S4 – Data Stewardship I D4 – Data and Ethics



Schedule

KW		Date	#	Topics	LernSetting WI	Lecturer
38 39	Self Study	First 2 weeks	0	Awareness - Entry Test with Moodle Test (20% counted to course grade)	Virtual	Selfstudy
38		KW38	0 + 7	Coaching Session (according to the information of the respective school)	on site	JRN= Juchler Norman Rerabek Martin Nyfeler Matthias
38	Fr, afternoon	23.09.2022	1	Personal Security	Virtual	Pascal Moriggl
39		KW39	1	Coaching Session	on site	FHNW: Pascal Moriggl ZHAW: JRN
39	Fr, afternoon	30.09.2022	2	Information Security & Cybersecurity I	Virtual	Petra M. Asprion
40		KW40	2	Coaching Session	on site	FHNW: Petra M. Asprion ZHAW: JRN
40	Fr, afternoon	07.10.2022	3	Information Security & Cybersecurity II	Virtual	Petra M. Asprion
41		KW41	3	Coaching Session	on site	FHNW: Pascal Moriggl ZHAW: JRN
41	Fr, afternoon	14.10.2022	4	Data Stewardship I	Virtual	Pascal Moriggl
42		KW42	4	Coaching Session	on site	FHNW: Pascal Monggl ZHAW: JRN
42	Fr, afternoon	21.10.2022	5	Data Stewardship II	Virtual	Pascal MoriggI
43		KW43	5	Coaching Session	on site	FHNW: Pascal Moriggl ZHAW: JRN
43	Fr, afternoon	28.10.2022	6	Data Ethics	Virtual	Pascal Moriggl
44		KW44	6	Coaching Session	on site	FHNW: Pascal Moriggl ZHAW: JRN
44	Fr, afternoon	04.11.2022	7	Data Privacy	Virtual (Flipped Classroom)	Pascal Moriggl

Agenda

Part I: Repetition Last Week

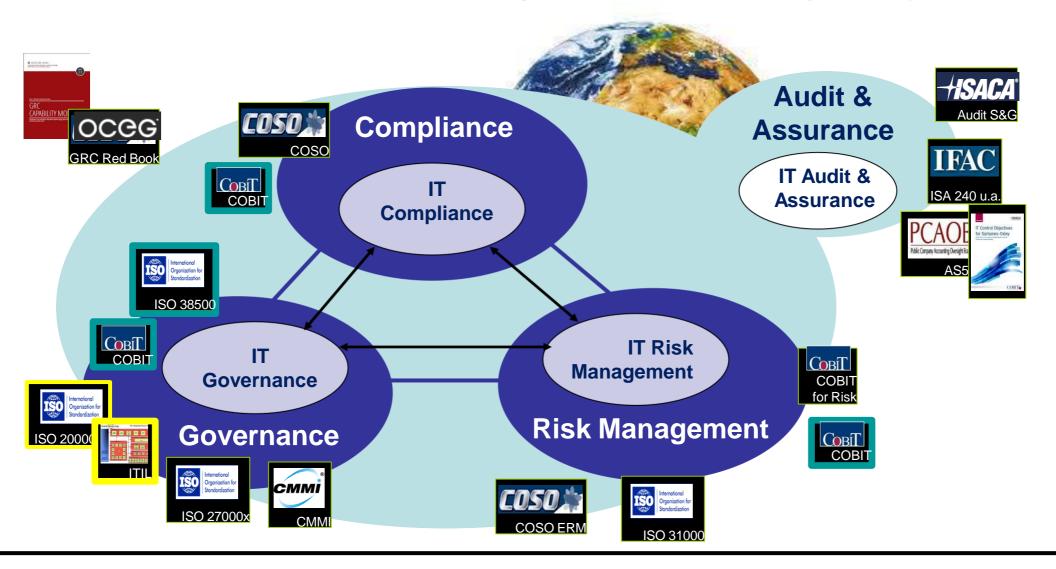
Part I: Introduction Data Stewardship

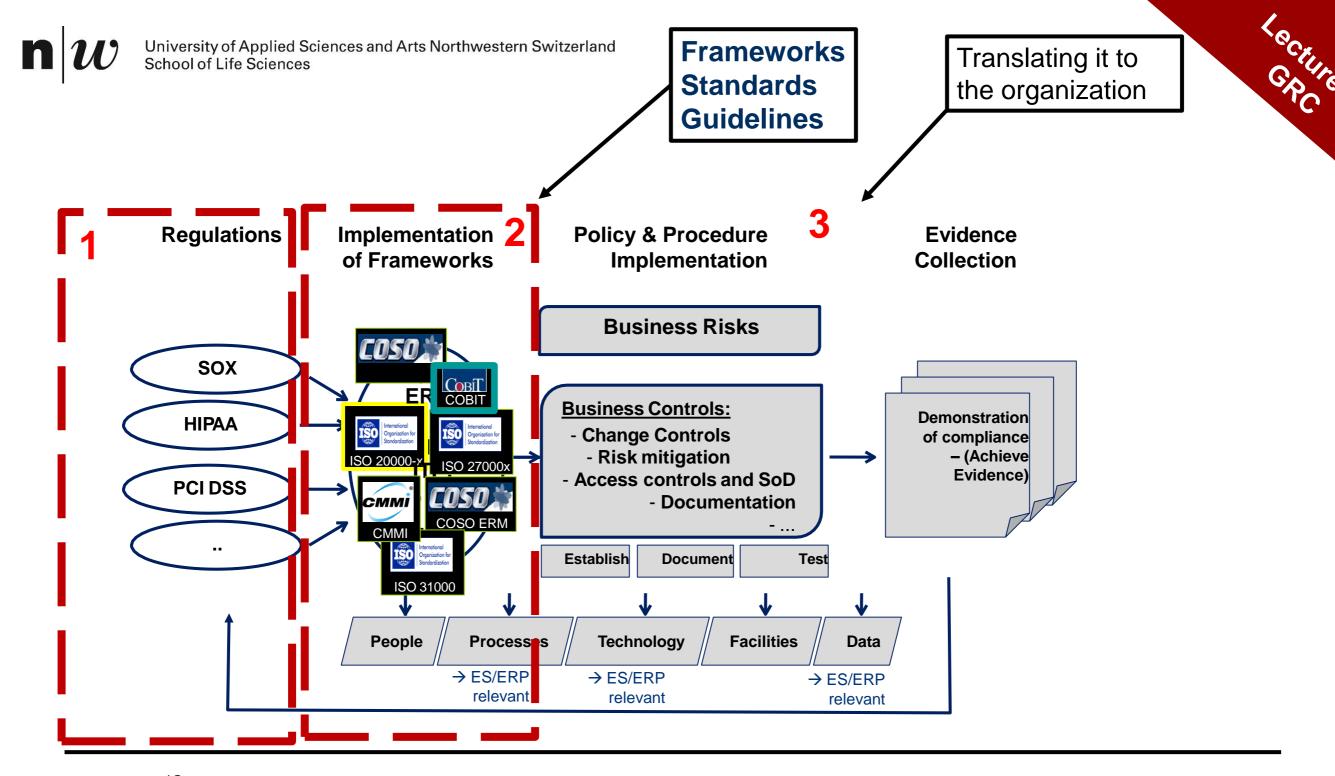
Part II: Data Management Plan

Part III: DMP Tool



Our topic -Governance, Risk and Compliance – GRC (I&CS)







