# Data integration of national surveys and nonprobability samples: balancing enhanced analytic capacity within representational constraints

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# Presentation

- Data Integration efforts: A model for enhanced analytic capacity and data quality
- Highlight potential gains in efficiency, accuracy, capacity and quality
- Data integration of national surveys and nonprobability samples
- Applications to Project Data Sphere
- Model for consideration

*The Project Data Sphere data integration effort is being funded by a grant from the Robert Wood Johnson Foundation*

# Data Integration Model

- Data integration is a process in which related and supplemental data from multiple sources are connected into a unified structure.
- The resultant integrated data resource serves as a platform to enhance analytic efforts.
- The data integration model facilitates greater analytic utility for each of the component data sets as a consequence of their “connectivity”.
- Data integration is often implemented in a data warehouse or data enclave setting to ensure the extraction, linkage and structure of the combine data resources are presented in a unified manner.

# Attributes of “Hub” Dataset and Supplemental Sources

Parameters

- Representativeness
- Accuracy
- Relevance
- Timeliness
- Accessibility
- Clarity
- Cost-efficient

# Integrated Survey Design Features

- Direct linkage between sample members in core survey with larger host survey; administrative records; or follow-up surveys
- Use of secondary data (e.g. aggregate data at the county/state level) as core component of survey
- Prior survey record of call data informs data collection strategies
- Informs sample design, nonresponse and poststratification adjustments, imputation and data supplement for item nonresponse
- Facilitates reductions in measurement error
- Need for greater attention to ensuring confidentiality: limitations in public use data

# Administrative Records and National Surveys Serving as Sampling Frames

- The Medicare Current Beneficiary Survey (MCBS) conducted by the Centers for Medicare & Medicaid Services (CMS) is a continuous, multipurpose survey of a nationally representative sample of the Medicare population: *the sample is selected from Medicare enrollment files*

- The National Health Interview Survey (NHIS) has a central role in the ongoing integration of household surveys in DHHS.
  - The National Survey of Family Growth has used the NHIS as a sampling frame and
  - the Medical Expenditure Panel Survey currently uses the NHIS as a sampling frame.
  - Other linkage includes linking NHIS data to Medicare and Medicaid administrative data from CMS and death certificates in the National Death Index (NDI).

# Medical Expenditure Panel Survey (MEPS)

Annual Survey of 14,000 households:

provides national and state estimates (most populous) of health care use, expenditures, insurance coverage, sources of payment, access to care and health care quality

Permits studies of:

- Distribution of expenditures and sources of payment
- Role of demographics, family structure, insurance
- Expenditures for specific conditions
- Trends over time

*Sponsored by the Agency for Healthcare Research and Quality*

# MEPS Integrated Design

Household Component (HC)

Medical Provider Component (MPC)

Medical Organization Survey (MOS)-support provided by *the Robert Wood Johnson Foundation*

Insurance Component (IC)

- Longitudinal design
- Linkage to CMS claims data
- Linkage to National Health Interview Survey
- Linkage to National Death Index
- Data Supplementation at the state and county levels.

# Data Integration Innovations

***Challenge:*** Enhancements to the analytic capacity and utility of cancer clinical trial data hosted by *Project Data Sphere, LLC ("PDS") :* Limited demographic information currently available on PDS patients to ensure confidentiality

