# **Introduction to Research Data Management Course: Supplementary Resources**

## **Module 1 - Data & research life cycle:**

* An introduction to the basics of Research Data: Louise Patterton <https://www.youtube.com/watch?v=q2aiDJzJPuw&feature=emb_logo>
* Rong & Zhan (2019). Providing Research Data Management (RDM) Services in Libraries: Preparedness, Roles, Challenges, and Training for RDM Practice. Data and Information Management. DOI:<https://doi.org/10.2478/dim-2019-0009>

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## **Module 2 - Curation, data types and privacy issues:**

These are in addition to some of the resources referenced at the end of video 5 in the Module 2 session 1 slides recorded and presented:

Publications:

1. Michener WK (2015) Ten Simple Rules for Creating a Good Data Management Plan. PLoS Comput Biol 11(10): e1004525. <https://doi.org/10.1371/journal.pcbi.1004525>

# Contaxis N, Clark J, Dellureficio A, Gonzales S, Mannheimer S, Oxley PR, et al. (2022) Ten simple rules for improving research data discovery. PLoS Comput Biol 18(2): e1009768. <https://doi.org/10.1371/journal.pcbi.1009768>

1. Tammaro, Anna Maria, Matusiak, Krystyna K., Sposito, Frank Andreas and Casarosa, Vittore. "Data Curator’s Roles and Responsibilities: An International Perspective " *Libri*, vol. 69, no. 2, 2019, pp. 89-104.<https://doi.org/10.1515/libri-2018-0090>
2. Tang YA, Pichler K, Füllgrabe A, Lomax J, Malone J, Munoz-Torres MC, et al. (2019) Ten quick tips for biocuration. PLoS Comput Biol 15(5): e1006906. <https://doi.org/10.1371/journal.pcbi.1006906>
3. Tiffin N, George A, LeFevre AEHow to use relevant data for maximal benefit with minimal risk: digital health data governance to protect vulnerable populations in low-income and middle-income countriesBMJ Global Health 2019;4:e001395. <https://gh.bmj.com/content/4/2/e001395>.

Useful sites:

1. Foundation of Data Curation: The Pedagogy and Practice of Purposeful Work with Research Data (<https://www.archivejournal.net/essays/foundations-of-data-curation-the-pedagogy-and-practice-of-purposeful-work-with-research-data/>)
2. Software Carpentries Introduction to Git (<https://librarycarpentry.org/lc-git/>)
3. How to store and manage your data (<https://plos.org/resource/how-to-store-and-manage-your-data/>)
4. Smithsonian Data Management Best practices for Describing your Data: Data Dictionaries (si.edu) <https://library.si.edu/sites/default/files/tutorial/pdf/datadictionaries20180226.pdf>
5. Smithsonian Data Management Best practices for File Naming and Organizing (si.edu) <https://library.si.edu/sites/default/files/tutorial/pdf/filenamingorganizing20180227.pdf>
6. Metadata Basics: [www.metadataetc.org/metadatabasics/](http://www.metadataetc.org/metadatabasics/)
7. Tulane Universities Data Curation Tutorial: <https://libguides.tulane.edu/datacuration/tutorial>
8. University of Minnesota, Research Data Curation checklist: <https://conservancy.umn.edu/bitstream/handle/11299/193233/DCN2016EngagementEventWorksheet.pdf?sequence=2&isAllowed=y>
9. GDPR consent: <https://gdpr-info.eu/issues/consent/>

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## **Module 3 - Standards, taxonomy & Ontology:**