University of Applied Sciences and Arts Northwestern Switzerland School of Life Sciences

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Published research Course catalogs Published faculty and staff information Student directory information* Basic emergency response plans (life safety) University-wide policies Harvard publications Press releases Published marketing materials Regulatory and legal filings Published annual reports Code contributed to Open Source Released patents Plans of public spaces *Directory information about students who have requested FERPA blocks must be classified and handled as L3, at minimum.	Department policies and procedures Employee web/intranet portals Harvard training materials Pre-release articles Drafts of research papers Work papers Patent applications Grant applications Non-public building plans or layouts (excluding L3 or L4 items) Information about physical plant (excluding L3 or L4 items)	Non-directory student information Non-published faculty and staff information Information protected under FERPA, in general HUID tied to an individual Personnel records** Donor information (excluding L4 data points or special handling) Non-public legal work and litigation information Budget /financial transactions information Non-public financial statements Information specified as confidential by vendor contracts and NDAs Information specified as confidential by Data Use Agreements General security findings or reports (e.g. SSAE16) Most Harvard source code Non-security technical specifications/architecture schema Library/museum object valuations IRB records	Passwords and PINs System credentials Private encryption keys Government issued identifiers (e.g. Social Security Number, Passport number, driver's license) Individually identifiable financial account information (e.g. bank account, credit or debit card numbers) Individually identifiable health or medical information*** Individually identifiable research data Details of significant security exposures at Harvard (e.g. vulnerability assessment and penetration test results) Security system procedures and architectures Trade secrets Systems managing critical Operational Technology	Research data classified as Level 5 by the IRB Information or research under a contract stipulating specific security controls beyond L4		





Introduction



Learning Goals

- ✓ Increase awareness of data trends and the related need for order
- ✓ Understand the difference and link between data governance and data stewardship
- ✓ Know the key principles of data stewardship.



Open Data

The benefits and value of open data



Building on the Digital Single Market efforts: open data in Europe today

== 22/01/2020
== Europe

Open data in Europe

Most national governments in Europe have developed an open data agenda and have established open data portals supported by solid open data policies and strategies. In 2019, an overall maturity of 74% was achieved by the EU28 in terms of policy maturity (visible on the ODM dashboard), indicating that Member States have developed a strong foundation in terms of their open data policy framework. The increased amount of national data portals is reflected in the evolution of datasets available on the European Data Portal (EDP). For example, in May 2016 the EDP only had over 400,000 available datasets, which grew to over 890,000 in August 2019 and is expected to grow further.

https://data.europa.eu/en/datastories/benefits-and-value-open-data

Open Data = Economic Growth, Positive Impact on Society

Increasing the quality, efficiency, and transparency of public services;

Cost saving, as it is for example forecasted that national governments of the <u>EU28+ could save 1,7 billion euro by 2020, Link opens in a new window</u>; and

Greater efficiency in processes and delivery of public services. This can be illustrated by an <u>example from the Netherlands</u>, <u>Link opens in a new window</u>, where the Ministry of Education publishes education-related data for re-use. Since then, the number of questions they receive has dropped, reducing workload and costs. The remaining questions are now also easier for civil servants to answer because it is clear where the relevant data can be found.

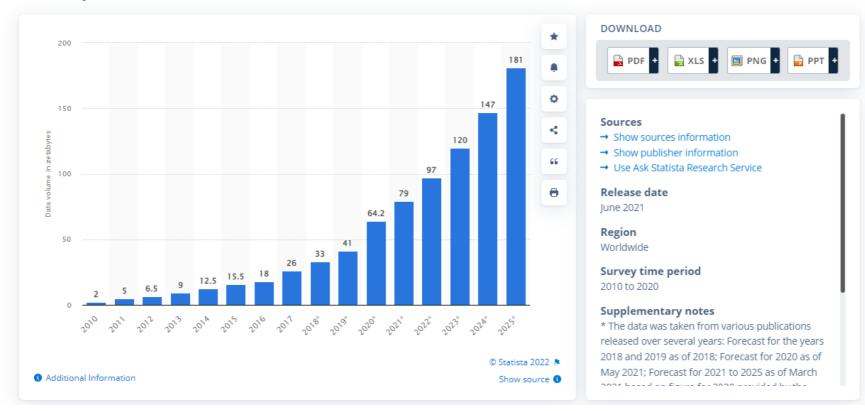
It is <u>estimated that by 2020, Link opens in a new window</u>, the market size for open data has increased by 36.9%, to a value of 75.7 billion EUR. When looking at the impact of open data in a specific sector, the public sector is expected to have the highest share in terms of <u>direct market size with a value of 22.11 million EUR, Link opens in a new window</u>. The growth of the open data market size is also expected to trigger a higher demand for skilled open data workers. It is forecasted that <u>open data has created 100,000 jobs by 2020</u>.

https://data.europa.eu/en/datastories/benefits-and-value-open-data



Volume of data/information created, captured, copied, and consumed worldwide from 2010 to 2020, with forecasts from 2021 to 2025

(in zettabytes)



Zettabyte Defined

A zettabyte is a measure of digital storage capacity. A zettabyte is read as the 2 to the 70th power bytes. It is also equal to a thousand exabytes, a billion terabytes or a trillion gigabytes. Simply, it would mean one billion, one terabyte hard drives would be needed to store one zettabyte of data.

Due to the zettabyte unit of measurement being so large, it is only used to measure large aggregate amounts of data. Even all the data in the world is estimated to be only a few zettabytes.

A byte is a data measurement unit that contains eight bits, or a series of eight zeros and ones. There is nine types of bytes.

Byte

Kilobyte

Megabyte

Gigabyte

Terrabyte

Petabyte Exabyte

Zettabyte

Yottabyte

https://www.indicative.com/resource/zettabyte/

https://www.statista.com/statistics/871513/worldwide-data-created/



Review > Drug Discov Today. 2020 Sep;25(9):1624-1638. doi: 10.1016/j.drudis.2020.07.005. Epub 2020 Jul 11.