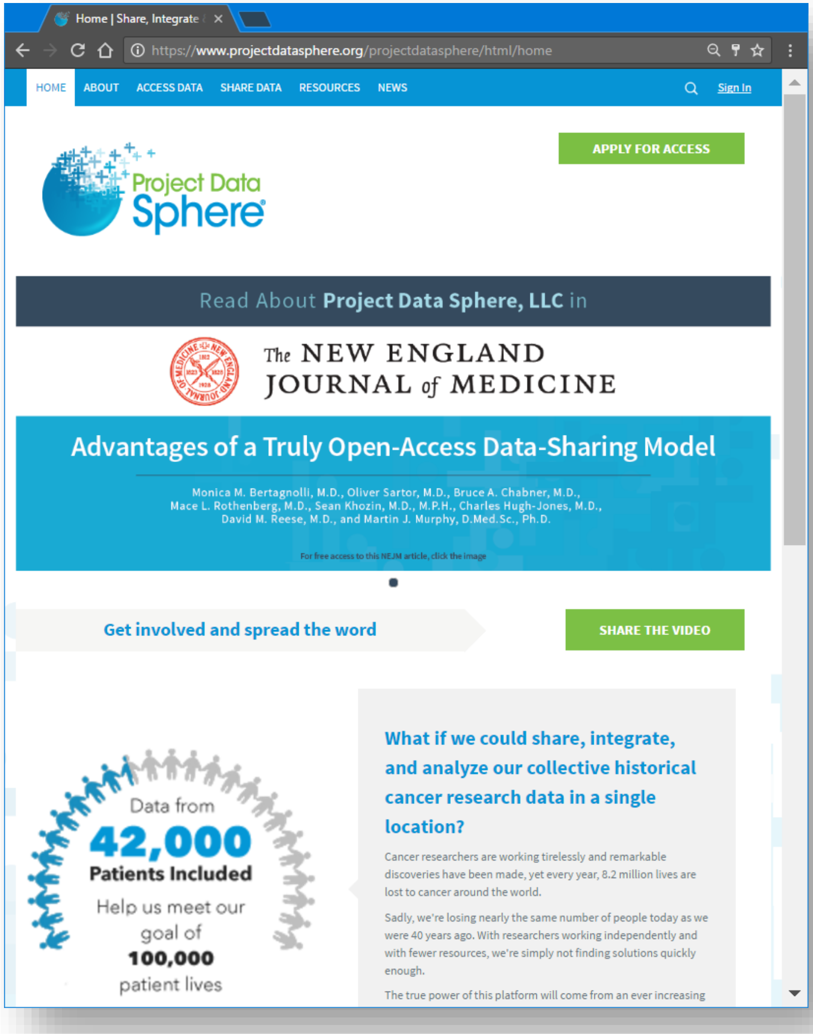
***Approach/Innovation:*** Data integration efforts employed to join PDS patient-level data with nationally representative health and healthcare related data.

***Collaborations/Partnerships:*** *Project Data Sphere, LLC ("PDS")-*
*RTI International-The Robert Wood Johnson Foundation*

***Impact/Next steps:*** Permit examination of the level of variation in patient outcomes attributable to differentials in access to care, health care service utilization, socioeconomic characteristics, and to health behaviors and preferences

# www.ProjectDataSphere.org

- Launched **April 8, 2014**
- **Phase III cancer trials** (Industry and National Cancer Institute)
  - – **Comparator arm data** at launch
  - – **Experimental arm data** now available
- **De-identified patient data, data dictionary, protocol, & CRFs**
- Free, powerful **analytic tools**
- **Easy-to-use,** with favorable IP
- An independent initiative of the CEO Roundtable on Cancer's *Life Sciences Consortium*



Read About **Project Data Sphere, LLC** in

The NEW ENGLAND JOURNAL of MEDICINE

Advantages of a Truly Open-Access Data-Sharing Model

Monica M. Bertagnolli, M.D., Oliver Sartor, M.D., Bruce A. Chabner, M.D., Mace L. Rothenberg, M.D., Sean Khozin, M.D., M.P.H., Charles Hugh-Jones, M.D., David M. Reese, M.D., and Martin J. Murphy, D.Med.Sc., Ph.D.

For free access to this NEJM article, click the image

Get involved and spread the word

Data from **42,000** **Patients Included**

Help us meet our goal of **100,000** patient lives

**What if we could share, integrate, and analyze our collective historical cancer research data in a single location?**

Cancer researchers are working tirelessly and remarkable discoveries have been made, yet every year, 8.2 million lives are lost to cancer around the world.

Sadly, we're losing nearly the same number of people today as we were 40 years ago. With researchers working independently and with fewer resources, we're simply not finding solutions quickly enough.

