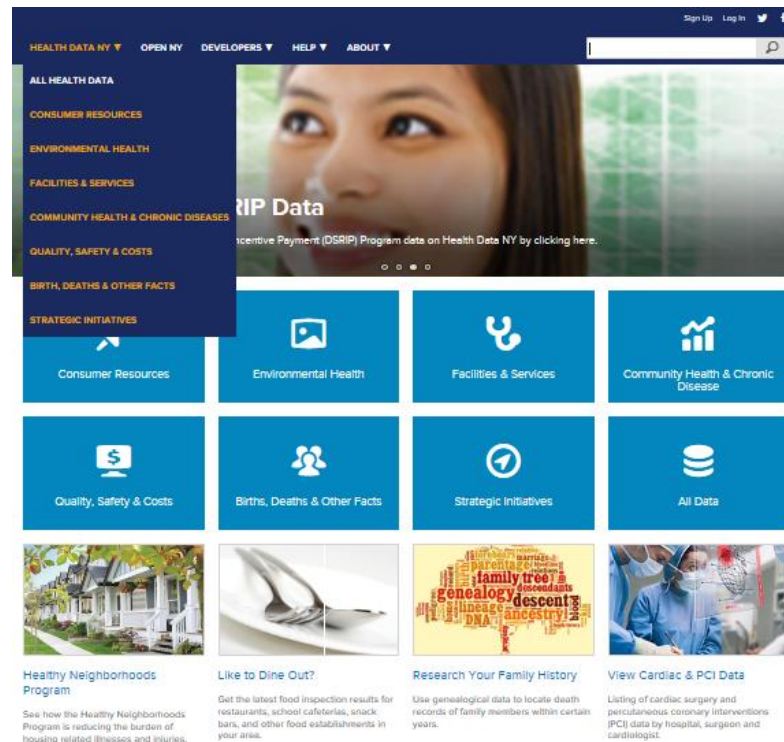
<http://profiles.health.ny.gov/>

# Health Data NY

## ■ Open Data Portal for Health Data

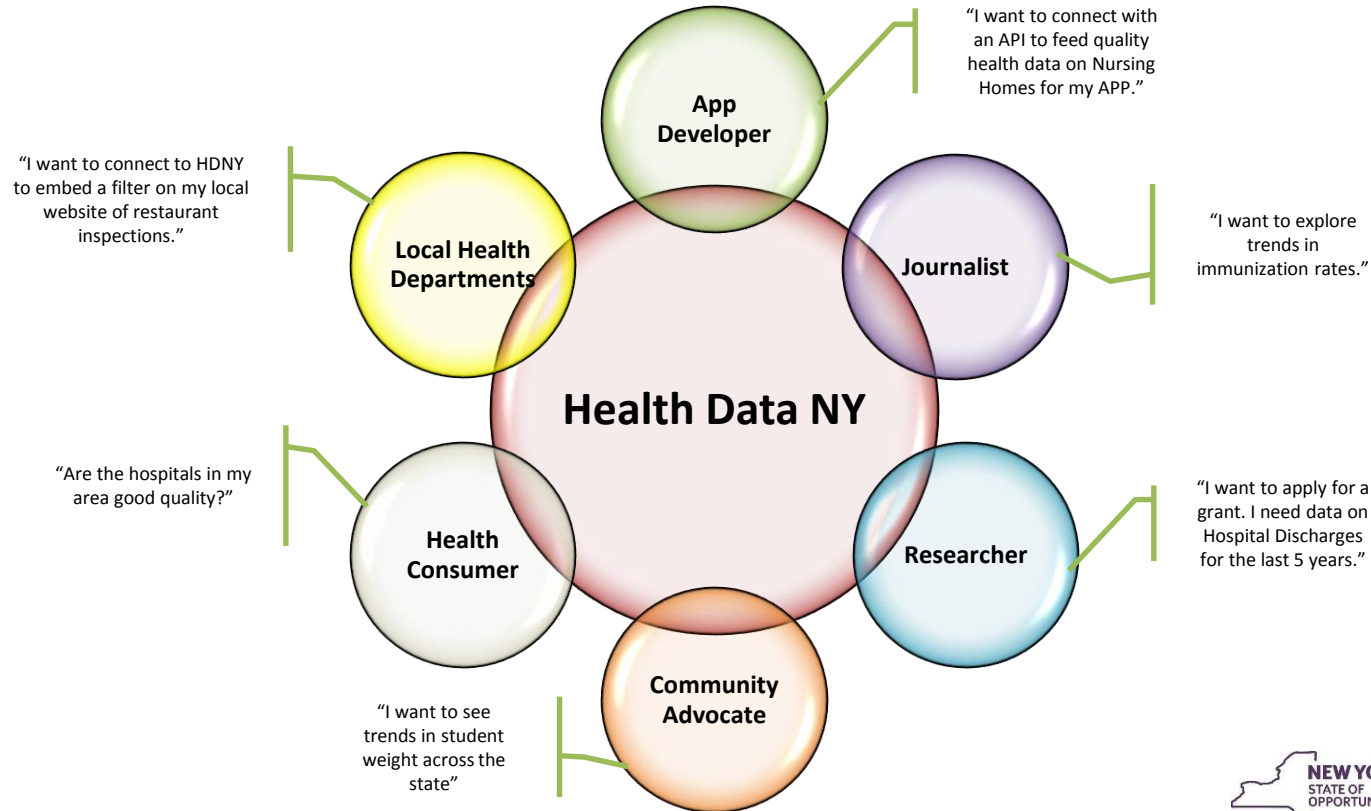
- Currently 150+ data sets available to the public
- Includes financial, utilization, quality, public health, surveillance, provider network data and vital statistics (birth, death data)
- Includes some de-identified discharge level data from the all payer hospital discharge data collection, including charges and costs (SPARCS)