Advancing computer-aided drug discovery (CADD) by big data and data-driven machine learning modeling

Linlin Zhao ¹, Heather L Ciallella ¹, Lauren M Aleksunes ², Hao Zhu ³

Affiliations + expand

PMID: 32663517 PMCID: PMC7572559 DOI: 10.1016/j.drudis.2020.07.005

Free PMC article

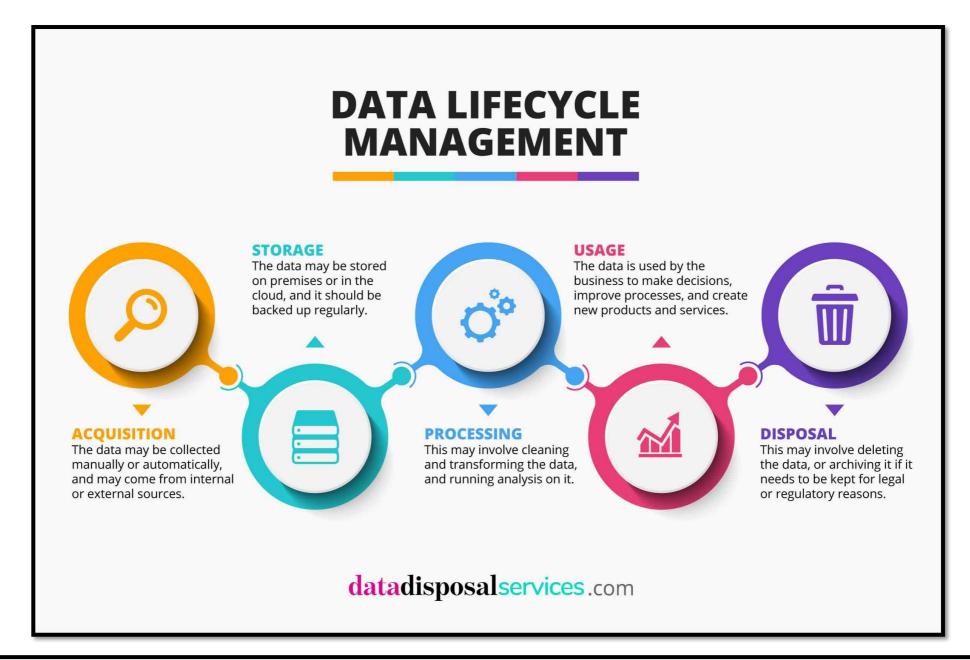
Abstract

Advancing a new drug to market requires substantial investments in time as well as financial resources. Crucial bioactivities for drug candidates, including their efficacy, pharmacokinetics (PK), and adverse effects, need to be investigated during drug development. With advancements in chemical synthesis and biological screening technologies over the past decade, a large amount of biological data points for millions of small molecules have been generated and are stored in various databases. These accumulated data, combined with new machine learning (ML) approaches, such as deep learning, have shown great potential to provide insights into relevant chemical structures to predict in vitro, in vivo, and clinical outcomes, thereby advancing drug discovery and development in the big data era.

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https://pubmed.ncbi.nlm.nih.gov/32663517/

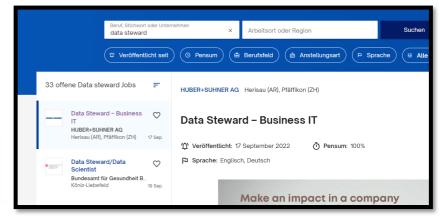








"Dear XY, You will become our new, internal data steward! Good Luck!"



Data Steward

Competencies

Departmental knowledge

Deep knowledge of the operational area they are responsible for, including understanding processes, rules and requirements. As well as functional understanding, a knowledge of the data flows and data sources will be important.

Communication skills

The ability to interpret and communicate policy or business rules to end users. At the same time being able to work with the technology and policy owners to ensure ideas are fed back.

Collaboration skills

Working with other Data Stewards and stakeholders across the organization to ensure data flows smoothly around the organization.

https://www.data-vault.co.uk/qualities-data-steward/

Data Steward

Responsibilities

Ensuring data quality, data definition and privacy standards are met.
Ensuring that data is fit for purpose (including completeness, accuracy and integrity).
Managing metadata and processes to ensure proper use of data being read, created, collected reported, updated or deleted.
Ensuring data is protected and security procedures are enforced.
Take an active part in the data governance framework to feedback on existing practise and recommend improvements.

https://www.data-vault.co.uk/qualities-data-steward/



Data Stewardship





Data Stewardship

"Data stewardship is concerned with the science and practice of data collection for the purposes of analysis, reflecting the values of fair information practices. In practice data stewardship is a collection of methods and mechanisms of data management encompassing acquisition, storage, protection, aggregation, deidentification, and procedures for data release, use, and re-use, to ensure that the data assets are of high quality, easily accessible, and used appropriately."

https://unece.org/

Data Stewardship

An Actionable Guide to Effective Data Management and Data Governance

SECOND EDITION

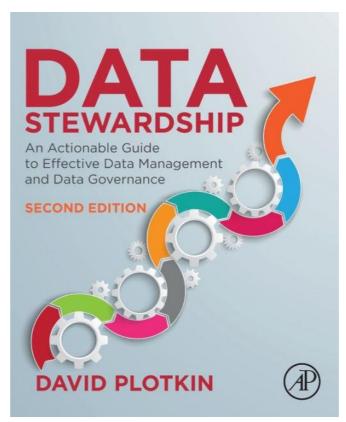
David Plotkin

Enterprise Information Management



Data Governance

"Data governance concerns decisionmaking and authority for data related matters, whether within or between public enterprises and agencies. According to a seminal text on data stewardship, data governance is a rights system of decision accountabilities information for related processes, executed according to agreed-upon models governing the kind of data stored, the authority to access data, and the methods of data access."



Plotkin, D. (2021). Data Stewardship: An Actionable Guide to Effective Data Management and Data Governance (2nd Ed.). London, UK: Academic Press.

Data Stewardship vs. Data Governance?

Data Governance is about **how** people manage and make decisions about data rather than about the data itself, whereas

Data Stewardship is about ensuring that people are properly organized and do the right things to make their data understood, trusted, of high quality, and ultimately, suitable and usable for the enterprise's purposes.