The true power of this platform will come from an ever increasing

*PDS*-inspired "Sounding Board" published in *New England Journal of Medicine,* March 23

**Join the conversation: bit.ly/NEJMDataSharing**

# *Project Data Sphere* Facts and Outputs

- **~145,000 pt. lives** of data from 32 providers
- **>2200 researchers** accessed data~10,000 times
- **Triple the usage** of other major, clinical trial data-sharing initiatives combined[1]

Project Data Sphere + RTI INTERNATIONAL

Enriching patient-level clinical trial data with representative socioeconomic data

Learn more about this collaboration

VIEW THE DATA

Made possible with support from the Robert Wood Johnson Foundation

- **21 publications in top tiered journals** citing PDS data, including:
  - Prognostic model to predict Prostate Cancer overall survival (OS)
  - Tumor growth model with statistically valid intermediate endpoint for OS
  - Efficacy differentiation for multiple FDA-approved Prostate Cancer therapies
  - Prediction of Pancreatic Cancer OS in patients treated with gemcitabine

The NEW ENGLAND JOURNAL of MEDICINE

THE LANCET Oncology

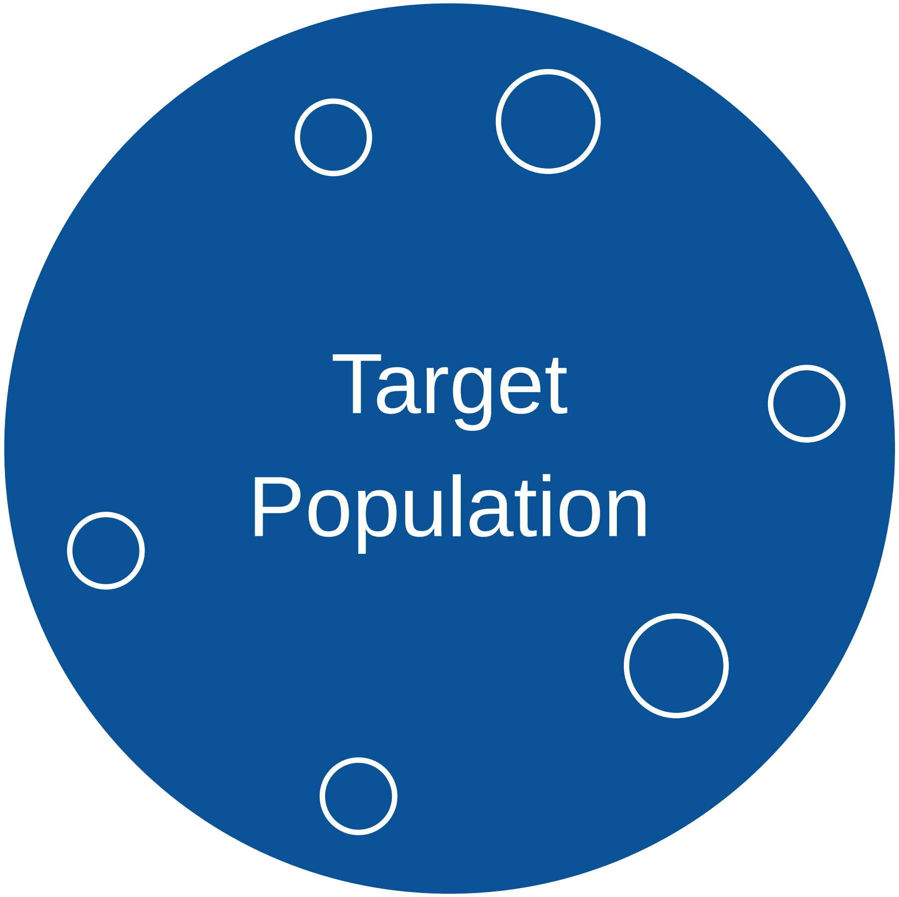
SCIENTIFIC DATA a natureresearch journal

