



دانشگاه علوم پزشکی خدمات بهداشتی درمانی گیلان



جمهوری اسلامی ایران
وزارت بهداشت، درمان و آموزش پزشکی



Data Management in Registries



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Defining Patient Registries

Patient registry is an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate *specified outcomes* for a population defined by a particular disease, condition, or exposure, and that serves one or more stated scientific, clinical, or policy purposes.



CPRD

UK data driving real-world evidence



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Clinical Practice Research Datalink

Clinical Practice Research Datalink (CPRD) is a real-world research service supporting retrospective and prospective public health and clinical studies. CPRD is jointly sponsored by the [Medicines and Healthcare products Regulatory Agency](#) and the [National Institute for Health Research \(NIHR\)](#), as part of the Department of Health and Social Care.

CPRD collects anonymised patient data from a network of GP practices across the UK. Primary care data are linked to a range of other health related data to provide a longitudinal, representative UK population health dataset. The data encompass 60 million patients, including 16 million currently registered patients.

For more than 30 years, research using CPRD data and services has informed clinical guidance and best practice, resulting in over 2,900 peer-reviewed publications investigating drug safety, use of medicines, effectiveness of health policy, health care delivery and disease risk factors.

In response to the coronavirus outbreak, CPRD is expediting processing of protocols relating to COVID-19 research. To ascertain whether your protocol is eligible for rapid review please email rdg@cprd.com before you submit your application and include a clear impact statement in terms of public health, safety or policy. To understand how the current situation may impact on data processing and access requests see



GP practices - Join today



Today's Data, Tomorrow's Discoveries



Increasing Access to the Results of Research Funded by the
National Science Foundation

National Science Foundation

March 18, 2015



**This presentation
is about:**

➤ **Introduction to data management & sharing**

- Why Manage Your Data?
- Formatting and organizing the data
- Storage and Security of Data
- Data documentation and meta data
- Quality control & Version controlling
- Controlled Vocabulary
- Common Data Elements
- Data Sharing
- Data management plans

➤ **Examples for routine practices**

➤ **Examples for modern practices**

Background

1. Research funders are increasingly mandating open access to research data
2. Governments internationally are demanding transparency in research
3. The economic climate is requiring much greater reuse of data
4. Fear of data loss calls for more robust information security practices.
5. Journal publishers increasingly require submission of the data up on which publications are based for peer review.
6. **Researchers and data users recognize the long-term value of well-prepared data.**

Why Manage Your Data?

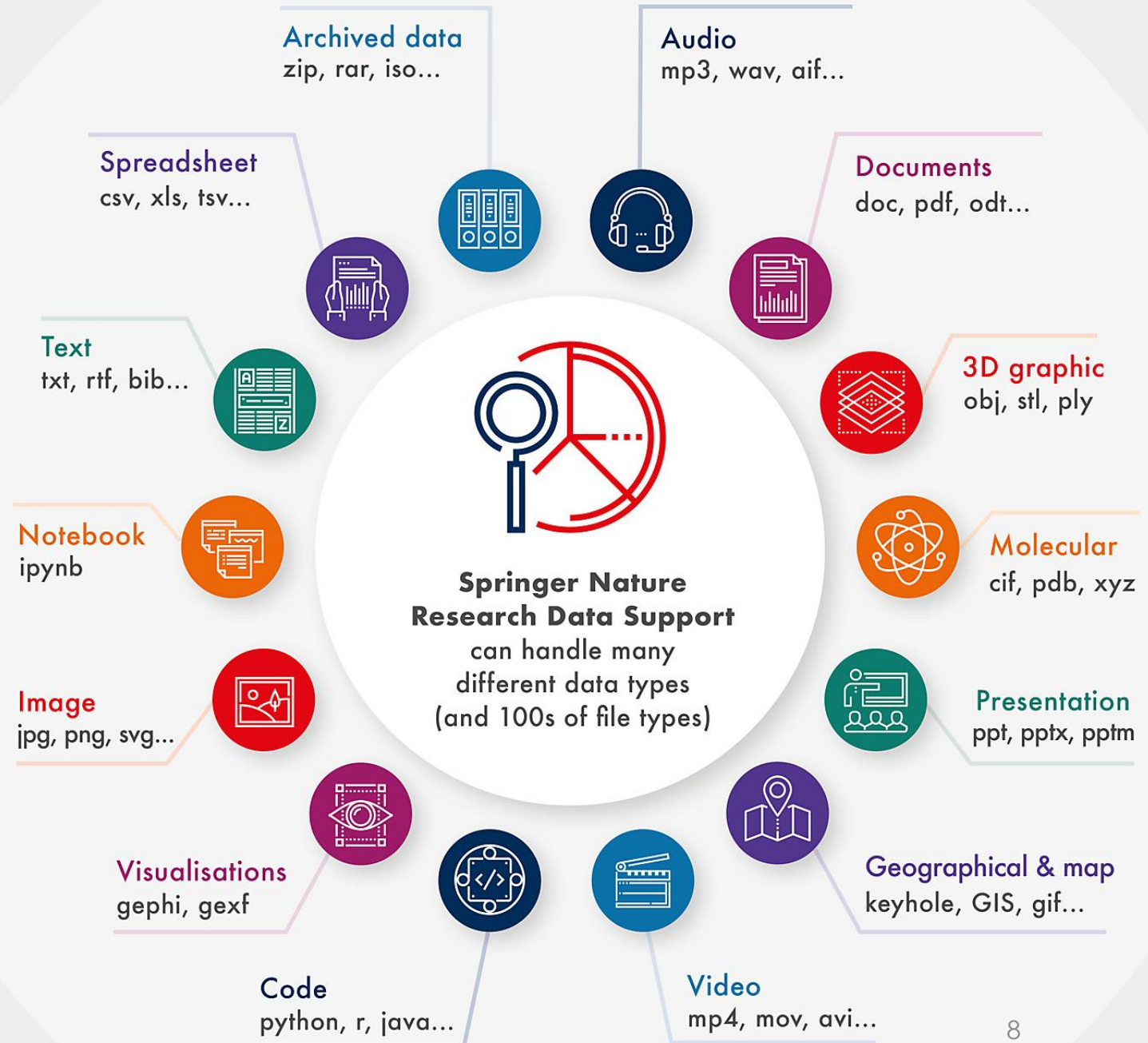


Types of Research Data

Research data can be many different things - it's not just spreadsheets and it's not just code!