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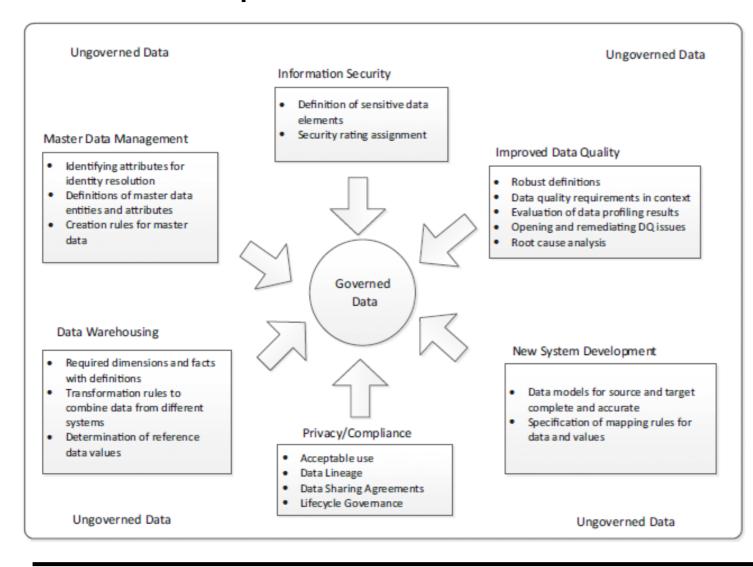
Context

exponential growth in data generated worldwide (e.g. IoT) and the arrival of new technologies (AI, Edge Computing) increases importance on data
use of electronic devices through communication networks has led to rich data pools discover patterns, infer indicators, develop business models,
digitalization of society and economy has placed data access and sharing at the core of innovation and public trust
there are huge possibilities for new types of data services, more timely and granular data, new insights by linking data from different sources and topics
but there are also huge risks: data could be used unethically, the 'digital divide' could become an 'information divide', invasion of privacy

https://unece.org/



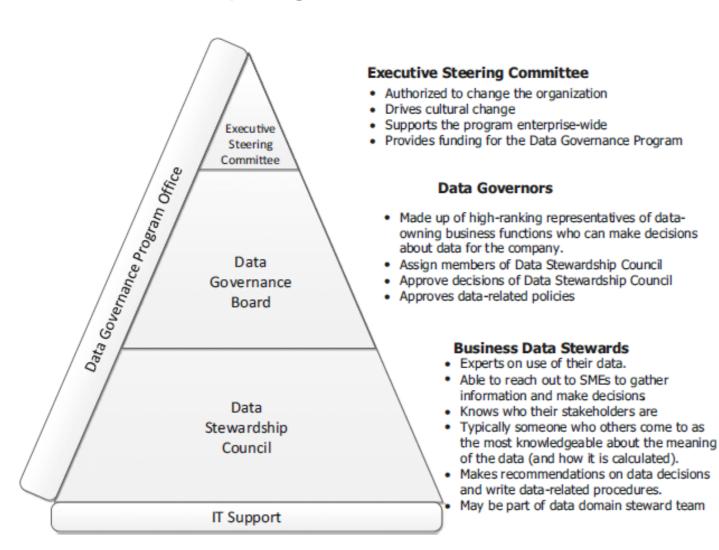
Data Stewardship: Drivers



There are many drivers for moving data from an ungoverned state to a governed state.

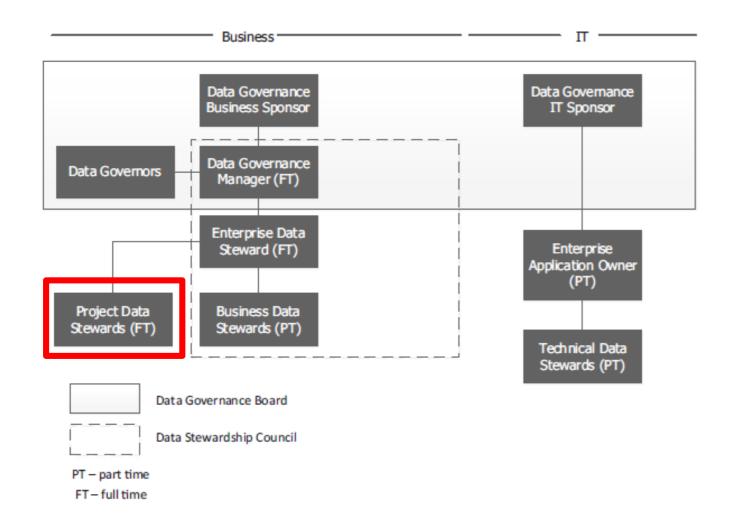
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Data Stewardship: Organisation



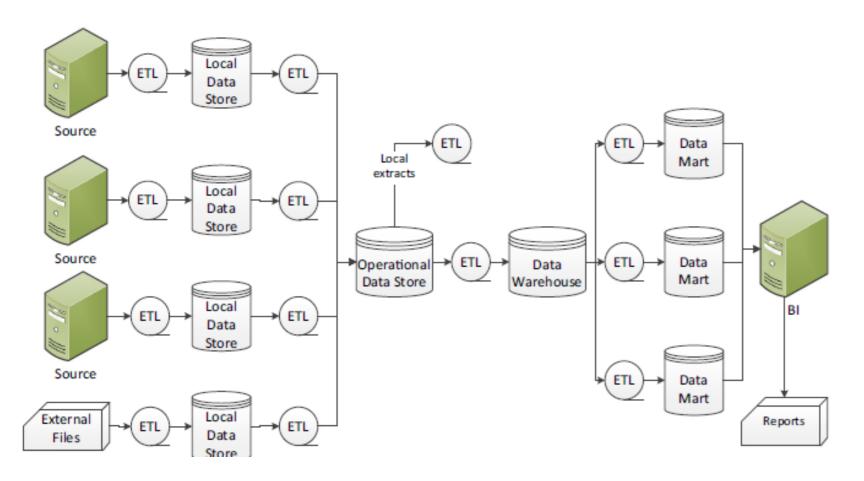
A Data Governance Program is often arranged as a pyramid, with support from IT and a Data Governance Program Office.

Data Stewardship: Business / IT Alignment



The Business and IT view of the Data Governance Organization.

Data Stewardship: The "Bigger" Flow-Picture



Information flows through an enterprise in the "Information Chain."



Let's get straight to the





Practical Data Stewardship

Applied Data Stewardship

4 G's

"gather" =

refers to all data ingestion, including the collecting and integrating of data assets through various systems of acquisition, as well as the policy instruments and ethics-based legislative frameworks through which the agency gains access to data and information (Rancourt, 2019). Sound data stewardship ensures that this data is acquired efficiently, ethically, and without duplication or redundancy.

Applied Data Stewardship

4 **G**'s

"guard" data =

special attention is paid to access rights and privileges, data audit trails are performed, data monitoring and back-up protocols are systematized and ongoing, and metadata standards and classification systems are consistently updated (Rancourt, 2019). The goal in guarding data is to adhere to the "privacy by design" principles, ensuring that data is secure and encrypted, confidential and de-identified, and with all necessary privacy protocols in place in order to function ethically and according to our trust framework.

Applied Data Stewardship

4 **G**'s

"grow" data =

the data is organized, processed, transformed, integrated, and extracted from for various uses (Rancourt, 2019). During this phase, data is cleaned and verified, quality assurance is performed, data is analyzed, explanations are developed, and hypotheses are tested. Efforts are made to grow data by ensuring its optimization and adhering to (and continually developing) data quality frameworks.