EUROPEAN UROLOGY

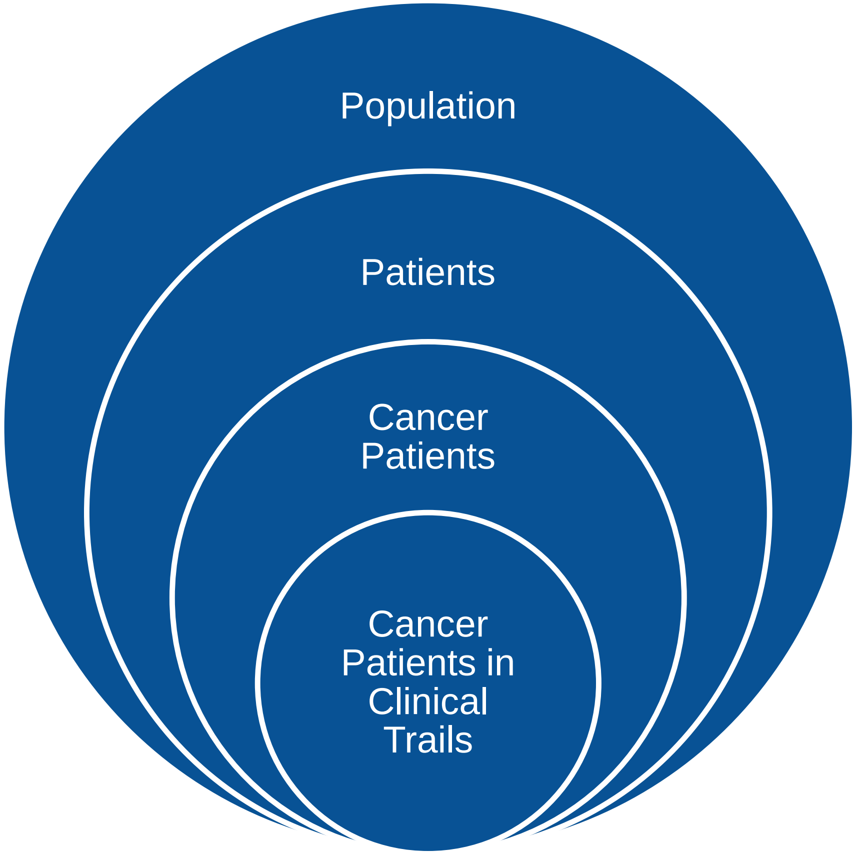
The Oncologist

[1] Navar A, et al. Use of Open Access Platforms for Clinical Trial Data. JAMA. 2016;315(12):1283-1284.