It's a whole myriad of files that can be created through research...essentially all outputs that are not a research publication!

<https://researchdata.springernature.com/posts/30232-infographic-types-of-research-data>



Data Lifecycle

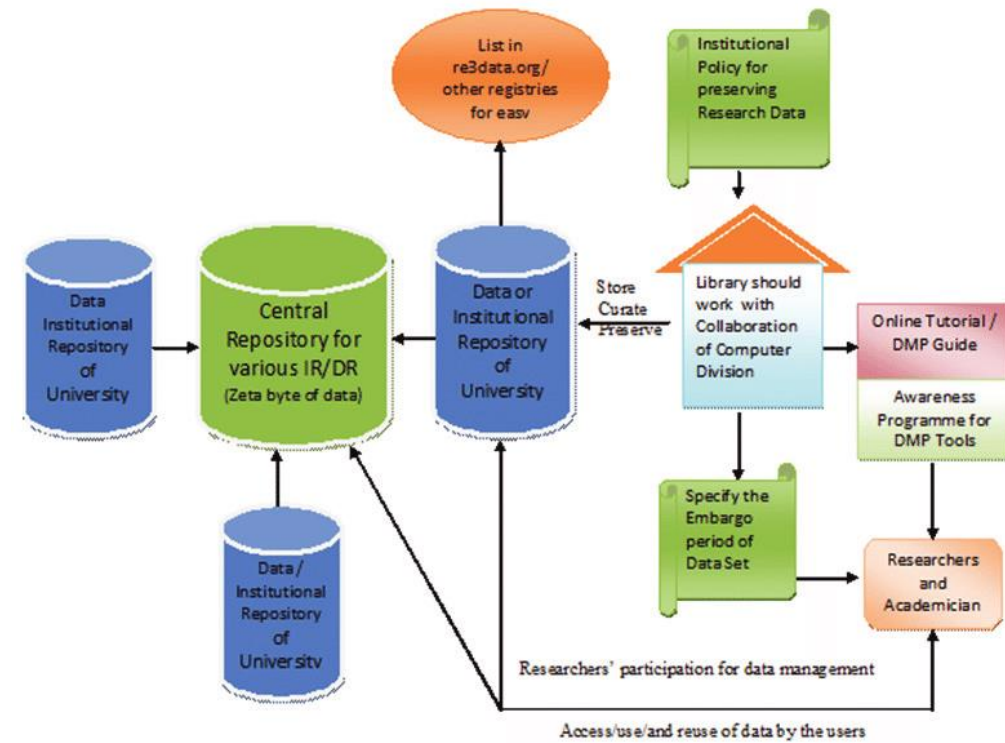


By Data Management we mean all data practices, manipulations, enhancements and processes that ensure that research data are of a high quality, are well organized, documented, preserved, sustainable, accessible and reusable.

Management of medical, health and clinical data is a critical part of the research process. It enables:

- ✓ Increased quality of your research
- ✓ Increased transparency and trust in data you obtain
- ✓ Reproducibility of research through increasing veracity of data
- ✓ Strengthening of researchers' reputation through increased citations and reach of all research outputs.

Different Processes in Research Data Management



Formatting and organizing the data

➤ Choosing File Formats

- Format best suited for data creation
- Format best suited for data analyses and other planned uses;
- Format best suited for long-term sustainability and sharing of data