Applied Data Stewardship

4 G's

"give" =

data and statistics are shared and published. Here, data access and interoperability are ensured, dissemination occurs regularly and with quality and accessibility, and the appropriate metadata is made available based on strategic requirements (Rancourt, 2019). The goal for Statistics Canada, and the public service more broadly, is to increase data discoverability and be "open by design", having sharable and open data, metadata, metainformation, and analysis.

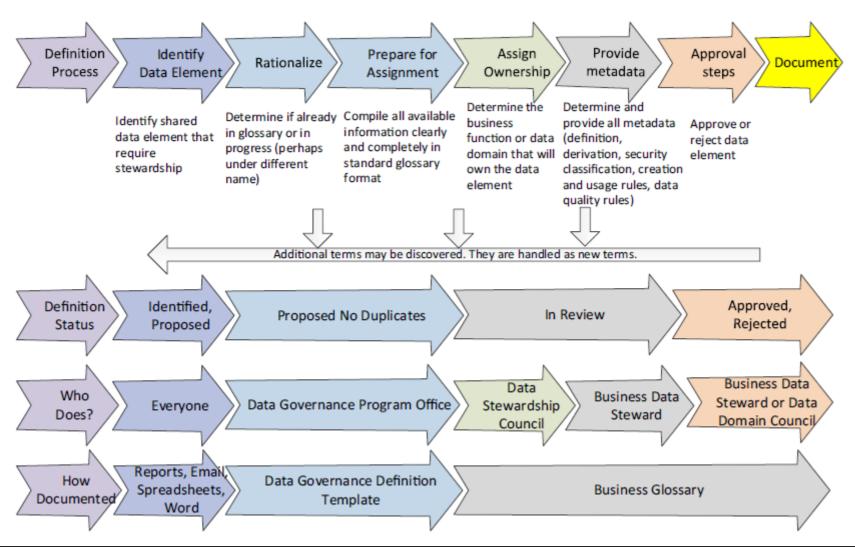


Applied Data Stewardship



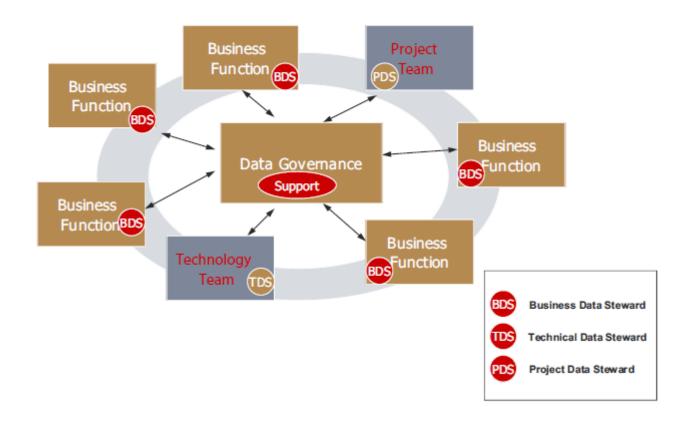


Starting Processes



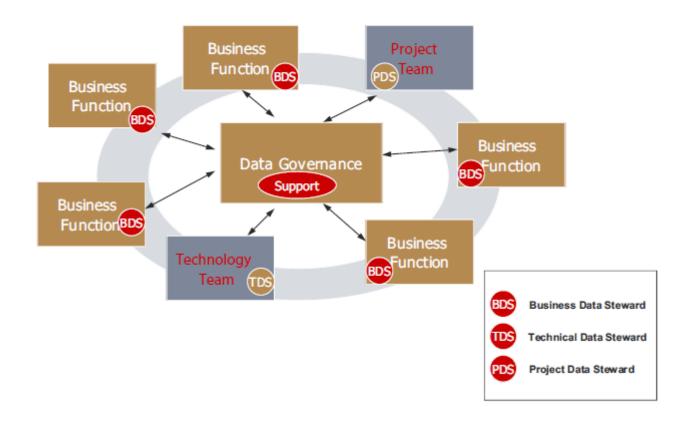
The flow (across the top) of the process to identify, assign business function owner, define, and approve a new business data element.

Starting Processes



The hybrid model of data stewardship on a project.

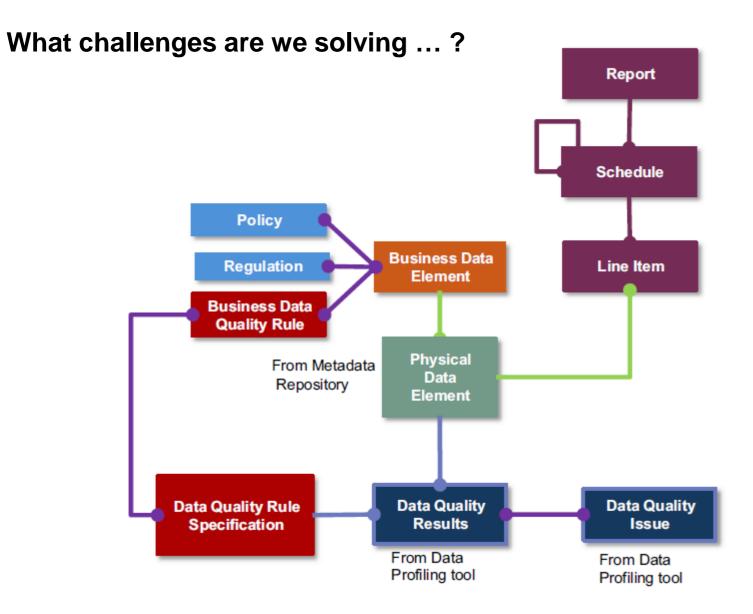
Starting Processes



The hybrid model of data stewardship on a project.

What challenges are we solving ...?

Table 6.6 Rationaliz	ble 6.6 Rationalizing the Data Elements					
Data Element	Different Names or Different Data?	Total Data Points				
Entry time	Ticket issue time, time of entry, transaction start time	1 or 4?				
Prepayment time	Ticket paid time, payment time	1 or 3?				
Amount due	Transaction total, transaction amount	1 or 3?				
Payment method	Payment type	1 or 2?				
Amount tendered	Amount paid, collected amount	1 or 3?				
Change issued	Overpayment amount, refund amount, amount due to client	1 or 4?				
Receipt issued	Receipt requested, receipt printed	1 or 3?				
Actual exit time	Exit time, departure time	1 or 3?				
Total		8 or 25?				