# Integration of Content from Nonprobablistic Samples With Unclear Signal of Representativeness



# Integration of Content from Nonprobablistic Samples With Capacity to Determine Signal of Representativeness



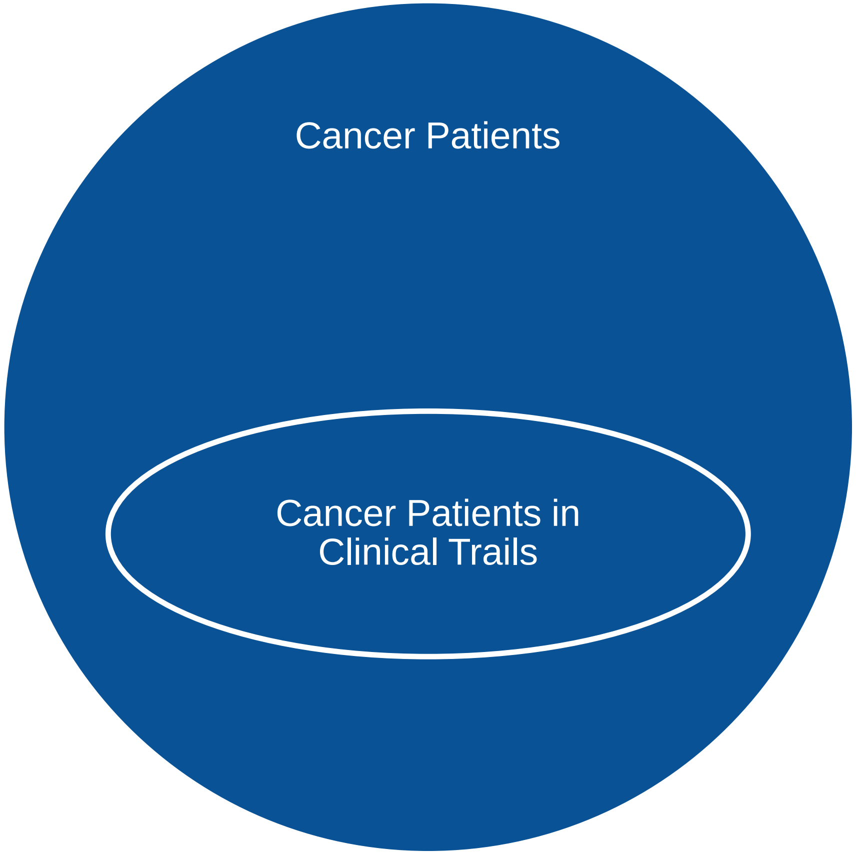
Population

Patients

Cancer Patients

Cancer Patients in Clinical Trails

# Integration of Content from Nonprobablistic Samples With Capacity to Determine Signal of Representativeness



# *Project Data Sphere* Applications

- For most patient-level records on the PDS platform, demographic measures available for statistical linkage are generally limited to age, race, and sex to reduce the possibility of re-identification.

- A data integration effort limited to these three demographic measures would produce a multitude of many-to- many exact linkages.

- To ameliorate this problem, our approach to data integration uses an additional measure that further distinguishes patients by their health-related quality of life assessments.

- This measure is the EQ-5D™ index score, derived from the EuroQOL five dimensions questionnaire, one of the most commonly used measures of health-related quality of life.

# *Project Data Sphere* Applications

- The EQ-5D™ descriptive system consists of the following five health-related components: Mobility, Self-care, Usual activities, Pain/discomfort, and Anxiety/depression.

- Each dimension has three levels, reflecting no health problems, moderate health problems, and extreme health problems.

- Consequently, there are $3^5$=243 health states defined by the instrument, with the associated 5-digit response profiles ranging from 11111 for perfect health to 33333 for the worst possible state.

- To calculate the EQ-5D™ index score based on the U.S. population-based preference weights, a scoring algorithm has been created and operationalized.

# *Project Data Sphere* Applications

- The EQ-5D has also been administered in the past in the MEPS, which also includes administration of the 12-Item Short Form Health Survey (SF-12).

- The SF-12 is a general health status instrument with 12 questions producing two summary scores, the Physical Component Summary (PCS-12) and the Mental Component Summary (MCS-12).

- EQ-5D index scores can be derived from MEPS using an algorithm developed by Sullivan and Ghushchyan (2006) that only requires the availability of the MCS-12 and PCS-12 scores.

**This method uses the following prediction equation:** $\mathbf{EQ\text{-}5D = 0.057867 + 0.010367\cdot(PCS\text{-}12) + 0.00822\cdot(MCS\text{-}12) - 0.000034\cdot(PCS\text{-}\ 12\cdot MCS\text{-}12) - 0.01067.}$

Both the direct values of the index scores (when available) and the predicted values of the EQ-5D index scores are used as an additional discriminatory variable in the statistical linkage.

# Project Data Sphere Data Enhancements

***PDS Data Used for Linkage***

- PDS data file *LungNo_MerckKG_2007_145* includes 507 lung cancer patients, representing the intent to treat population

***MEPS Data Used for Linkage***

- MEPS lung cancer survivors were identified among all MEPS cases from the 2000-2013 Household Component (HC) Survey Full Year
- MEPS cases with ICD9CODX = 162 were identified as lung cancer survivors.
- There are 653 MEPS lung cancer survivors

# Criteria Used for Linkage

| Summary of Criteria Used for Linkage | EQ-5D Value Used for Linkage | |
|---|---|---|
| | MEPS | PDS |
| **2000 - 2003 MEPS** | | |
| 1st Step: Single year age, sex, race, direct EQ-5D | Direct | Direct |
| 2nd Step: Categorized age, sex, race, direct EQ-5D | Direct | Direct |
| 3rd Step: Collapsed categorized age (75+), sex, race, decile categories of EQ-5D | Decile Cat (Dolan) | Decile Cat (Dolan) |
| **2004 - 2013 MEPS** | | |
| 1st Step: Single year age, sex, race, decile categories of EQ-5D | Decile Cat (SG) | Decile Cat (Dolan) |
| 2nd Step: Collapsed categorized age (75+), sex, race, decile categories of EQ-5D | Decile Cat (SG) | Decile Cat (Dolan) |

Age, sex, race, and measures of the EQ-5D were used to link to PDS cases.

Age categories:18-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+.

Many-to-many linkages were allowed, with the variable LINKMETHOD indicating the method under which each linkage was attained.