➤ Data conversion

➤ File Names

➤ Best Practice for File/folder Structure

Storage and Security of Data

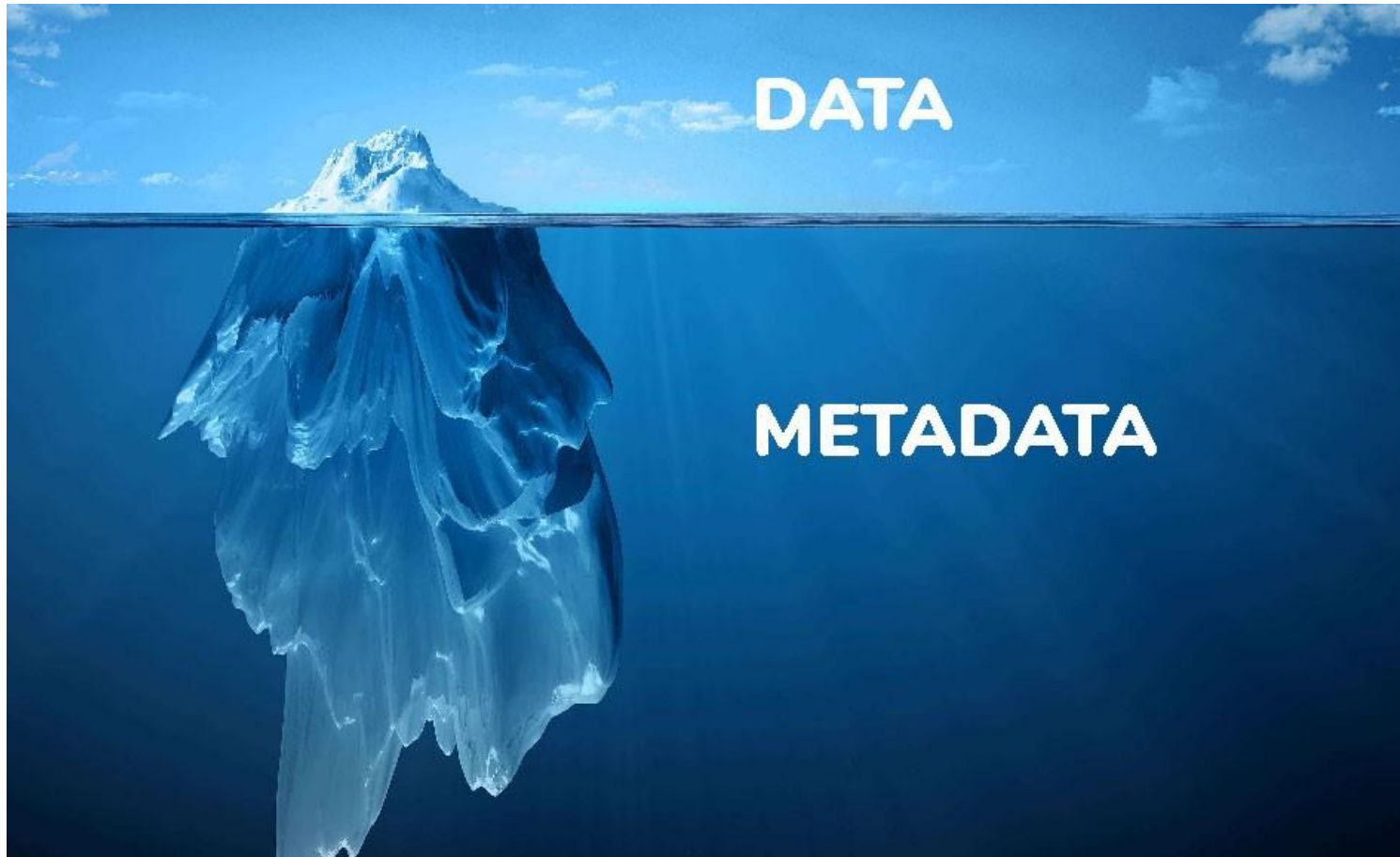
- Backup Your Data
- Physical data security
- Network Security
- Security of computer systems
- Data Encryption
- Access controlling and security

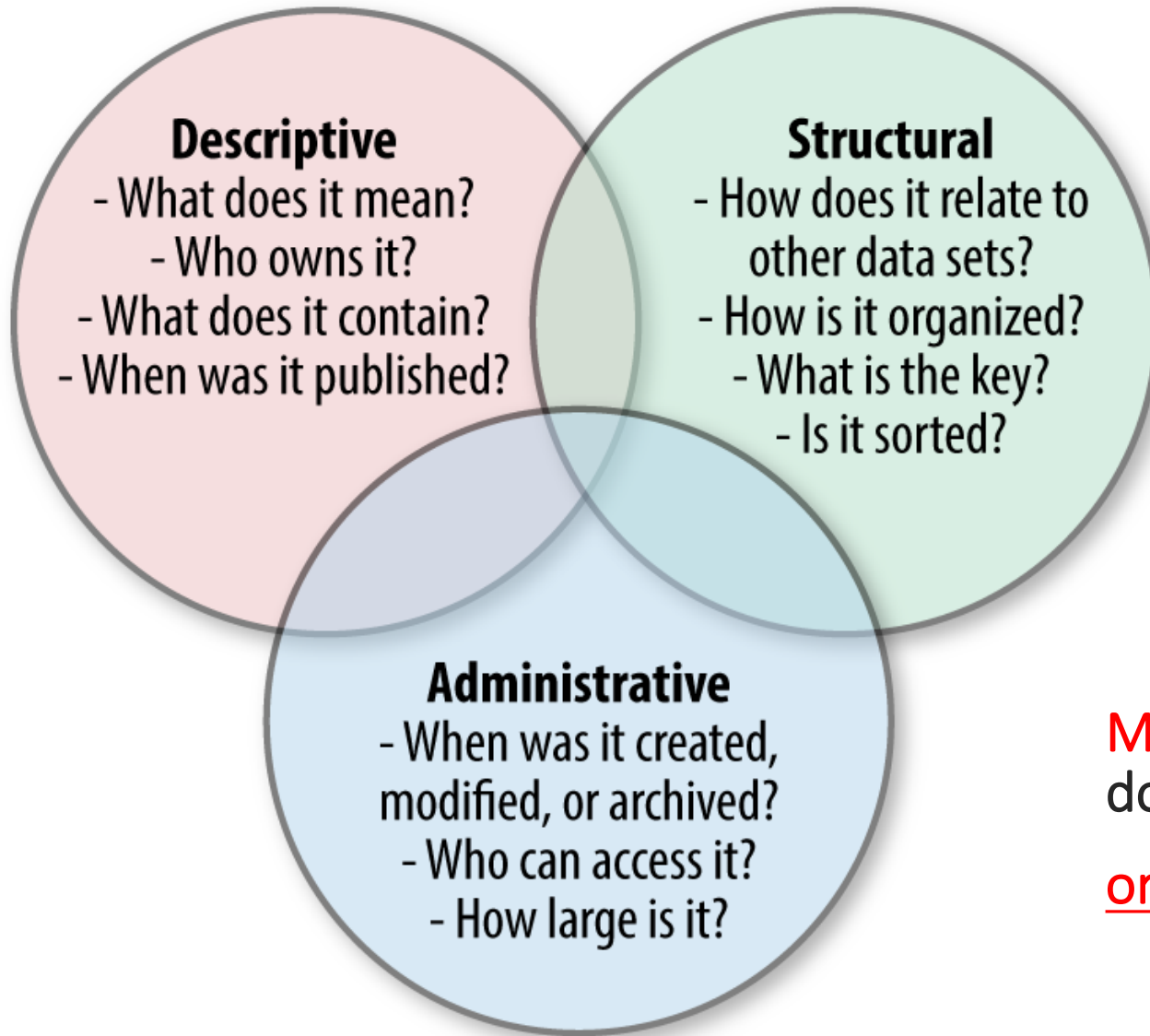
Data documentation and Meta Data

Metadata = Data about data



Metadata vs. Data





Metadata are a specific subset of data documentation that provides organized searchable information

Data documentation and Meta Data

- Study-level data documentation
- Data - level data documentation

Data Dictionary



Good study-level data documentation includes:

Research design and context of data collection

Data collection methods

Structure of data files, with number of cases, records, files and variables, as well as any relationships among such items;

Secondary data sources used and provenance

Data validation, checking, proofing, cleaning and other quality assurance procedures

Modifications made to data over time since their original creation and identification
different versions of datasets;

Information on data confidentiality, access and any applicable conditions of use;

Publications, presentations and other research outputs that explain or draw on the data.