Data Management Plan



https://datamanagement.hms.harvard.edu/training-events/rdm-seminar-series

Learning Goals

- ☐ Understand why data management plans are important
- ☐ Review example data management plan language
- ☐ Review DMPTool platform and templates

Data Sharing // Snafu in 3 Short Acts



https://youtu.be/66oNv_DJuPc

Research Data Management

"The active and ongoing management of data through its lifecycle of interest and usefulness to scholarship, science, and education."

—The University of Illinois' Graduate School of Library and Information Science



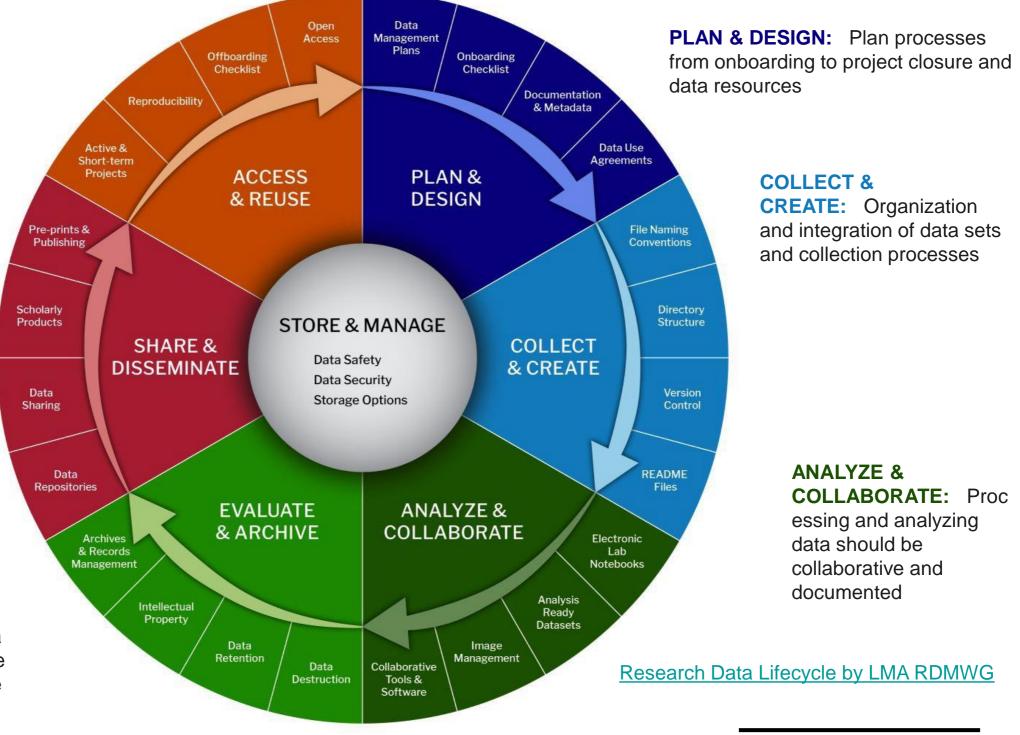


ACCESS &
REUSE: Ensuring the
broad utility of your
research data efforts for
other researchers

SHARE & DISSEMINATE: Esta blishing and supporting the reach and impact of your data

EVALUATE & ARCHIVE: Identify essential research records and evaluate for retention

STORE & MANAGE: Each stage of the Biomedical Data Lifecycle revolves around the management of data storage



Research Planning

Concerns all aspects of preparing for a project:

- Seeking funding, awareness of Company and sponsor requirements
- Organization of data, records, tools, and/or resources needed to conduct the research and disseminate and archive valuable results

Important steps for sensitive data:

- If you know you will share data, get permission from participants as part of informed consent
- If you don't know if you'll share data in the future, consider getting permission anyway!

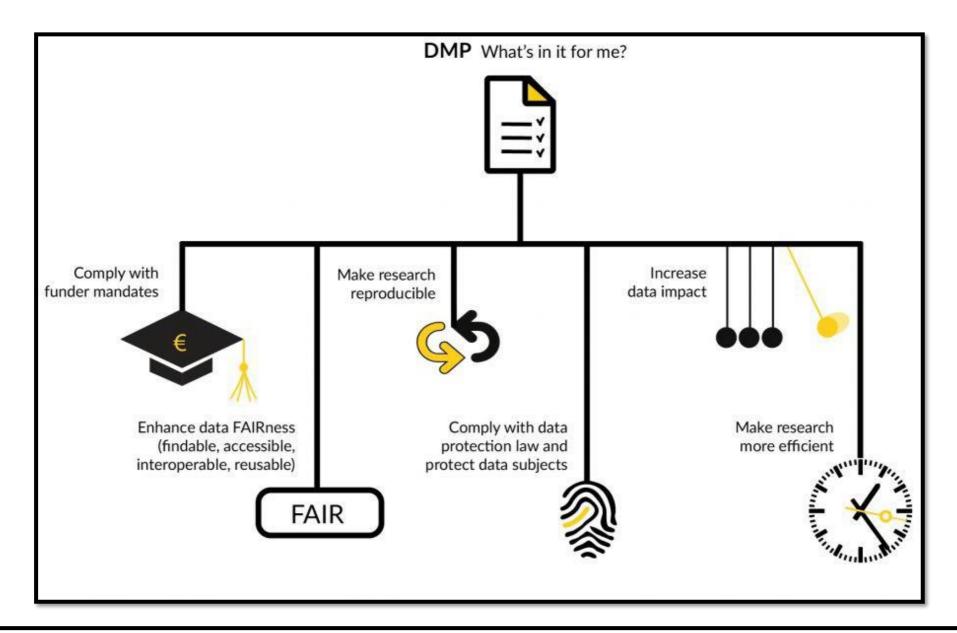


Data Management – Key Points

- ✓ Easier to analyze organized, documented data
- ✓ Find data more easily
- ✓ Don't drown in irrelevant data
- ✓ Don't lose data
- ✓ Get credit for your data
- ✓ Avoid accusations of misconduct

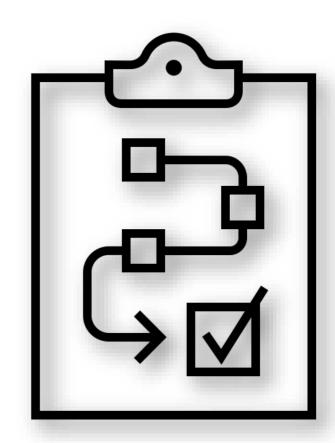


Research Planning



Data Management Plan

- ✓ Written document outlining plans for handling all of the data resulting from a research project in the short and long term
- ✓ Detailed procedures for data collection, all aspects of organization and processing before your data leaves your lab
- ✓ Plan for when data leave your lab so that others can find and access it in perpetuity
- ✓ Living, working document describing the entire project and is frequently referred to and updated



Poll Question

Have you written a Data Management Plan before?