# Linkage Results

### *Linkage Results*

- 401 PDS cases (507 in PDS) achieved a linkage to MEPS lung cancer survivors.
- 283 MEPS lung cancer survivors (653 in MEPS) achieved a linkage to PDS lung cancer cases.

### *MEPS Survey Weights and Sample Design Variables*

It is advised to produce average nationally representative estimates of lung cancer survivors using the MEPS lung cancer survivors included in the linked dataset.

To do so, the file should either be de-duplicated by MEPSID to account for many-to-many linkages or the weights averaged among the multiple MEPS linkages

# Assessment of Factors that Distinguished the Characteristics of Lung Cancer Cases in the PDS clinical trial

***Socio-demographic factors:***

- Age, race/ethnicity, sex, marital status, employment status, education level, income level, year in MEPS

***Access related factors:***

- Insurance coverage, ability to obtain necessary medical care

***Health related:***

- EQ5D, health status, work limitations, smoker status

***Healthcare related:***

- Office based physician visits, in-patient stays, ER visits, Rx purchases, total expenditures

# Factors that Distinguished the Characteristics of Lung Cancer Cases in the PDS clinical trial

| Contrast | DF | Wald F | P-value |
|---|---|---|---|
| Overall Model | 9 | 6.95 | <0.0001 |
| Model minus intercept | 8 | 7.10 | <0.0001 |
| | | | |
| Marital Status | 1 | 6.16 | 0.0134 |
| Sex | 1 | 11.04 | 0.0010 |
| MEPS Year | 1 | 6.47 | 0.0113 |
| EQ5DDEC | 1 | 14.81 | 0.0001 |
| Race/ethnicity | 2 | 25.94 | <0.0001 |
| Difficulty in access to necessary medical care | 1 | 3.17 | 0.0758 |
| Smoker Status | 1 | 4.46 | 0.0352 |

# Exploratory Assessments of Factors that Suggest Association with Survivorship in the Comparator Arm

***PDS Measures:***

- Age, race/ethnicity, sex
- ECOG Performance: scale used to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis
- Microscopic verification, Surgery / non-surgery, Smoking history
- Response to chemo-radiotherapy
- Type of chemo-radiotherapy
- N Stage

**Supplemented with MEPS Measures**

# Exploratory Assessments of Factors that Suggest Association with Lung Cancer Survivorship in the Comparator Arm

| Contrast | | DF | Wald F | P-value |
|---|---|---|---|---|
| Overall Model | | 11 | 7.11 | 0.0000 |
| Model minus intercept | | 10 | 3.49 | 0.0002 |
| Response to chemo-radiotherapy | | 1 | 2.82 | 0.0940 |
| Type of chemo-radiotherapy | | 1 | 2.49 | 0.1155 |
| N Stage | | 2 | 4.24 | 0.0151 |
| **MEPS Measures** | | | | |
| Income | | 1 | 2.33 | 0.1273 |
| Medicaid coverage | | 1 | 7.43 | 0.0067 |
| Private HMO coverage | | 1 | 3.34 | 0.0684 |
| Smoker Status | | 1 | 3.81 | 0.0515 |
| Believes health insurance is not needed | | 1 | 3.64 | 0.0573 |
| Had labtests | | 1 | 6.05 | 0.0143 |

# *Project Data Sphere* Applications

The PDS-MEPS Data Integration permits studies that examine:

*Are the demographic characteristics of those cancer patients enrolled in specific phase III clinical trials comparable to cancer patients with the same disease in the general population?*

How are variations in cancer patients' access to health care and income impacting patient outcomes in specific phase III clinical trials?

What variations in patient outcomes are associated with specific demographic, socioeconomic, and health-related factors?

# Questions

Given the availability of the data and characteristics of the target population, and the constraints on the content available from the nonprobability based sample, what other analyses would you recommend to distinguish the subset of the target population represented by the available sample.

What other gains and limitations of including content drawn from nonprobability based samples into these integrated data platforms to enhance analytic capacity.

On occasion, content from nonprobablistic samples are adjusted by weighting strategies and used to draw inferences to a more expansive target population. What are your thoughts on a different model that requires 1) the identification of the subset of the population represented by the nonstandard sample, 2) the conduct of a representative sample, and 3) compositing the overlap to gain statistical precision.