Good data-level data documentation includes:

- Names, labels and descriptions
- Value code labels
- Coding and classification schemes
- Codes for missing values
- Derived new concepts from other variables
- Weighting variables

فرا داده و فرهنگ لغت مطالعه قند و لیپید تهران



پژوهشکده علوم غدد درون ریز و متابولیسم
دانشگاه علوم پزشکی شهید بهشتی

گروه آمار و اپیدمیولوژی

۱۳۹۹

ویرایش دوم

فهرست مطالب

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| ۵۵ | آزمایشگاه (Lab measurement) |
| ۵۷ | پیامدها (Outcomes) |
| ۵۹ | تاریخ های پیگیری (Followup dates) |

حیطه های موجود در پرسشنامه قند و لیپید تهران شامل موارد زیر است:

| ردیف | اصطلاح فارسی | اصطلاح انگلیسی | مخفف حیطه | مخفف روش جمع آوری داده ها |
|------|-----------------------------|------------------------------|-----------|---------------------------|
| ۱ | اطلاعات دموگرافیک | Demographic information | DEM | Q |
| ۲ | سوابق پزشکی | Past medical history | PMH | Q |
| ۳ | عادات مصرف دخانیات نوجوانان | Adolescent smoking | ASS | Q |
| ۴ | عادات مصرف دخانیات بالغین | Adult smoking | ADS | Q |
| ۵ | فعالیت بدنی نوجوانان | Adolescent physical activity | ASP | Q |
| ۶ | فعالیت بدنی بالغین | Adult physical activity | ADP | Q |
| ۷ | درد سینه و لنگش متناوب | Chest pain & claudication | ROS | Q |
| ۸ | سوالات خاتمها | Women | WMN | Q |
| ۹ | تغذیه | Nutrition | NUT | Q |
| ۱۰ | معاینات پزشکی | Medical examinations | MED | E |
| ۱۱ | تن سنجی | Anthropometric measurement | ANT | E |
| ۱۲ | نوار قلب | ECG | ECG | E |
| ۱۳ | آزمایشگاه | Lab | LAB | P |
| ۱۴ | پیامد | Outcome | OUT | F |
| ۱۵ | تاریخ پیگیری | Followup date | FUD | F |

File Name: admit1_v2_20Jun2020

| Name | Label | Description in Persian |
|-------------|-----------------------------------|-------------------------------|
| day_1 | plqdem2a: day of interview | تاریخ مصاحبه به روز |
| month_1 | plqdem2b: month of interview | تاریخ مصاحبه به ماه |
| year_1 | plqdem2c: year of interview | تاریخ مصاحبه به سال |
| enterdate_1 | plqdem2d: date of interview | تاریخ میلادی مصاحبه |
| center_1 | plqdem3: center | نام مرکز بهداشتی |
| family_1 | plqdem4: household no | شماره خانوار |
| cluster_1 | plqdem5: cluster no | شماره خوشه |
| birth_date | plqdem10: documented birth date | تاریخ تولد شناسنامه ای |
| ageyr_1 | plqdem12a: self-reported age | سن براساس اظهارات فرد |
| agemon_1 | plqdem12b: age in month | سن برحسب تعداد ماه |
| sex_1 | plqdem13: sex | جنس |
| spouse_1 | plqdem14: marital status | وضعیت تاهل |
| relative_1 | plqdem15: situation in the family | وضعیت فرد در خانوار |
| literacy_1 | plqdem18: literacy | وضعیت سواد |
| ifstud_1 | plqdem19: studying now | در حال حاضر تحصیل می کنید؟ |

Quality Control & Data Checking

- They are fit for their intended uses in operations, decision making and planning.
- Completeness
- Validity
- Reliability
- Consistency
- Timeliness

Version controlling and tracking

- In the case of research data, a new version of a dataset may be created when an existing dataset is reprocessed, corrected or appended with additional data.
- Versioning is one means by which to track changes associated with 'dynamic' data that is not static over time.

- Decide how many versions of a file to keep
- Identity milestone versions to keep
- Uniquely identity different versions of files using a systematic naming convention, such as using version numbers or dates
- Record changes made to a file when a new version is created

Working with sensitive data

Sensitive data are data that can be used to identify an individual, species, object, or location that introduces a risk of discrimination, harm, or unwanted attention.

A person's identity can be disclosed from:

- Direct identifiers such as names, addresses, postcode information, telephone numbers or pictures
- Indirect identifiers which, when linked with other publicly available information sources, could identify someone, for example information on workplace, occupation or exceptional values of characteristics like salary or age.

List of PHI

(Protected Health
Information)



Names

Dates



Addresses / Zip Codes /
Geocodes

Phone Numbers



Fax Numbers

Email Addresses



Social Security
Numbers

Medical Record
Numbers



Health Plan
Beneficiary Numbers

Account Numbers



AB-12 34

Certificate /License
Numbers



Device
Identifiers

Vehicle Identifiers



www

URLs



IP Addresses



Biometric Identifiers

Facial Images



Any Other Unique
Identifiers



Selecting and Defining Exposure & Outcome Measures for Registries

The selection and definition of patient outcomes of interest together with the exposures(s) of interest, is a critical step in designing a patient registry.