https://www.menti.com/alqqhhxm6p3o

The voting code is 87 25 63 1

Data Management and Sharing Plan (DMSP)

Data Management Plans (DMPs) are a key element of good data management. A DMP describes the data management life cycle for the data to be collected, processed and/or generated by a Horizon 2020 project.

https://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/open-access-data-management/data-management_en.htm

n|w

Data Management and Sharing Plan (DMSP)

Required Elements*:

- Data Type
- 2. Related Tools, Software and/or Code
- 3. Standards
- 4. Data Preservation, Access, and Associated Timelines
- 5. Access, Distribution, or Reuse Considerations
- 6. Oversight of Data Management and Sharing



Data Management and Sharing Plan (DMSP)

1. Data Type

- Identifying estimated type and amount of data to be generated (i.e., modality, level of aggregation, and degree of data processing)
- Which data to be preserved and shared
- Accompanying metadata, other relevant data, and associated documentation to be made available

2. Related Tools, Software and/or Code

Tools and software needed to access and manipulate data

3. Standards

Standards to be applied to scientific data and metadata

Data Management and Sharing Plan (DMSP)

4. Data Preservation, Access, and Associated Timelines

- Proposed repository to be used consistent with Supplemental Information
- How data will be findable and accessible (e.g., persistent unique identifier)
- When data will be made available and for how long

5. Access, Distribution, or Reuse Considerations

- Description of factors potentially affecting data access, distribution, or reuse related to informed consent or privacy and confidentiality protections
- Whether access to human data will be controlled

6. Oversight of Data Management and Sharing

Plan compliance will be monitored/ managed and by whom

Example: Standards

Formal standards for our data have not yet been widely adopted. However, our data and other materials will be structured and described according to best practices.

Data will be stored in common and open formats, such as .txt files for our clinical data. Information needed to make use of this data will be recorded in codebooks that will be accessible to the research team and will subsequently be shared alongside final datasets.

Information about our research process, including the details of our analysis pipeline will be **maintained contemporaneously, using protocols**. This information will be accessible to all members of the research team and will be shared alongside our data.

STANDARDS

FORMATS

DOCUMENTATION

Example: Data Preservation, Access, & Associated Timelines

Data will be publicly shared and preserved in the repository **Zenodo**.

Zenodo is freely available to anyone to use, and the data will be securely stored in the CERN Data Center. Once deposited in Zenodo and published, the data set will be **assigned a DOI** and will be findable via a web search, the Zenodo repository search feature, or by the assigned DOI.

The data will be published **concurrently with the first associated publication**, but no later than the end of the award period. The data will **be available for at least 20 years**; <u>Zenodo's policies</u> currently state "Items will be retained for the lifetime of the repository. This is currently the lifetime of the host laboratory CERN, which currently has an experimental programme defined for the next 20 years at least."

PRESERVATION

ACCESS

TIMELINES

Example: Access, Distribution, or Reuse Considerations

In order to ensure participant consent for data sharing, IRB paperwork and informed consent documents will include language describing plans for data management and sharing data, describing the motivation for sharing, and explaining that personal identifying information will be removed.

To protect participant privacy and confidentiality, **shared data will be de-identified using the Safe Harbor method** per

§164.514(b) to comply with the HIPAA Privacy Act.

CONSENT

ACCESS

DISTRIBUTION

Poll Question

Do you have a better understanding about Data Management Plans?

https://www.menti.com/alajov8q5oyu

The voting code is 25 69 85



DMP Tool



Learning Goals

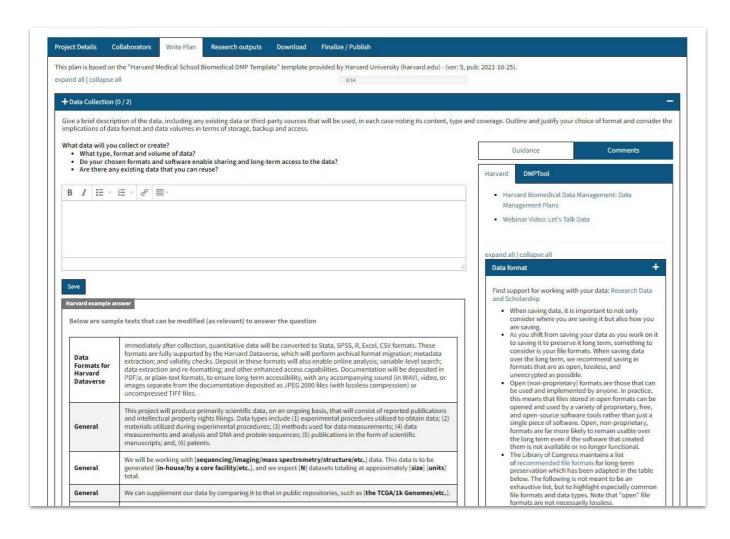
- □ Review DMPTool platform
- ☐ Have knowledge about templates

DMSP Resources

- ☐ Customized **DMPTool** Templates
- Onboarding and Offboarding Checklists
- □ Data Use Agreement Resources
- ☐ <u>ELN</u> Resources (Electronic Lab Notebook)
- Metadata Guides
- ☐ Repository Resources



DMPTool Harvard Templates





A free tool that helps researchers create data management plans that fulfill the requirements of different funders.

- 1. Go to https://dmptool.org
- Sign up and login using your fhnw / zhaw mail address



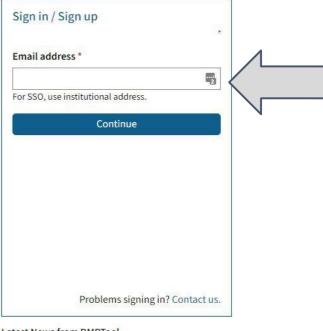
DMPTool Demo https://dmptool.org





Funder Requirements Public DMPs Help





Language -







Latest News from DMPTool

Announcing the FASEB Dataworks! Data Management Plan Challenge

View all news







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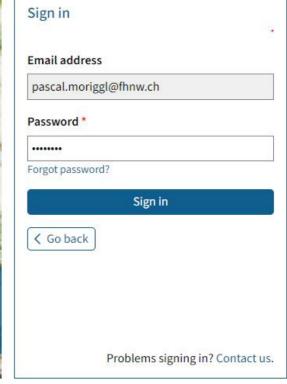
Language -



Build your Data Management Plan

Funder Requirements Public DMPs Help





78,770 Users





Latest News from DMPTool

FAIR Island Project Receives NSF Funding

View all news











Peter Parker ▼ Language ▼

My Dashboard

Create Plan

Funder Requirements

Public DMPs

Signed in successfully.

My Dashboard

The table below lists the plans that you have created, and that have been shared with you by others. You can edit, share, download, make a copy, or remove these plans at any time.