## ■ Other digital tools include: Quality Measurement (eQARR) and Managed Care Consumer Guides



<https://health.data.ny.gov/>

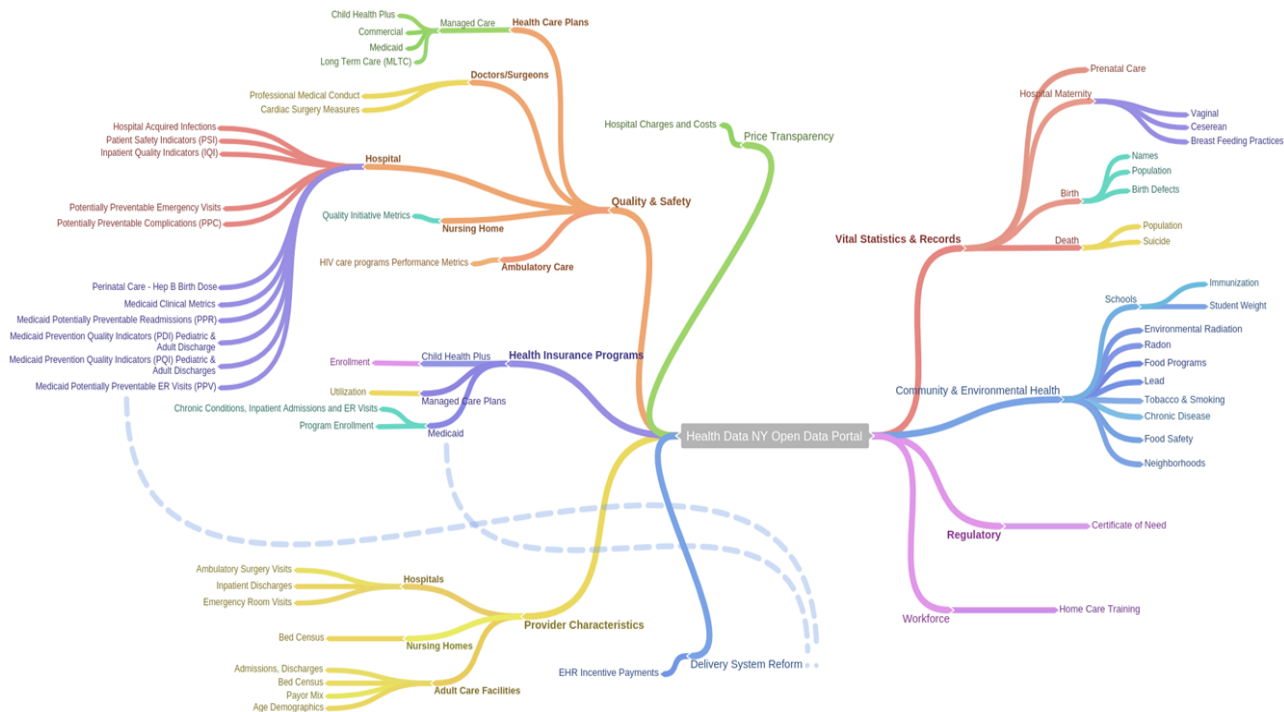
# Health Data NY Stakeholder View



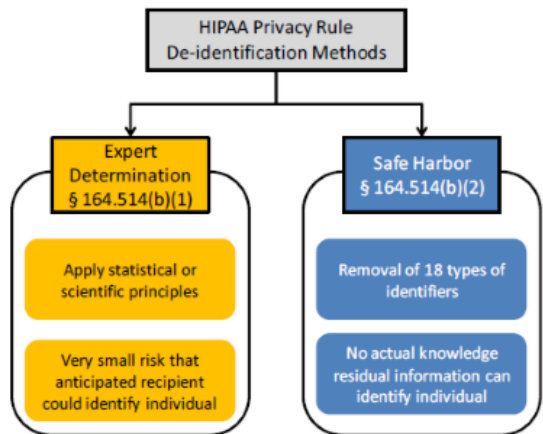
# Data Available on Health Data NY

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All data released on the open data portal is accompanied by an **Expert Determination** signed statement that the data are sufficiently de-identified to minimize risk of re-identification.



# Open Data – Expert Determination



1) **Expert Determination**, where statistical and scientific principles are applied to determine risk of identifying an individual.

2) **Safe Harbor**, includes a list of 18 identifiers of an individual (or of relatives, employers, or household members of the individual) that are removed from the data set.

1. Names
2. Zip Codes (except first three)
3. All elements of dates (except year)
4. Telephone Numbers
5. Fax Numbers
6. Email Addresses
7. Social Security Numbers
8. Medical record numbers
9. Health plan beneficiary numbers
10. Account numbers
11. Certificate / license numbers
12. Vehicle identifiers and serial numbers, license plates
13. Device identifiers and serial numbers
14. Web Universal Resource Locators (URLs)
15. Internet Protocol Addresses
16. Biometric identifiers (fingerprints, voice prints, retinal scans)
17. Full face photographic images
18. Any other unique identifying number, characteristic or code

# Contact Information

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