Standard terminologies not only improve efficiency in establishing registries but also promote more effective sharing, combining, or linking of datasets from different sources.

Controlled Vocabulary



- Controlled vocabularies ensure shared understanding of the terminologies used in taxonomies and classifications.
- Using established vocabularies promotes interoperability, discovery and re-use of data.

Health Vocabulary examples



Australian Doctor Command
Language (DOCLE)



Australian Medicines
Terminology

SNOMED CT
The global
language of
healthcare

AIHW Authoritative information and statistics
to promote better health and wellbeing



OpenGALEN



ICD-10
INTERNATIONAL CLASSIFICATION OF DISEASES
ICD-10 is a new code set for reporting
medical diagnoses & inpatient procedures.

Victorian Admitted Episodes Dataset (VAED)

**R_xN
orm**

Cumulative Index of Nursing
and Allied Health Literature
(CINAHL)



ands
ANALYTICAL DATA SERVICES



Australian Research Data Commons

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OPEN CALLS

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SEARCH 🔍

Research Vocabularies Australia

An easily accessible portal to controlled vocabularies used in research

A controlled [vocabulary](#) reflects agreement on terminology used to label concepts. When research communities agree to use common language for the concepts in datasets, then the discovery, linking, understanding and reuse of research data are improved.



مرکز مدیریت آمار و فناوری اطلاعات
وزارت بهداشت، درمان و آموزش پزشکی

سامانه مکسا




جستجو

کد

ترم

ترمینولوژی

نمایش تمامی موارد

| مشاهده | شرح ترمینولوژی | عنوان ترمینولوژی |
|---|--|------------------|
|  | ترمینولوژی زمان فعالیت مراکز سلامت می باشد. | ActivationTime |
|  | DentalCodeing | ADA |
|  | ترمینولوژی نوع عامل مانند نرم افزار، تجهیز و می باشد. | AgentType |

Country در جستجو

ایران ، بیمه ، جراحی ،

نمایش تمامی موارد

| توضیحات | Value | Code | TerminologyId |
|---------|-------------------|------|---------------|
| | آرژانتین | AR | Country |
| | آروبا | AW | Country |
| | آفریقای جنوبی | ZA | Country |
| | آلبانی | AL | Country |
| | آلمان | DE | Country |
| | آنتیگوا و باربودا | AG | Country |
| | آندورا | AD | Country |
| | آنگولا | AO | Country |
| | آنگویلا | AI | Country |

نمایش تمامی موارد

جستجو در CPT

ایران ، بیمه ، جراحی ،

| توضیحات | Value | Code | TerminologyId |
|---------|--|-------|---------------|
| | GRADE-AID" (DEVICE TO PREVENT ROLLING BACK ON AN INCLINE) FOR WHEELCHAIR" | E0974 | CPT |
| | HYDROXYPREGNENOLONE-17 | 84143 | CPT |
| | MUTATION ANAL (IN INDIV W KNOWN MLH1&MLH2 MUTATION THE FAMILY), HEREDITARY NONPOLYPOSIS-1 COLOREC CA (HNPCC) GENETIC TSTING | S3831 | CPT |
| | NF NON-SEALED LEAD ACID BATTERY, EACH 22 | K0082 | CPT |
| | NF SEALED LEAD ACID BATTERY, EACH (E.G., GEL CELL, ABSORBED GLASS MAT) 22 | K0083 | CPT |
| | DEXTROSE AND 45% NORMAL SALINE, 1000 ML 5% | S5010 | CPT |
| | DEXTROSE IN LACTATED RINGER'S, 1000 ML 5% | S5011 | CPT |
| | DEXTROSE WITH POTASSIUM CHLORIDE, 1000 ML 5% | S5012 | CPT |
| | DEXTROSE/0.45% NORMAL SALINE WITH POTASSIUM CHLORIDE AND MAGNESIUM SULFATE 1500 ML 5% | S5014 | CPT |

| | | | |
|-------------------------|--|-----------|----------|
| | Abdominal aortic pulse, function (observable entity) | 80050220 | SNOMEDCT |
| توده شکمی | Abdominal mass (finding) | 271860004 | SNOMEDCT |
| درد شکم | Abdominal pain (finding) | 21522001 | SNOMEDCT |
| درد شکم و پهلوها | Abdominal pain through to back (finding) | 74704000 | SNOMEDCT |
| تندرنس شکم | Abdominal tenderness (finding) | 43478001 | SNOMEDCT |
| قادر به لباس پوشیدن | Able to dress (finding) | 284973007 | SNOMEDCT |
| قادر به غذا خوردن است | Able to eat (finding) | 288884008 | SNOMEDCT |
| قادر به پرش | Able to jump (finding) | 282600008 | SNOMEDCT |
| توانایی شناسایی چهره ها | Able to recognize faces (finding) | 285170004 | SNOMEDCT |
| قادر به تشخیص چهره | Able to recognize faces by sight (finding) | 285168008 | SNOMEDCT |
| قابلیت غلت زدن | Able to roll (finding) | 282620009 | SNOMEDCT |
| قادر به دویدن است | Able to run (finding) | 282474007 | SNOMEDCT |
| نشستن بدون کمک | Able to sit unsupported (finding) | 302040002 | SNOMEDCT |
| توانایی ورق زدن | Able to turn pages (finding) | 288375004 | SNOMEDCT |
| تشنه | Abnormal (qualifier value) | 262654008 | SNOMEDCT |