### Publications

1. Kim K. Clinical Data Standards in Health Care: Five Case Studies. California Healthcare Foundation. iHealthReports (2005).
2. Blaum WE, et al. Towards Web 3.0: taxonomies and ontologies for medical education -- a systematic review. GMS Zeitschrift fur medizinische Ausbildung vol. 30,1 (2013): Doc13.
3. Basu A, et al. Call for Data Standardization: Lessons Learned and Recommendations in an Imaging Study. JCO clinical cancer informatics vol. 3 (2019): 1-11.
4. Saripalle R, et al. Using HL7 FHIR to achieve interoperability in patient health record. Journal of biomedical informatics vol. 94 (2019): 103188.
5. Danecek P, et al. The variant call format and VCFtools. Bioinformatics (Oxford, England) vol. 27,15 (2011): 2156-8. d
6. Hoehndorf R, et al. The role of ontologies in biological and biomedical research: a functional perspective. Briefings in bioinformatics vol. 16,6 (2015): 1069-80.
7. Danese, M.D., Halperin, M., Duryea, J. et al. The Generalized Data Model for clinical research. BMC Med Inform Decis Mak 19, 117 (2019).
8. Shin, S. J., You, S. C., Roh, J., Park, Y. R., & Park, R. W. (2019). Genomic Common Data Model for Biomedical Data in Clinical Practice. Studies in health technology and informatics, 264, 1843–1844.

### Tools

1. H3ABioNet (<https://www.h3abionet.org/data-standards/datastds>)
2. BioPortal (<https://bioportal.bioontology.org/>)
3. OLS (<https://www.ebi.ac.uk/ols/index>)
4. ZOOMA (<https://www.ebi.ac.uk/spot/zooma/>)
5. OxO (<https://www.ebi.ac.uk/spot/oxo/>)
6. HL7 (<http://www.hl7.org>)
7. FHIR (<http://hl7.org/fhir/>)

### Initiatives

1. OBO Foundry (<http://www.obofoundry.org/>)
2. PhenX (<https://www.phenxtoolkit.org/>)
3. FAIRsharing (<https://fairsharing.org/>)
4. CDISC (<https://www.cdisc.org/standards>)
5. GA4GH (<https://www.ga4gh.org/genomic-data-toolkit/>)
6. GENSC (<https://gensc.org/>)
7. RDA (<http://rd-alliance.github.io/metadata-directory/standards/>)

### Data Models

1. The Hyve (<https://www.thehyve.nl/articles/cdm-for-fair-biomedical-data>)
2. OMOP (<https://www.ohdsi.org/data-standardization/the-common-data-model/>)
   1. <https://ohdsi.github.io/CommonDataModel/>
   2. Biedermann, P., Ong, R., Davydov, A. et al. Standardizing registry data to the OMOP Common Data Model: experience from three pulmonary hypertension databases. BMC Med Res Methodol 21, 238 (2021).
   3. <https://www.coursera.org/lecture/clinical-data-models-and-data-quality-assessments/a-quick-tour-of-a-common-data-model-omop-cwyn0>

## **Module 4 - Preservation, repositories, security and policies:**

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## **Module 5 - FAIR & Reproducibility:**

## **Module 6 - Data Management Plan (DMP):**

1. Fadlelmola FM et al. Data Management Plans in the genomics research revolution of Africa: Challenges and recommendations. J Biomed Inform. 2021 Oct;122:103900. doi: [10.1016/j.jbi.2021.103900](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9123155/).
2. Best practice for developing a Data Management Plan: H3ABioNet DMP Poster presented at the 13th H3Africa Consortium Meeting, 8-12 April 2019, Tunis, Tunisia. [Link](https://h3abionet.org/images/2020/dmp_poster_final_faisal_fadlelmola_april2019.pdf)
3. 10 Simple Rules for Creating a Good DMP: [Link](https://doi.org/10.1371/journal.pcbi.1004525)
4. 10 principles for machine actionable DMPs (maDMPs): [Link](https://doi.org/10.1371/journal.pcbi.1006750)
5. Checklist for a Data Management Plan[: Link](https://www.dcc.ac.uk/sites/default/files/documents/resource/DMP/DMP_Checklist_2013.pdf)
6. Framework for Creating a Data Management Plan: [Link](http://www.icpsr.umich.edu/icpsrweb/content/datamanagement/dmp/framework.html)
7. DMPonline: [Link](https://dmponline.dcc.ac.uk/%20)
8. The Digital Curation Centre (DCC): [Link](http://www.dcc.ac.uk/resources/data-management-plans)