Project Title 💲	† Template ‡	Edited ▼	Role	Test	Visibility	Shared	
Clinical Trial	Digital Curation Centre	10-07-2022	Owner	~	N/A	Yes	Actions▼

Create plan



Peter Parker ▼ Language ▼



My Dashboard

Create Plan Funder Requirements

Public DMPs

Create a new plan

Before you get started, we need some information about your research project to set you up with the best DMP template for your needs.

* What research project are you planning?

Test * Select the primary research organization

Research organization

University of Applied Sciences and Arts Northwestern Switzerland (fhnw.ch)

* Select the primary funding organization

Begin typing to see a list of suggestions.

Cancel Create plan

Funder



mock project for testing, practice, or educational purposes

☐ No research organization associated with this plen or my research organization is not listed

- or -

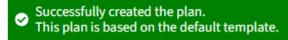
- or -

✓ No funder associated with this plan or my funder is not listed

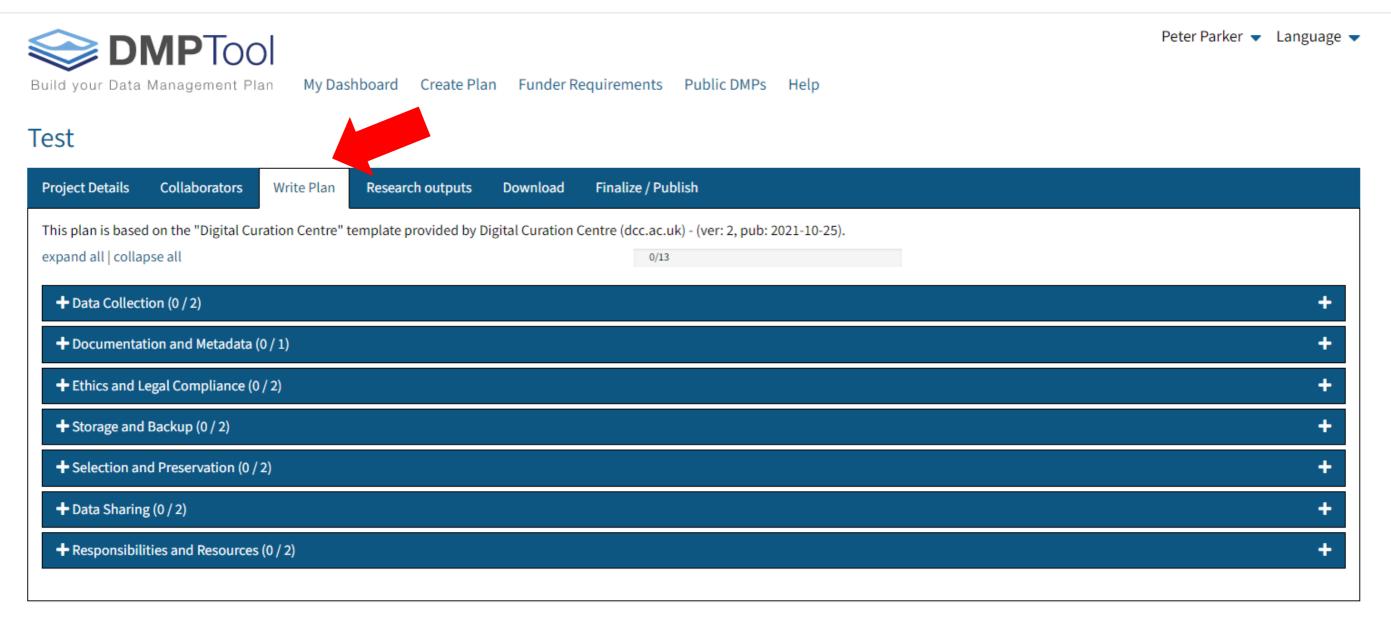
My Dashboard

Create Plan

Funder Requirements Public DMPs Help

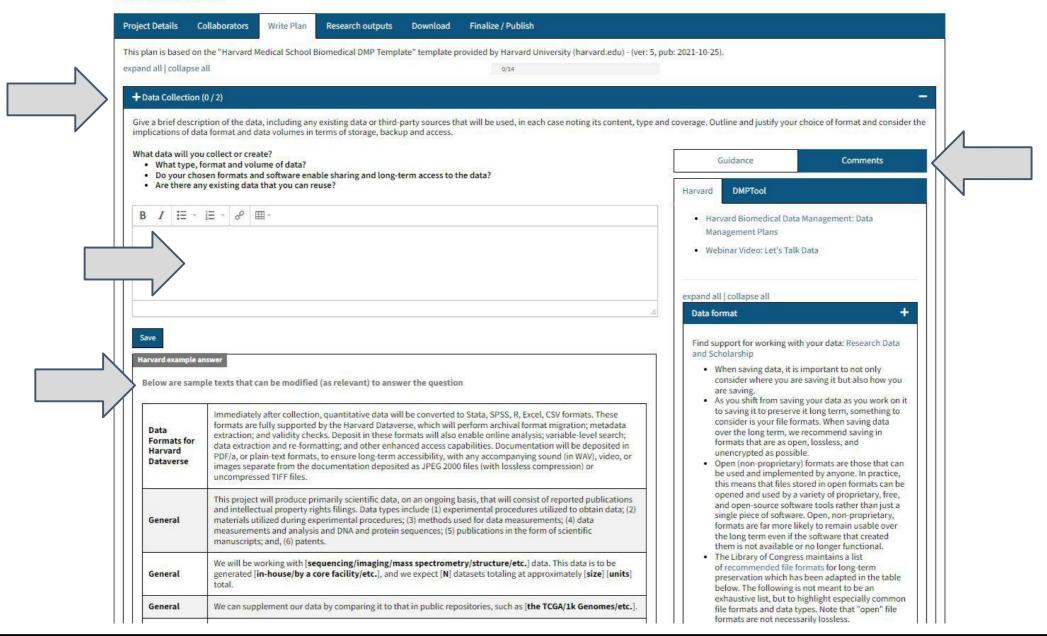


Test Project Details Collaborators Research outputs Download Finalize / Publish Write Plan Project title * Select Guidance Test To help you write your plan, DMPTool can show you guidance from a variety of organizations. ✓ mock project for testing, practice, or educational purposes Select up to 6 organizations to see their guidance. Project abstract DMPTool Find guidance from additional organizations below See the full list Save Research domain - Please select one -**Project Start** Project End tt.mm.jjjj tt.mm.jjjj Research outputs may have ethical concerns Funder





Research Grant



Key takeaways

- Data management is important to keep data safe from harm and make data usable and discoverable
- Adata management plan includes strategies and processes to organize, describe, preserve, and share data
- Some funding agencies have their own DMP policy
- DMPTool can be used for templates and guidance to create a DMP

Further Reading

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