| توضیحات | Value | Code | TerminologyId |
|---------|--|-------|---------------|
| | Abnormal findings in specimens from female genital organs : abnormal histological findings | R87.7 | ICD10 |
| | Abnormal findings in specimens from female genital organs : abnormal immunological findings | R87.4 | ICD10 |
| | Abnormal findings in specimens from female genital organs : abnormal level of enzymes | R87.0 | ICD10 |
| | Abnormal findings in specimens from female genital organs : abnormal level of hormones | R87.1 | ICD10 |
| | Abnormal findings in specimens from female genital organs : abnormal level of other drugs, medicaments and biological substances | R87.2 | ICD10 |
| | Abnormal findings in specimens from female genital organs : abnormal level of substances chiefly nonmedicinal as to source | R87.3 | ICD10 |
| | Abnormal findings in specimens from female genital organs : abnormal microbiological findings | R87.5 | ICD10 |
| | Abnormal findings in specimens from female genital organs : other abnormal findings | R87.8 | ICD10 |
| | Abnormal findings in specimens from female genital organs : unspecified abnormal finding | R87.9 | ICD10 |
| | Abnormal findings in specimens from male genital organs | R86 | ICD10 |
| | Abnormal findings in specimens from male genital organs : abnormal cytological findings | R86.6 | ICD10 |
| | Abnormal findings in specimens from male genital organs : abnormal histological findings | R86.7 | ICD10 |

Common Data Elements and Standards - Definitions

- Data Element
 - information that describes a piece of data to be collected in a study
- Common Data Elements
 - a data element that is common to multiple datasets across studies
 - a combination of a precisely defined question (variable) paired with a specified set of responses to the question that is common to multiple datasets or used across different studies
- Every effort should be made to use common data elements (CDEs) to facilitate data sharing across research projects. CDEs describe the type of data to be collected and use standardized language for the question as well as the associated values.

Typical Data Elements Captured in Studies

- Demographic data
- Eligibility criteria
- Family history
- Patient history and physical examination including performance status
- Surgical history
- Prior treatment
- Concomitant medications
- Laboratory and radiology results
- Pathology
- Review of current symptoms
- During the study
- Study treatment (dosing, frequency)
- Laboratory and radiology results
- Concomitant medications including over-the-counter medications and
- indications
- Adverse events
- Toxicities
- Hospitalizations
- Treatment response
- Study termination
- Treatment stop date and reason
- Follow-up
- Disease status
- Nonprotocol treatment
- Long-term adverse events
- Date of death
- Cause of death
- Autopsy results if performed

Common Data Elements and Standards - Tools

- [The NIH Common Data Elements \(CDE\) Repository](#)
 - The NIH Common Data Elements (CDE) Repository has been designed to provide access to structured human and machine-readable definitions of data elements that have been recommended or required by NIH Institutes and Centers and other organizations for use in research and for other purposes
- [PhenX Toolkit](#)
 - The PhenX Toolkit (consensus measures for **Phen**otypes and **eX**posures) provides recommended standard data collection protocols for conducting biomedical research.
- [METeOR](#)
 - METeOR is Australia's repository for national metadata standards for health, housing and community services statistics and information.
- [The United States Health Information Knowledgebase \(USHIK\)](#)
 - The United States Health Information Knowledgebase (USHIK) is an on-line, publicly accessible registry and repository of healthcare-related metadata, specifications, and standards.
- [The Clinical Data Interchange Standards Consortium \(CDISC\)](#)
 - CDISC is an international, nonprofit group working to develop consensus-based standards to enhance interoperability in clinical research.



Search Data Elements



Enter keyword, classification, or topic

AHRQ

Agency for Healthcare Research
and Quality

91 elements

External Forms

External Forms

241 elements

GRDR

Global Rare Diseases Patient
Registry Data Repository
Source

75 elements

NCI

National Cancer Institute
Source

1529 elements

NEI

National Eye Institute

235 elements

NHLBI

National Heart, Lung and Blood
Institute
Cure Sickle Cell Initiative
Source

2859 elements

NICHD

Eunice Kennedy Shriver National
Institute of Child Health and
Human Development
Source

638 elements

NIDA

National Institute on Drug Abuse
Source

120 elements

NINDS

National Institute of
Neurological Disorders and
Stroke

NINR

National Institute of Nursing
Research
Source

NLM

National Library of Medicine

ONC

Office of the National
Coordinator

Data sharing

International statements on data sharing:

- Berlin Principles
- OECD
- NSF
- NIH
- OA 2020
- European Commission
- NRC

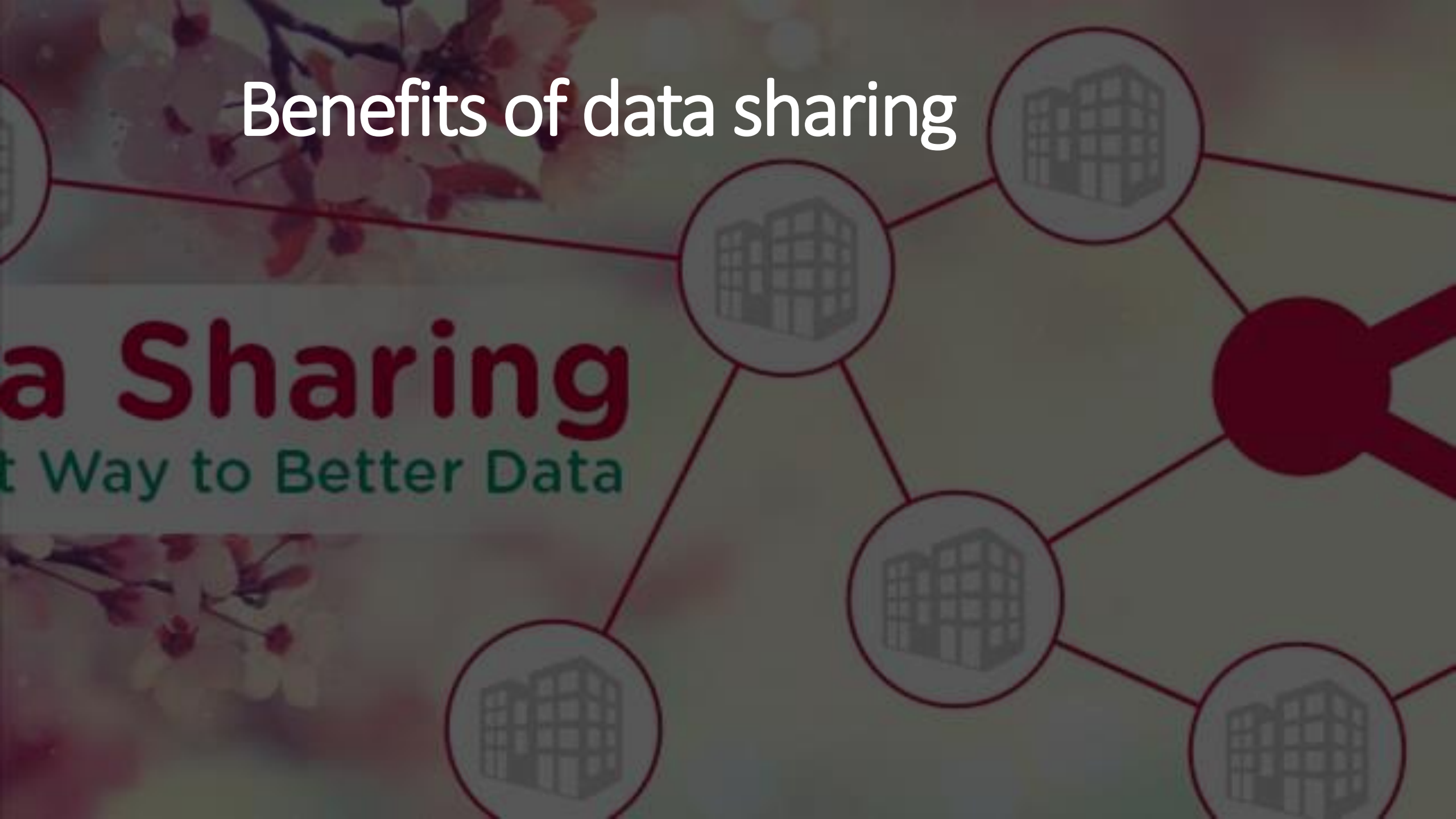
Berlin Declaration on Open Access to Knowledge in the Sciences and Humanities

Open access contributions include original scientific research results, raw data and metadata, source materials, digital representations of pictorial and graphical materials and scholarly multimedia material.

<https://openaccess.mpg.de/Berlin-Declaration>

Benefits of data sharing

Data Sharing
The Best Way to Better Data



Benefits for researchers

- Increases visibility of scholarly work;
- Likely to increase citations rates,
- Enables new collaborations;
- Encourages scientific enquiry and debate;
- Promotes innovation and potential new data uses;
- Establishes links to next generation of researchers.

Benefits for research funders

- Promotes primary and secondary use of data;
- Makes optimal use of publicly funded research;
- Avoids duplication of data collection;
- Maximizes return on investment.

Benefits for the scholarly community

- Maintains professional standards of open inquiry;
- Maximizes transparency and accountability;
- Promotes innovation through unanticipated and new uses of data;
- Enables scrutiny of research findings;
- Improves quality from verification, replication and trustworthiness;
- Encourages the improvement and validation of research methods;
- Provides resources for teaching and learning.

Benefits for research participants

- Allows maximum use of contributed information;
- Minimizes data collection on difficult-to-reach or over-researched populations;
- Allows participants' experiences to be understood as widely as ethically possible.

Benefits for the public

- Advances science to the benefit of society;
- Adopts emerging norms such as open access publishing
- To be, and appear to be, open and accountable;
- Complies with openness laws and regulations.

Barriers for data sharing

Inappropriate Use of Data

- There are concerns that others will use the data inappropriately or out of context from the original purpose of the research.

Data confidentiality

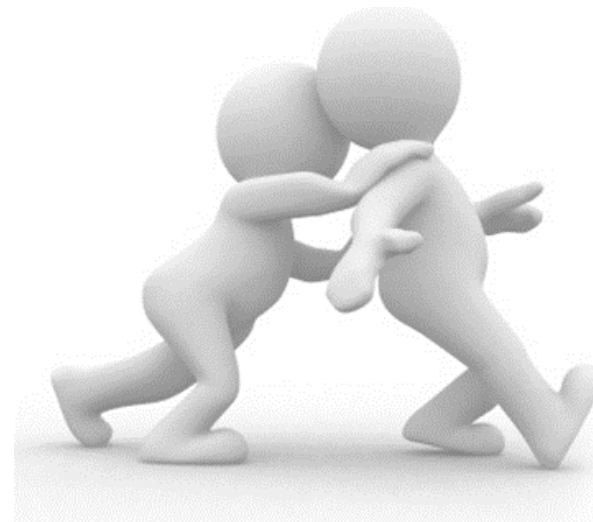
- Data may have sensitive information, and apprehensions about maintaining confidentiality are reasonable.

Appropriate Acknowledgement

- Researchers may be uneasy about the prospect of not receiving acknowledgement by others who use their data, or that others will use their data to gain a competitive advantage.

Why some researchers remain reluctant to share their own research data?

- 42% Intellectual property or confidentiality issues
- 36% My funder/institution does not require data sharing
- 26% I am concerned that my research will be scooped
- 26% I am concerned about misinterpretation or misuse
- 23% Ethical concerns
- 22% I am concerned about being given proper citation credit or attribution
- 21% I did not know where to share my data
- 20% Insufficient time and/or resources
- 16% I did not know how to share my data
- 12% I don't think it is my responsibility
- 12% I did not consider the data to be relevant
- 11% Lack of funding
- 7% Other



Considerations before data sharing

- Good data management
- Meeting ethical and legal obligations
- Intellectual property rights
- Data licensing
- Meta data schema and cross-walking

Data can only be shared if they are of high quality, well-curated, well-documented, and can be referenced and indexed.



Effective Research Data Management

<https://www.elsevier.com/connect/10-aspects-of-highly-effective-research-data>

قوانین داخلی

1. کلیه دستگاهها و نهادهایی که از بودجه عمومی کشور استفاده مینمایند موظفند نسبت به در اختیار قراردادن بانکهای رقومی (دیجیتالی) خود به استثناء موارد طبقه بندی شده، حریم خصوصی و مواردی که در قوانین افشاء اطلاعات ممنوع شده است، اقدام نمایند (قانون برنامه پنجم توسعه)

2. قانون انتشار و دسترسی آزاد به اطلاعات

شماره ابلاغیه : 56348/32 تاریخ ابلاغیه : 1388/11/04

- <https://rc.majlis.ir/fa/law/show/780303>

قانون انتشار و دسترسی آزاد به اطلاعات

اطلاعات

- هر نوع داده که در اسناد مندرج باشد یا به صورت نرم افزاری ذخیره گردیده و یا با هر وسیله دیگری ضبط شده باشد.

اطلاعات شخصی

- اطلاعات فردی نظیر نام و نام خانوادگی، نشانی‌های محل سکونت و محل کار، وضعیت زندگی خانوادگی، عادت‌های فردی، ناراحتی‌های جسمی، شماره حساب بانکی و رمز عبور است.

اطلاعات عمومی

- اطلاعات غیرشخصی نظیر ضوابط و آیین نامه ها، آمار و ارقام ملی و رسمی، اسناد و مکاتبات اداری که از مصادیق مستثنیات فصل چهارم این قانون نباشد.

قانون انتشار و دسترسی آزاد به اطلاعات

ماده 2

- هر شخص ایرانی حق دسترسی به اطلاعات عمومی را دارد، مگر آن که قانون منع کرده باشد. استفاده از اطلاعات عمومی یا انتشار آنها تابع قوانین و مقررات مربوط خواهد بود.

ماده 5

- مؤسسات عمومی مکلفند اطلاعات موضوع این قانون را در حداقل زمان ممکن و بدون تبعیض در دسترسی مردم قرار دهند.

ماده 7

- مؤسسه عمومی نمی تواند از متقاضی دسترسی به اطلاعات هیچ گونه دلیل یا توجیهی جهت تقاضایش مطالبه کند.

Data management plans

- A Data Management Plan (DMP) document shows data will be managed, stored and shared during and after a research project.
- Some research funders and human research ethics committees are now requesting that researchers submit a DMP as part of their project proposal.
- By planning ahead, the research team can improve research efficiency, guard against data loss, enhance data security, and ensure research data integrity and replicability.
- Many Data Management Plan templates are now freely available for reuse.

Data Management Plan

1. Data Collection and Documentation



- ☐ What kind of data are generated
- ☐ How will data be generated
- ☐ What metadata are needed

2. Ethics, legal and security Issues



- ☐ How will ethical issues be handled
- ☐ How are the data accessed
- ☐ Are there copyright issues
- ☐ Are there sensitive data
- ☐ What about intellectual property rights

3. Data Storage and Preservation



- ☐ How are the data stored?
- ☐ Are there back up systems
- ☐ How are data safely preserved

4. Data Sharing and reuse



- ☐ How and where will the data be shared?
- ☐ How are sensitive data protected
- ☐ How can data be accessed

DMPTool

- DMPTool is a service of the University of California Curation Center
- It allow researchers to create **D**ata **M**anagement **P**lans that meet institutional and funder requirements

<https://dmptool.org/>





Vitamin D Deficiency and Pregnancy and Neonatal Outcomes



Shahrood Eye Cohort Study



Shahed Beheshti University of Medical Sciences, Health of Employees Cohort study



Pars Cohort Study



Isfahan Cohort Study ICS



Assessment of the trial of low cost technology assisted integrated care delivery programme to prevent serious cardiovascular events in disadvantaged populations



Urmia Lake Cohort Study



Rafsanjan Birth Cohort Study



Mashhad University of Medical Sciences and Ferdows University Organizational Cohort Study



Howzesh Cohort Study



Dema Cohort Study



Childhood and Adolescence Surveillance and Prevention of Adult Non-communicable disease



Azar Cohort Study



TUMS Employees Cohort Study



Shahrood School Children Eye Cohort Study



Ravansar (RANCO) Cohort Study



Persian Youth Cohort



Isfahan Diabetes Prevention Cohort



Employees Health Cohort Study of Iran



Azar Cohort Study



Tehran Lipid and Glucose Study TLGS



Shahrood Driver Cohort Study



Rafsanjan Youth Cohort Study



Rafsanjan Cohort Study



Mazandaran Cohort Study



Guilan Cohort Study



Faraman Brucellosis Cohort Study



Behvaaz Health Study



Surveillance of Risk Factors of Non Communicable Diseases in Iran STEPS 2016



Subclinical Thyroid Dysfunctions and Pregnancy and Neonatal Outcomes



Shahedeh Cohort Study



Qazvin Metabolic Diseases Study



Kerman Coronary Artery Diseases Risk Factor Study



Golestan Cohort Study



Bushehr Elderly Health Program



SLIMS Employees Health Cohort Study



Shahrood Cohort Study



Sabzevar Cohort Study



Prospective Epidemiological Research Studies in Iran



Isfahan Thyroid Cohort Study



Fasa Cohort Study



Bendareh Kang Cohort Study





ABOUT IRAN COHORT CONSORTIUM (ICC)

Cohort studies play a central role in medical research to improve public and individual health. Since cohort studies are growing in number across the country, the Iran Cohort Consortium (ICC) was established to enhance the



JOINT PROJECTS



WORKGROUPS



EVENTS



MEMBERSHIP



ORGANIZATION



PUBLICATION



COHORT STUDIES



Thank you

thank
you

